

How has the COVID-19 pandemic affected Ealing residents living with a disability and their carers?

A report by Healthwatch Ealing

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Contents

<i>Disclaimer</i>	3
<i>Acknowledgments</i>	3
<i>Executive summary</i>	4
<i>Introduction</i>	5
<i>Aim & Objectives</i>	6
<i>Methodology</i>	7
<i>Data Analysis</i>	9
<i>Findings & Analysis: Survey Responses</i>	10
<i>Section 1: Your health condition(s) and wider circumstances</i>	10
<i>Section 2: Your Social Care Support</i>	12
<i>Section 3: Access to Healthcare</i>	16
<i>Section 4: Your Mental Health Well-being</i>	19
<i>Section 5: COVID-19 and the Vaccination</i>	20
<i>Findings & Analysis: Discussion Forum Responses</i>	23
<i>Monitoring Information</i>	31
<i>Findings & Analysis: Family Carer Survey Responses</i>	31
<i>Conclusion</i>	36
<i>Recommendations</i>	38
<i>Limitations</i>	42
<i>Appendix - 1: Survey Questionnaire</i>	43
<i>Appendix - 2: Themes & Subthemes</i>	52

Disclaimer

The information presented within this report reflects the individual experiences of those who completed the survey and participated in the engagement events. Healthwatch Ealing presents this as information to be considered and utilised to improve service provision and highlight areas of good practice.

Acknowledgments

Healthwatch Ealing would like to thank the residents who took the time to complete our Disabilities survey as well as Ealing Council, Public Health Ealing, Ealing Clinical Commissioning Group (CCG), the NWL CCG Collaborative Group, Ealing Mencap & Ealing Power Group and the Deaf and Hard of Hearing Women's Group for their support during this project.

We would also like to extend our appreciation to our Healthwatch Ealing volunteers for the time that they dedicated to this project.

Executive summary

From July 2021, Healthwatch Ealing partnered with Ealing Council to identify how adult residents living with disabilities and their unpaid family carers have been affected by the pandemic, including their experiences of the Health and Social Care system. Residents provided their feedback via physical copies of Healthwatch Ealing's Disabilities survey, participating in the survey over the phone with a member of the research team, submitting their survey online via our Google Forms version of the survey or participating in one of two discussion forums that took place with the Ealing Mencap & Ealing Power Group and the Deaf and Hard of Hearing Women's Group.

Altogether, 152 people shared their views and experiences. Out of this total, 90 individuals were Ealing residents living with a disability (or disabilities) and 62 were family carers fulfilling an informal, unpaid caring role. Out of the 90 individuals living with a disability, 72 responded via the Healthwatch Ealing Disabilities Survey and the other 18 participated in one of two discussion forums.

Overall, the views and experiences expressed by individuals during this project provides evidence that health and social care partners must work together to improve communication with disabled individuals around their care and ensure that all aspects of care are being consistently delivered to the highest standard. The feedback also indicated that a more person-centered approach to care should be implemented to ensure that people are being appropriately supported. This includes identifying the best method of contact for individuals where a virtual approach to care is insufficient.

Further insight into the pandemic's impact was provided during the discussion forums in which individuals indicated that their paid support had been decreased during the pandemic, that the reliance on digital technology did make access to services and information difficult and that the isolation they experienced significantly affected their mental wellbeing and that of family members who supported them during this time.

Lastly, the impact of the pandemic on unpaid, family carers' health was made clear. These individuals highlighted the need for more effective communication from their loved one's social care provider and the delivery of mental health support for them, in order to improve the health inequalities experienced by their loved ones and themselves.

The findings from this report have led to a series of recommendations made by Healthwatch Ealing that include prioritising easy and straight forward communication from social care providers, ensuring that the standard of social care is consistently met, identifying barriers to mental health support, adopting a more person-centred approach to health and social care and the continuation of research and engagement work with these communities to understand the most efficient ways that Ealing health partners can alleviate inequalities.

