



Experiences of disabled North East London residents in the Covid-19 pandemic *Carers' Questionnaire- printable form*





Thank you for agreeing to take part in our questionnaire!

This questionnaire has been created by the local North East London Healthwatch (Tower Hamlets, Hackney, City of London, Newham, Waltham Forest, Redbridge, Barking and Dagenham, and Havering) in partnership with the East London Health and Care Partnership (the eight councils and 12 NHS organisations in East London).

Please fill in this questionnaire if you look after somebody who would not be able to answer questions themselves- for example if you are the parent of a disabled young child, the carer for someone with a severe learning disability or dementia.

If the person you are caring for could answer the questions with assistance, please assist them to fill in the general or easyread questionnaire for themselves instead, or contact your local Healthwatch and they will be able to provide assistance.

We want to understand disabled residents' experience of health and social care services during the Covid-19 pandemic to address any challenges they may be facing now and to plan future services. Your answers are strictly confidential; you will not be required to provide your name or identifiable personal data. The results of this questionnaire will be shared with community partners such as hospital trusts, local authorities and Clinical Commissioning Groups, in an entirely anonymised format from which respondents cannot be personally identified. We hope that this will reassure you that you can be as honest as you wish without fear of any consequences in terms of the services you receive.

We do, however, want to involve participants in developing the recommendations from the questionnaire and let you know what difference they make. At the end of the questionnaire we will ask you to provide your contact details. You do not have to submit them, and you can still take part if you choose not to do so. These details will never be shared outside of our organisation.

The questionnaire will take approximately 20 minutes to complete. As an appreciation of your time anyone who completes the questionnaire and leaves their details will go into the draw to win a £200 Amazon voucher or one of the three £100 vouchers.

If you would like an Easy Read copy of the questionnaire or would like help with completing the questionnaire please don't hesitate to contact us:

Telephone: 0800 145 5343

Email: info@healthwatchtowerhamlets.co.uk





1A. Are you the carer of a disabled person ?

- Yes, I am the main carer for a family member or close friend
- Yes, I regularly help look after a family member or close friend, but I am not the main carer
- Yes, I regularly help look after a family member or close friend, but I am not the main carer
- Yes, I am a professional/ paid carer

End questionnaire if none of these

1B. What borough does the person you look after live in?

- Barking and Dagenham
- City of London
- Hackney
- Havering
- Newham
- Redbridge
- Tower Hamlets
- Waltham Forest

End questionnaire if none of these

1C. What is your relationship with the person that you look after?

Eg. Child, sibling, friend

2A. Does the person you care for have any of the below?

Please check all that applies

- Mobility issues (including wheelchair and scooter users)
- Upper limb or back problems or repetitive strain injury
- Chronic pain affecting your day to day life
- Other physical disability or impairment
- Motor or coordination disorder, including severe dyspraxia
- Autism Spectrum Disorder (including Asperger Syndrome)
- Learning disability or difficulties, including ADHD or dyslexia
- Blind or partially sighted
- Deaf or hard of hearing
- A severe long-term condition (eg multiple sclerosis, parkinson's, ME/CFS, cancer, HIV, epilepsy)
- A long term condition that makes me extremely vulnerable to Covid-19 (eg severe asthma, heart or lung disease)
- Mental health issues affecting your day to day life
- Any other disabilities, including unseen ones; any other impairments or long-term conditions.

Please specify



2B. In no more than two sentences, please tell us a bit about the nature of their disability, impairment or long-term condition; how it impacts their daily life and how they manage it/ how you help them manage.

2D. Which of the following describes your situation?

- They rarely or never leave their home; this is because they are shielding since the start of the pandemic.
- They rarely or never leave their home; this is because of their disability or long-term conditions and they would still be in a similar situation without the pandemic.
- They are able to leave their home on a reasonably regular basis.

2E. Do they receive any help with personal care, such as washing and dressing themselves?

Please check all that applies

- Yes, I help them with this
- Yes, family members or friends other than me help them with this
- Yes, professional carers other than me help them with this



Staying informed in the Covid-19 pandemic

3A. Where do you and the person you care for usually receive information about your health and social care during the Covid-19 pandemic?

I have received information from this source

The person I care for has received information from this source

Yes

No

Not sure

Yes

No

Not sure

TV

Radio

Newspapers

NHS website

Govt website

Charity website

Other websites

Social media

Letter from NHS or govt

Text from NHS or govt

Your health professionals

Your social care professionals

Friends and family

Other



Staying informed in the Covid-19 pandemic

3B. Have you or the person that you look after received any information about changes to their healthcare in the Covid-19 pandemic?