Introduction

The COVID-19 pandemic, the resulting lockdowns and the drastic adaptations that had to be made to health and social care service delivery have further exacerbated the health disparities experienced by those living with a disability or disabilities. National¹² and pan-London³ research has shown that, during the pandemic, the disabled population in the UK have felt forgotten and abandoned by policy makers and health and social care services and, in some cases, have even felt discriminated against.

Indeed, the research shows that disabled individuals experience higher levels of unrecognised and unmet physical and mental health needs as they face multiple barriers to accessing health services. These include problems with communication, inadequate facilities, rigid procedures, and a lack of accessible health promotion information.

There is approximately 6,791 people aged over 18 years who have a learning disability⁴ living in the London Borough of Ealing and 3,200 people aged over the age of 18 years that are receiving support for long-term physical disabilities.

To build on current national and pan-London research, Healthwatch Ealing partnered with Ealing Council to ask these Ealing residents living with disabilities how the pandemic and the resulting lockdowns have affected their lives and the care that they ordinarily receive.

This piece of research is at the forefront of Ealing borough health partners' collective strategy that aims to address the inequalities experienced by people living with disabilities and will contribute an evidence-based foundation for which corrective actions should be based upon.

¹ [Statement on COVID-19 and the human rights of Disabled people \(2020\)](#)

² [Exploring the UK's digital divide, Office of National Statistics \(March 2019\)](#)

³ [Abandoned, forgotten and ignored – The impact of COVID-19 on Disabled people, Inclusion London](#)

⁴ [Learning Disability in the London Borough of Ealing](#)

Aim & Objectives

This project aims to effectively build on preliminary research that has taken place at national and pan-London level. To do this, Healthwatch Ealing will:

- Gather feedback from disabled people on the impact that the pandemic has had on their lives and their access to basic provisions.
- Understand what aspects of disabled individuals' health and social care have been most affected by the pandemic.
 - Identify the ways in which the local authority and health and social care service providers have been able to support disabled individuals during this time.
 - Gather feedback from unpaid carers regarding how their lives and access to care have been affected by the pandemic.
- Listen to the ideas that disabled people and their carers have as to how care services and local CVS's can effectively improve the support that they receive.

Through achieving these aims, Healthwatch Ealing will be able to collect, analyse and present local insight that will help to uncover the broader issues affecting disabled individuals care as well as any borough-specific nuances that have not yet been identified by the current literature. This insight will highlight areas of good practice and identify those areas that need to be developed in order to improve care for these communities.

Meeting these aims will enable us to achieve the objective of this research: To produce a comprehensive, evidence-based set of recommendations that health partners can work together on to address the inequalities experienced by disabled individuals and their informal carers. This research will also provide the necessary foundation for future research into local health inequalities experienced by these residents and should be used as a rationale for effective engagement work for health and social care services and local community organisations.

Methodology

Over the course of several meetings with Ealing Council and Public Health Ealing, Healthwatch Ealing produced a proposal for this piece of research, outlining the research approach, the areas that we were interested in hearing about and the methods we would use to collect the data.

Approach

As a result of this collaborative work, the decision was made by Healthwatch Ealing to adopt a mixed-methods approach to the data collection for this research. To gather both quantitative and qualitative insight into, the data collection process included the distribution of a survey containing both quantitative and qualitative questions. To supplement these survey findings with further qualitative insight, two discussion forums were conducted at which the Healthwatch Ealing research team asked residents a series of open-ended questions that were based on the questions in the survey and, therefore, covered the same topics of discussion.

Healthwatch Ealing Disabilities Survey

With the support of Ealing Council and Public Health Ealing, Healthwatch developed the Disabilities Survey, specifically designed for this research project. Not only did these collaborative meetings help to establish a clear sectional divide within the survey pertaining to the areas of interest, but it also led to the novel incorporation of Section 6 of the survey, that asks informal family (or friend) carers to provide their feedback on how their own health and wellbeing has been affected by the pandemic.

The final version of the Disabilities Survey consisted of 32 questions (not including monitoring information questions) that were split into 7 sections:

- **Section 1:** Your health condition(s) and wider circumstances
- **Section 2:** Your Social Care Support
- **Section 3:** Access to Healthcare
- **Section 4:** Your Mental Wellbeing
- **Section 5:** COVID-19 and the Vaccination
- **Section 6:** To be answered by your family (or friend) carer
- **Section 7:** Monitoring information

Participants either indicated their answer to questions by choosing from a list of answer choices (selecting more than one answer where appropriate) and provided further insight into their experiences and views by including more detail in the free text boxes positioned throughout the survey.

Data Collection

In total Healthwatch Ealing used four different methods of data collection:

- Distributed paper copies of our survey, via Ealing Council to 500 Ealing Council customers. The package that the customers received comprised of the survey, a Freepost envelope to be able to send the survey back to Healthwatch Ealing, free of charge and an instruction page outlining the steps that the individual needed to take to submit their response.
- Created a Google Forms Survey to allow residents to fill out the survey online
- Healthwatch Ealing Research Team conducted 1:1 telephone interview over the phone to walk support individuals with the completion of the survey.
- Hosted two discussion forums with the facilitatory support of the Ealing Power Group and the Deaf and Hard of Hearing Women's Group.

After initially promoting the project for several weeks, we encourage people to access and complete the live survey. This included promotion through our own website, sending out our promotional content - an explanatory email and promotional materials - to our mailing list and promoting the project on our social media channels. We also asked colleagues at statutory and community organisations to assist with the survey promotion through their own networks.

The promotional materials included the link to the online Google Forms survey as well as Healthwatch Ealing's contact details, with the reassurance that if individuals were unable to fill out the survey themselves, they could contact our team who would support them through the process.

In cases where service users were hard of hearing or had limited English abilities, survey packages were posted to their home address so that they could complete the survey and post it back to Healthwatch with support of a friend or family member. These packages included the instruction document and the Freepost Envelope. Lastly, we utilised our organisations Patient Experience programme visits to GP surgeries to conduct face-to-face interviews with individuals in the waiting rooms at GP surgeries who met the inclusion criteria for this project.

In addition to the survey distribution, Healthwatch Ealing hosted two discussion forums. These forums were facilitated by the Ealing Power Group, who support individuals with learning difficulties and the Deaf and Hard of Hearing Women's Group. The research team gained consent from all parties to record the sessions and take notes of the discussions for transcription and analysis. The recordings were deleted once the transcription process had been completed. These forums provided the opportunity to gather feedback from those that did not necessarily have access to our online or paper surveys as well as enabling individuals to provide more detail and further insight into matters that may be difficult to express via a survey. To be able to draw comparisons between all participants' experiences, the discussion forums followed the same line of questioning as the surveys themselves.

Data Analysis

In total, we collected feedback from 152 individuals:

- 72 disabled individuals completed surveys (paper copy, online, via telephone)
- 18 disabled individuals attended one of the two discussion forums
- 62 informal carers completed the section of the survey asking for their feedback

The Findings and Analysis section below is split into these three categories. First the findings from the survey responses from disabled individuals are explored. The second part of the findings and analysis summarises the qualitative insight that we received from individuals during the discussion forums. The monitoring information for survey respondents and discussion forum attendees is then shown in the Monitoring Information section. Lastly, the responses from informal carers are explored.

A simple data analysis was conducted on the multiple-choice questions whilst a thematic analysis was conducted on the qualitative answers provided. The main findings pertaining to each survey section are included alongside several example comments and the themes which they are associated with. The qualitative insight provided by the discussion forum attendees and from informal carers was manually analysed by the Healthwatch Ealing research team to identify and explore any key themes and trends.

It should be noted that for each question the number of responses received varies. This is due to some individuals choosing not to answer certain questions, some questions not pertaining to certain individuals and some questions asking individuals to provide more than one multiple choice answer.