- Myself or other carers/ family members were informed
- They were informed directly, and the information was accessible to them
- They were informed directly, but the information was not accessible to them
- No information was received at all
- Not sure if any information was received

3C. Have you or the person that you look after received any information about changes to their social care in the Covid-19 pandemic?

- Myself or other carers/ family members were informed
- They were informed directly, and the information was accessible to them
- They were informed directly, but the information was not accessible to them
- No information was received at all
- Not sure if any information was received

3B. Have you received any information about....

- Yes, they received information accessible and suitable for them
- Yes, myself or other carers/ family members helped them understand it
- They have access to the info, but it's too difficult for them to understand
- No info was offered to them
- Not sure

Staying healthy and safe in the Covid-19 pandemic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shielding if you are extremely vulnerable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-isolating if you have been exposed to Covid-19	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social distancing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mask wearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting tested for Covid19	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NHS Test and Trace	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The Covid-19 vaccine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



3C. Do you have any suggestions on how to make these messages more accessible for the person you are caring for?

Please tell us about any issues that may have caused them to struggle with the information available to them, as well as about any good examples of communication that was accessible for them.



Experience of the Covid-19 pandemic

4. Please describe how you think COVID-19 has impacted on the daily life of the person you care for. e.g. their routine and mental wellbeing.

Is there anything in particular, that they have stopped doing in your normal daily or weekly routine because of the pandemic? If yes, what was it and why?

5A. When you are offered the Covid-19 vaccine, will you have it?

- Yes, I would (or already had at least one dose)
- No, I would not
- Not sure, haven't decided yet

5B. Do you know if the person you are caring for is going to take the vaccine?

- Yes, they would (or already had at least one dose)
- No, they would not
- I don't know

5C. If not, why not?



The Covid-19 vaccine

5C. What would be the best way for the person you care for to receive information about the vaccine and about how to obtain it?

- *Should the information target them directly or their carers?*
- *Are there any tools that would help you, as their carer, talk to them about the vaccine?*
- *How can we make sure that the information is easy to understand and accessible for them?*

5D. How can we make sure that Covid-19 vaccination sites are accessible for the person you care for and other people with their impairment?

5E. Do you have any other concerns or comments about the Covid-19 vaccine?

Including any concerns about the vaccine itself, its distribution, access to it and communication about it.



The Covid-19 vaccine

5B. How would you prefer to receive information about the vaccine and about how to obtain it?

- Phone Email Letter Text message Video call Face to face
 Other _____

5C. Who would you like to receive this information from?

e.g. your GP, an official Government communication, a trusted person in your community.

5D. How can we make sure that information about the Covid-19 vaccine is accessible and easy to understand for people with your impairment?



Experience of Covid-19

6. Has the person you care for had Covid-19?

- Yes, they had a positive test and went to hospital.
- Yes, they had a positive test but did not need hospitalisation/ stayed at home.
- Possibly, they had Covid-19 symptoms but were not tested.
- No, they never experienced Covid-19 symptoms → GO TO QUESTION 7 - GP SURGERY
- Not sure → GO TO QUESTION 7 - GP SURGERY

6A. If they had or may have had Covid-19, please tell us their or your experience getting medical care and/or advice for it.

Including from the NHS 111 advice line, your GP, hospital etc.



GP surgery

7. Has the person you care for seen their GP or contacted their GP surgery since the start of the pandemic?

Including if you contacted their GP for them

Yes

No → *GO TO QUESTION 8 - HOSPITAL SPECIALISTS AND OUTPATIENTS*

7A. Since the beginning of the COVID-19 pandemic, getting the care the person you care for has needed from their GP surgery has been...

Much easier Somewhat easier About the same

Somewhat harder Much harder Don't know

7B. Why do you feel this way? What changes, positive and negative, have you noticed in your GP surgery?

- *Would you like to see any of these changes kept after the end of the pandemic?*
- *How can we make sure that GP services work for the person you are caring for?*

7C. Since the start of the COVID-19 pandemic, has the person you are caring done any of the following? Or have you done it on their behalf?

Please check all that applies, leave blank if not sure.

- Filed an e-consult form online to receive a telephone call from a GP or practice nurse.
- Had an online consultation with a GP or practice nurse (via web chat, email or video call).
- Had a telephone consultation with a GP or practice nurse.
- Booked online an appointment with a GP or practice nurse.
- Ordered a repeat prescription online.
- Used any other online service with your GP surgery

Please specify

7D. What is their GP surgery? *Leave blank if unsure or you prefer not to say*



Hospital specialists and outpatients

8. Does the person you care for regularly see any hospital-based health professionals, such as consultants, physiotherapists, specialist nurses?

Yes

No → GO TO QUESTION 9 - MENTAL HEALTH

Don't know → GO TO QUESTION 9 - MENTAL HEALTH

8A. Which health professionals do they see and how often?

If you are comfortable disclosing it, please also mention which hospital they are based at.

8B. Since the beginning of the COVID-19 pandemic, getting the care the person you care for has needed from hospital-based services has been...

Much easier Somewhat easier About the same

Somewhat harder Much harder Don't know

8C. Why do you feel this way? What changes, positive and negative, have you noticed in the service?

- *Would you like to see any of these changes kept after the end of the pandemic?*
- *How can we make sure that hospital services work for the person you care for?*



8D. Since the start of the COVID-19 pandemic, has the person you are caring done any of the following? Or have you done it on their behalf?

Please check all that applies, leave blank if not sure.

- Had an online consultation with my consultant or other hospital-based professional (via web chat, email or video call).
- Had a telephone consultation with my consultant or other hospital-based professional
- Booked online an appointment with my consultant or other hospital-based professional
- Used any other online service with the hospital

Please specify

8E. Were any of their regular appointments or treatment sessions cancelled or delayed because of COVID-19?

- Yes No Don't know

8F. If their appointments or treatment sessions were cancelled or delayed, did this affect their health and wellbeing?

- Yes, a great deal Yes, a little No, not at all Not sure
- Not applicable/ we did not experience delays or cancellations

8G. If their appointments or treatment sessions were cancelled or delayed, did they receive any alternative treatments or advice on how to manage their health in the meantime?

- Yes, and we found it useful. Yes, but we did not find it useful.
- No, we did not. Not sure/ can't remember.
- Not applicable/ we did not experience delays or cancellations.



Mental health

9. Since the start of the pandemic, did you see any mental health professionals such as psychotherapists, psychiatrists or mental health nurses??

Yes, they did

No, but they received mental health treatment and/or advice from their GP

➔ GO TO QUESTION 10 - COMMUNITY HEALTH PROFESSIONALS

No; they may have needed mental health services but couldn't access them

➔ GO TO QUESTION 10 - COMMUNITY HEALTH PROFESSIONALS

No; and they didn't need mental health services.

➔ GO TO QUESTION 10 - COMMUNITY HEALTH PROFESSIONALS

Not sure

➔ GO TO QUESTION 10 - COMMUNITY HEALTH PROFESSIONALS

9A. Which mental health professionals do they see and how often?

9B. The mental health professionals they see are from...

Please check all that applies.

An NHS hospital An NHS community mental health team (CMHT)

An NHS psychotherapy/ counselling service

A school or university psychotherapy/ counselling service

Their GP A private practice or health service

Other *Please specify*

9C. Since the beginning of the COVID-19 pandemic, getting the care they have needed for their mental health has been...

Much easier Somewhat easier About the same

Somewhat harder Much harder Don't know



9D. Why do you feel this way? What changes, positive and negative, have you noticed in the service?

- *Would you like to see any of these changes kept after the end of the pandemic?*
- *How can we make sure that mental health services work for you?*

9E. Since the start of the COVID-19 pandemic, has the person you are caring done any of the following? Or have you done it on their behalf?

Please check all that applies, leave blank if not sure.

- Had a psychotherapy session online (via web chat or video call).
- Had a psychotherapy session over the phone.
- Had an online consultation with a psychiatrist or mental health nurse (via web chat, email or video call)
- Had a telephone consultation with a psychiatrist or mental health nurse
- Booked online an appointment with a mental health professional
- Used an app or website for my mental health or wellbeing
- Used any other online service for my mental health

Please specify

9F. Were any of their regular appointments or treatment sessions cancelled or delayed because of COVID-19?

- Yes No Don't know

9G. If their appointments or treatment sessions were cancelled or delayed, did this affect their health and wellbeing?

- Yes, a great deal Yes, a little No, not at all Not sure
- Not applicable/ we did not experience delays or cancellations

9H. If their appointments or treatment sessions were cancelled or delayed, did they receive any alternative treatments or advice on how to manage their health in the meantime?

- Yes, and we found it useful. Yes, but we did not find it useful.
- No, we did not. Not sure/ can't remember.
- Not applicable/ we did not experience delays or cancellations.



Community health services

10. Does the person you care for you regularly see community health professionals?

e.g. district nurses, chiropodists, occupational therapists etc.