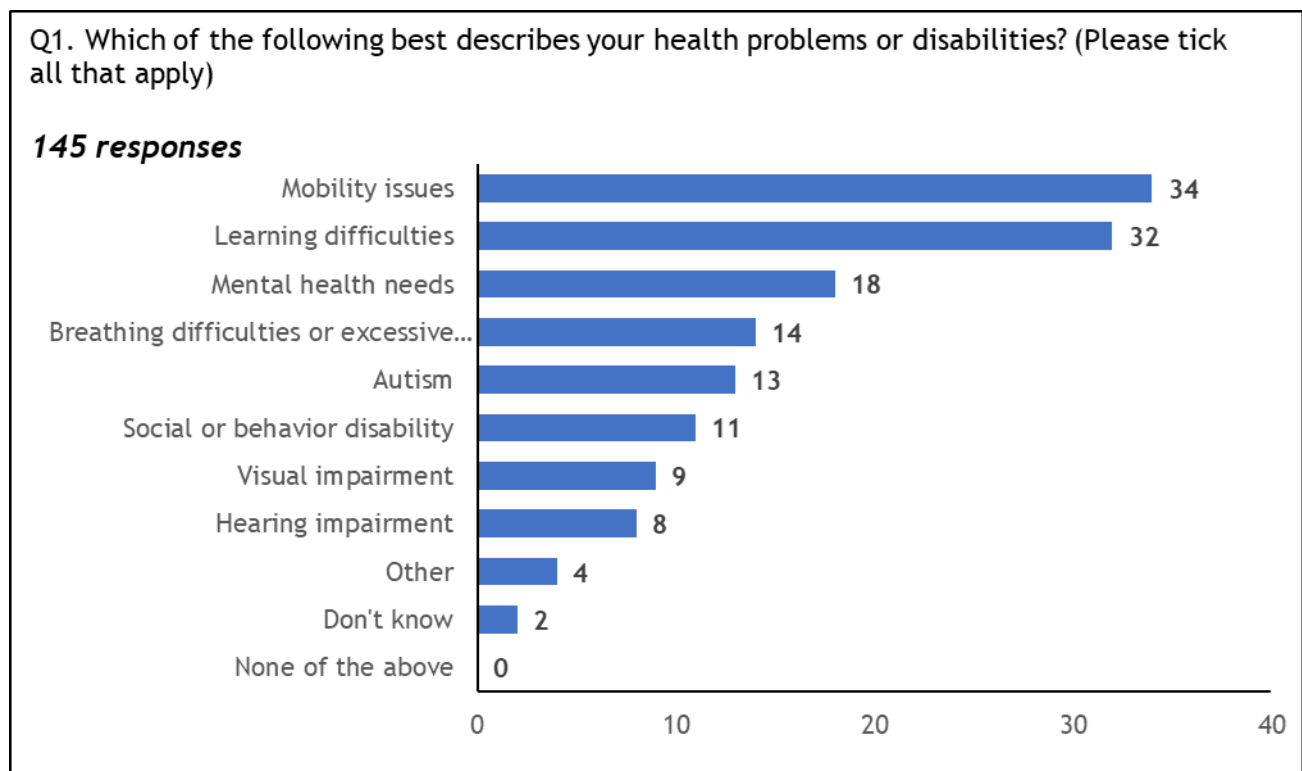
Findings & Analysis:

Survey Responses

In total, 72 survey responses were received online, via telephone interviews and from completed paper copies. These findings from the analysis are outlined in the sections below.

Section 1: Your health condition(s) and wider circumstances

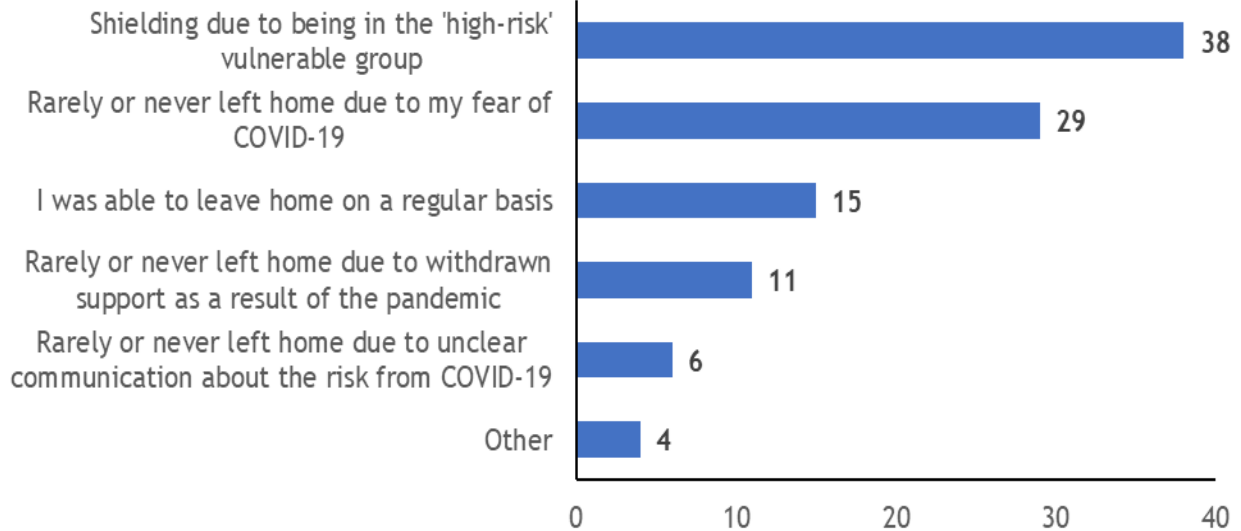
This section highlights the answers that participants gave in response to questions regarding their health conditions, living situation and state of employment.



The chart above shows the number of participants that suffer from each health problem or disability. A total of 145 responses were received from 72 participants. *Mobility issues* (e.g., difficulty walking short distances, climbing stairs, lifting) (n.34, 47%) was the most identified disability category followed by *Learning difficulties* (n.32, 44%). Fourteen (19%) participants indicated that they suffered from *Breathing difficulties or excessive fatigue* and eight (11%) participants indicated that they were *Hearing impaired* (e.g., deafness, partial hearing impairment).

Q2. Describe your living situation since the start of the COVID-19 pandemic in March 2020?
(please tick all that apply)

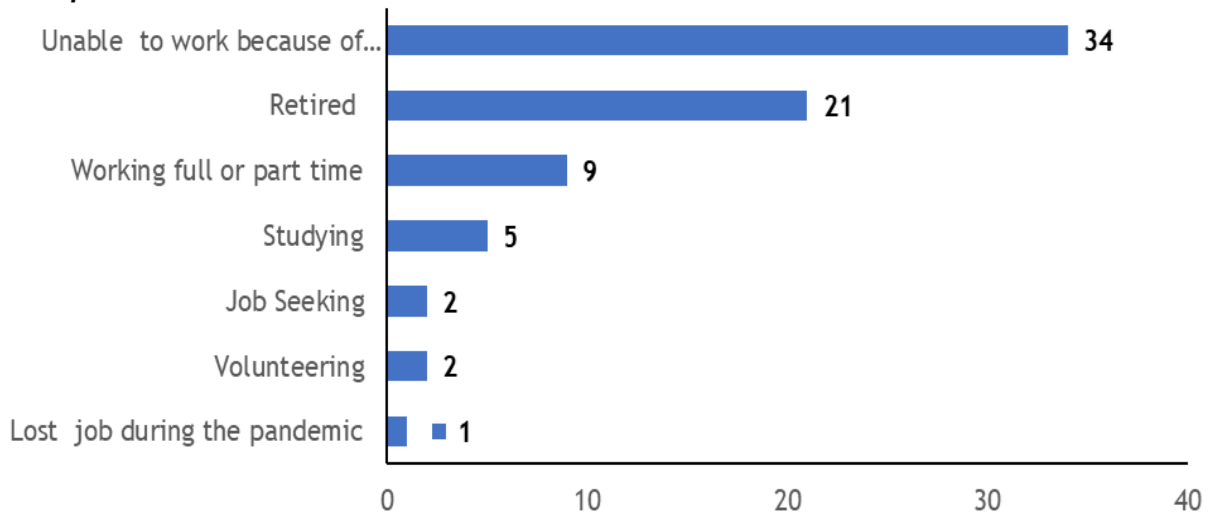
103 responses



A total of 103 responses were received for the question pertaining to individuals' living situations during the pandemic. Most participants (n.38) stated that they had been *Shielding due to being in the high-risk, vulnerable group*. Out of all 72 participants, 25% (n.15) indicated that they were able to leave home as and when they needed during the pandemic period, whereas other participants indicated that they rarely or never left home, either due to fear of COVID (n.29), a lack of assistance as a result of withdrawn support (n.11) or unclear communication about the risks of COVID-19 (n.6) or a combination. Most of the individuals who selected *Other* stated that they were able to leave for essential reasons, but "took extra precautions".