Yes

No → GO TO QUESTION 11 - CARE AT HOME

Don't know → GO TO QUESTION 11 - CARE AT HOME

10A. Which community health professionals do they see and how often?

e.g. district nurses, chiropodists, occupational therapists

10B. Since the beginning of the COVID-19 pandemic, getting the care they have needed from community health professionals has been...

Much easier Somewhat easier About the same

Somewhat harder Much harder Don't know

10C. Why do you feel this way? What changes, positive and negative, have you noticed in the service?

- *Would you like to see any of these changes kept after the end of the pandemic?*
- *How can we make sure that community health services work for them?*



10D. If these professionals visit their home, how safe do you feel with this during the COVID-19 pandemic?

- Very safe Quite safe Not very safe Not at all safe
 Don't know N/a, they don't receive healthcare at home

10E. Were the professionals visiting their home provided with adequate PPE during the pandemic?

- Yes, as soon as the pandemic started
 Yes, but only after some time
 No, they were not
 Don't know
 N/a, they don't receive healthcare at home

10F. Were any of their regular appointments or treatment sessions cancelled or delayed because of COVID-19?

- Yes No Don't know

10G. If their appointments or treatment sessions were cancelled or delayed, did this affect their health and wellbeing?

- Yes, a great deal Yes, a little No, not at all Not sure
 Not applicable/ we did not experience delays or cancellations

10H. If their appointments or treatment sessions were cancelled or delayed, did they receive any alternative treatments or advice on how to manage their health in the meantime?

- Yes, and we found it useful. Yes, but we did not find it useful.
 No, we did not. Not sure/ can't remember.
 Not applicable/ we did not experience delays or cancellations.



Domiciliary care

11. Does the person you care for regularly receive visits from professional carers or personal assistants at home?

Yes

No → GO TO QUESTION 12 - DAY CENTRE

No → GO TO QUESTION 12 - DAY CENTRE

11A. How often do they receive care or help from professional/paid carers in your own home?

11B. What kind of things do carers help them with?

e.g. dressing, washing themselves, cleaning, cooking

11C. Since the beginning of the COVID-19 pandemic, getting the care they have needed from their carers has been...

Much easier Somewhat easier About the same

Somewhat harder Much harder Don't know

11D. Why do you feel this way? What changes, positive and negative, have you noticed in the service?

- *Would you like to see any of these changes kept after the end of the pandemic?*
- *How can we make sure that domiciliary care services work for you?*



11E. How safe do you feel with carers coming into their home during the COVID-19 pandemic?

- Very safe Quite safe Not very safe Not at all safe Not sure

11F. Were carers visiting their home provided with adequate PPE during the pandemic?

- Yes, as soon as the pandemic started
 Yes, but only after some time
 No, they were not
 Not sure

11G. Were any of their care appointments cancelled or delayed because of COVID-19?

- Yes No Can't remember

11H. If their appointments were cancelled or delayed, did this affect their health and wellbeing?

- Yes, a great deal Yes, a little No, not at all Not sure
 Not applicable/ we did not experience delays or cancellations

11I. If their appointments were cancelled or delayed, did they, you or other family members receive any alternative treatments or advice on how to manage your health in the meantime?

- Yes, and we found it useful. Yes, but we did not find it useful.
 No, we did not. Not sure/ can't remember.
 Not applicable/ we did not experience delays or cancellations.



Day centre

12. Does the person you care for attend a day centre?

- Yes, and it is still open during the pandemic
 - ➔ *GO TO QUESTION 12.1 - DAY CENTRE CURRENTLY OPEN*
- They used to, but it's currently closed
 - ➔ *GO TO QUESTION 12.2 - DAY CENTRE CURRENTLY CLOSED*
- No, they do not
 - ➔ *GO TO QUESTION 13- TECHNOLOGY AND ADAPTATIONS*





Day centre currently open

12.1A Since the beginning of the COVID-19 pandemic, attending your day centre has been...

- Much easier Somewhat easier About the same
 Somewhat harder Much harder Don't know

12.1B Why do you feel this way? What changes, positive and negative, have you noticed in the day centre?

- *Would you like to see any of these changes kept after the end of the pandemic?*
- *How can we make sure that the day centre works for the person you care for?*

12.1C Is the day centre doing activities online nowadays?

- Yes, and they take part
 Yes, but they do not take part
 No
 Not sure

12.1D How safe do you feel with the person you care for attending their day centre during the COVID-19 pandemic?