Q3. What is your current state of employment?

74 responses



In terms of participants’ employment status, most indicated that they were unable to work due to their disabilities (n.34). Another 21 individuals were retired, and 9 were working full or part time. Only one respondent indicate that they had lost their job due to the pandemic. Worth noting is that two participants chose 2 options for this question indicating that they were *Unable to work because of their disability but, were currently Studying*.

Section 2: Your Social Care Support

Q4. Who provides you with your social care support (i.e. your paid carer)?

72 responses



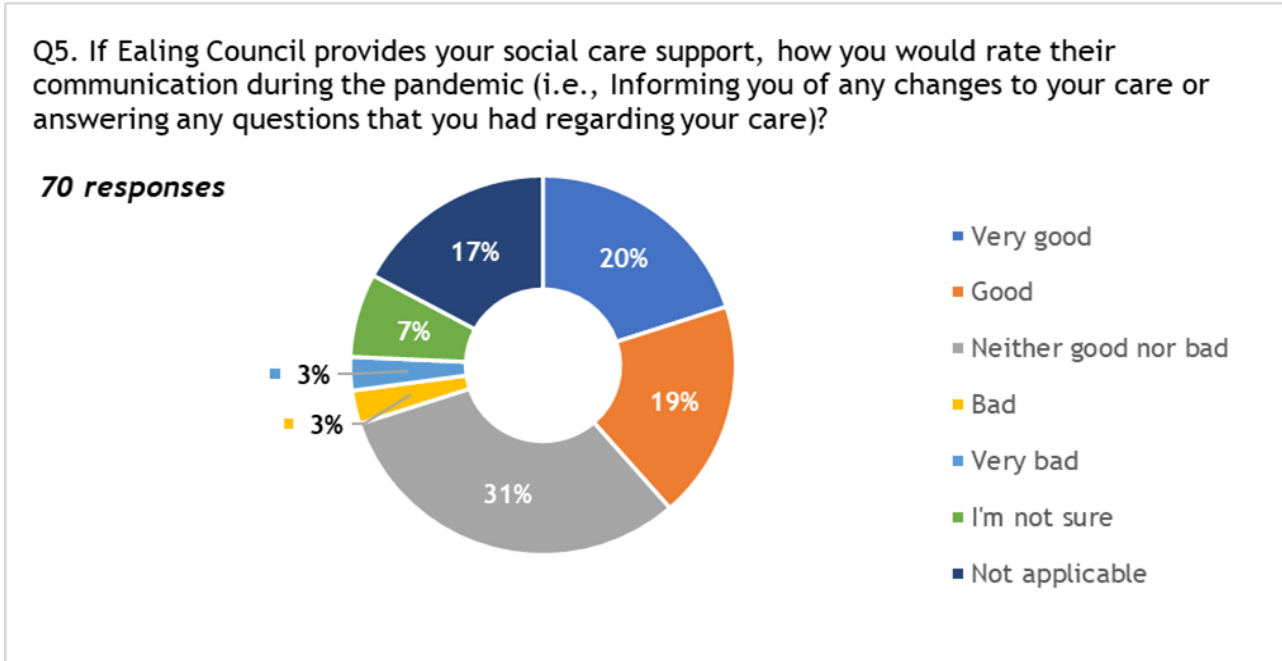
In total, 53 (74%) of the disabled individuals who participated in the survey currently receive social care support from *Ealing Council*. We received feedback from 4 (5%) individuals who indicated that they need social care support, but do not currently receive any. Out of the 7 individuals who selected *None of the above*, 5 stated that they only received support from family and friends during the pandemic.

COMMUNICATION:

Overall, the feedback received around the quality of Ealing Council’s communication as a social care provider suggests a mixed experience (chart below). Excluding those that answered *Not Applicable* (n.12, 17%), 39% of participants (n.27) rated Ealing Council’s communication as *Very Good* or *Good*. Several participants stated how grateful they were for the welfare calls that they received from their care provider throughout the pandemic, with one individual wishing this had remained consistent throughout. This positive sentiment is reinforced by the fact that only 4 participants (6%) rated communication from the Council as *Very Bad* or *Bad*.

“Knowing that someone made the time to just pick up the phone was so appreciated and beneficial for my mental health, even if I didn’t need anything in particular and the person calling wasn’t offering anything specific.”

However, the aggregate number (n.27, 38%) of those who indicated that they were *Unsure* (n.5) or that the communication that they received was *Neither Good nor Bad* (n.22) suggests that Ealing Council’s communication remains an area of social care provision that can be further improved. For example, some of those who answered *Neither Good nor Bad* expressed their concern by stating, “*I contacted the council to provide me extra support. I’m waiting for the support. Ealing Council need to be more responsible to provide proper information and communicate.*” and “*...services cut, and it is unclear when these will restart fully, if ever. There is a lack of information from the providers.*”.



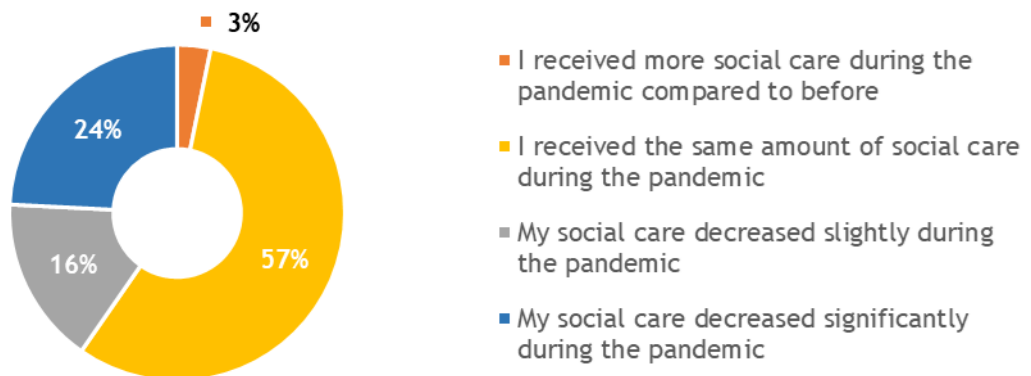
Another participant’s comment highlighted a related concern - “*I never got any support at all, due to being deaf.*” While it is highly unlikely that this is the case, it does demonstrate one instance in which a lack of communication has been the root cause of an individual not receiving the care and support that they are entitled to leading them to feel demoralised and forgotten during a time of need. Taken together, the more negative comments from individuals highlight a need for more consistency in Ealing Council’s communication regarding the changes being made to individuals’ social care support as well as more general communication regarding the level of social care that individuals living with disabilities are entitled to.

STANDARD OF CARE:

The chart below shows that the majority of participants (n.36, 57%) received the same amount of care during as they did prior to the pandemic. Out of these individuals, 30 received their care from Ealing Council. One of the recipients of Ealing Council care summarised the daily support that they receive by stating: “*I could not survive and function without the essential care and vital support via social care team*”.

Q6. To what extent was your paid social care affected during the COVID-19 pandemic?