- Very safe Somewhat safe Not very safe Not at all safe Don't know



AFTER THIS SECTION GO TO QUESTION 13- TECHNOLOGY AND ADAPTATIONS



Day centre currently closed

12.2A For how long has their day centre been closed?

12.2B Were you, the person you care for or other family members informed about the day centre's closure?

Definitely To some extent Not at all

12.2C Is the day centre doing activities online nowadays instead?

- Yes, and they take part
 Yes, but they do not take part
 No
 Not sure

12.2D Did the closure of the day centre affect their health and wellbeing?

Yes, a great deal Yes, a little No, not at all Not sure/ can't remember

12.2E If you feel like the closure of your day centre affected you or the person you care for- in what way was that?

12.2F Did you, they or other family members receive any advice or support on how to manage while the day centre was closed?

Yes, and we found it useful. Yes, but we did not find it useful.
 No, I did not. Not sure/ can't remember.

12.2G Did you, they or other family members receive any extra care or other forms of respite during the closure of the day centre?

Yes, and I found it useful. Yes, but I did not find it useful.
 No, I did not. Not sure/ can't remember.



Technology and adaptations

13 Are there any devices, technologies or adaptations that the person you care for uses to manage their disabilities in your daily life? If yes, what are they?

e.g wheelchair, walking stick, bathroom rails, hearing aid, Braille display, screen reader app. Please include any such devices/adaptations that you or other family members use to support them.

13A Has the Covid-19 pandemic impacted their ability to obtain, access or use any of the devices, technologies or adaptations they need? If yes, in which way?



About you

This helps us to make sure that we are hearing the views of a wide range of disabled people so that services can be designed to meet their needs. It is completely anonymous.

14. What gender is the person you are caring for?

Male Female Other _____

15. What ethnicity are they?

White:

- British English Welsh Scottish Northern Irish Irish Irish Traveler
 Roma Polish Turkish/ Turkish Cypriot Greek/ Greek Cypriot Romanian
 Bulgarian Italian Kurdish Other Eastern European Other Western European
 European- mixed or other North American Australian or New Zealander Other

Asian:

- Bangladeshi Indian Pakistani Chinese Vietnamese Nepali
 Sri Lankan Tamil Sri Lankan Sinhalese Sri Lankan Other Japanese
 Korean Malay Thai Other

Black:

- British Angolan Caribbean Congolese Ghanaian Nigerian
 Sierra Leonean Somali Sudanese Other

Mixed:

- White and Black African White and Caribbean White and Asian Other

Other:

- Afghan Lebanese Moroccan Egyptian Libyan Iraqi Yemeni
 Arab- other than above Filipino Iranian Kurdish Latin American
 Polynesian Jewish Charedi Jewish Other ethnicity



16. How old are they?

- Under 18 18 to 24 25 to 49 50 to 64 65+

17. At the moment, are they...

- Working full time Working part time Unemployed and looking for jobs
 Unemployed and unable to work because of my disability/ long term condition
 Retired Stay at home parent Carer to another adult
 Volunteering/ doing unpaid work Student

18. Do they share a household with any of the following?

- Partner Children under 18 Adult children Other family members
 Friends/ housemates Friends/ housemates Professional carers
 No one, I live alone

19. Which of the following devices do they have access to at home?

- Desktop computer Laptop Tablet Smartphone
 Other devices _____ None of these

20. Do they have access to...?

- Wi-fi at home Internet on your phone None of these

21. How confident do they feel using a device such as a computer, tablet or smartphone to access online services?

- Very confident Somewhat confident Not very confident Not at all confident



Thank you for taking part in this questionnaire!

22. Do you have any other comments about health and social care during the last nine months since the pandemic started?



Keep in touch?

Would you like to take part in future research?

This could mean taking part in an in-depth interview or focus group

Yes No

Would you agree to be asked follow-up questions as part of future research?

For example, about long Covid or about your specific type of impairment

Yes No

Would you like to take part in our raffle?

Yes No

Would you like to be informed about the results of this survey and have the opportunity to be involved in developing the recommendations and designing future local services?

Yes No

If yes to any of the above, please leave us your contact details.

These will be strictly confidential. They will not be used for any other purpose than the raffle and/or inviting you to take part in future research. They will never be passed on to any third party outside of Healthwatch. Unless you have opted in to being asked follow-up questions, your contact details will be stored separately from your survey answers.

You can fill in the questionnaire without giving us your contact details, but you will not be able to take part in our raffle or in future research. If you do not wish to give your contact details, please leave these fields blank.

Your name

Your phone number

Your email address