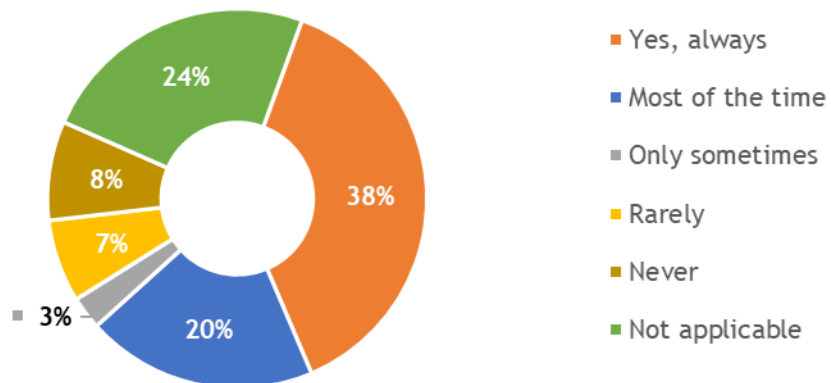
62 reponses



Yet, whilst some suggested their care was very much “*business as usual*”, this was not the case for all. In total, 16% (n.10) of participants thought that their care had *Decreased Slightly* - 8 of whom were recipients of Ealing Council care and even more stated that their care during this period had *Decreased Significantly* (24%, n.15) - 11 of whom were recipients of Ealing Council care. One of these individuals stated that their care plan was reduced “...without any prior information” with another suggesting that both the quantity and quality of their care was insufficient, “*Insufficient carers. They don't stay for longer periods. The duration is very short they don't finish their jobs. I have to do everything on my own.*”

Q7. During the pandemic, was your paid social care delivered to a high standard (e.g. your paid carer regularly visited you, cared for your specific needs, stayed for the allocated period of time)?

71 responses

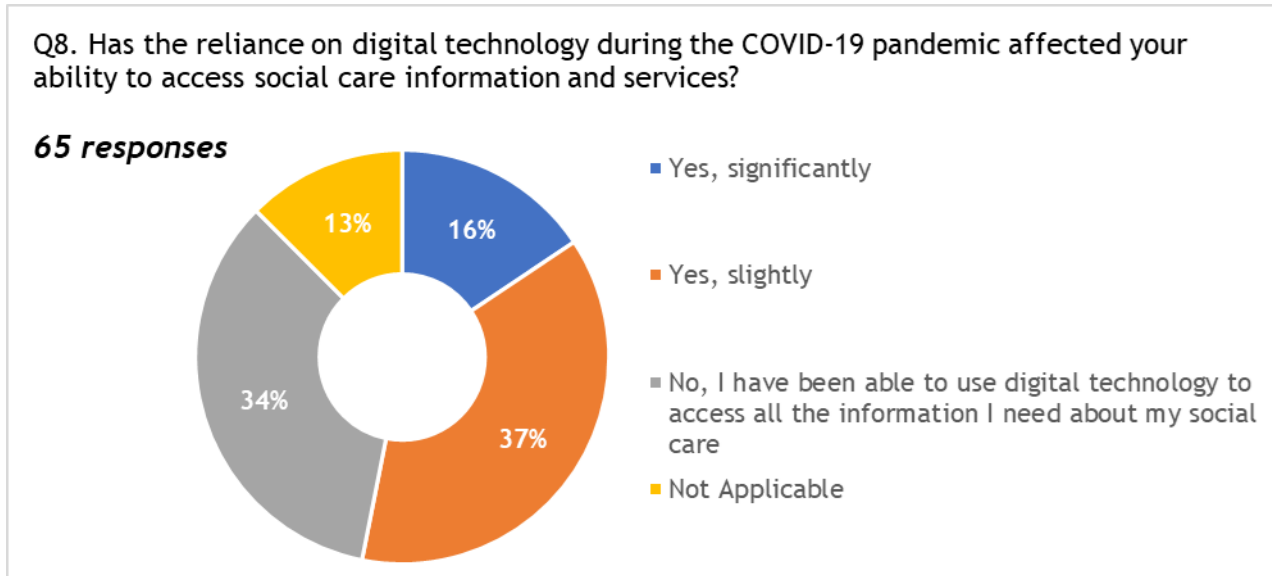


However, as seen in the chart above, a larger proportion of participants were positive about the quality of social care that they received. Out of 71 individuals, 27 (38%) indicated that the care they’ve received during the pandemic was always delivered to the highest standard. Given that a further 14 individuals (20%), stated that the social care they receive is delivered to a high standard *Most of the time* the findings suggest that social care provided during this period was, for the most part, sufficient in meeting individual needs. Some of the individuals who receive social care support from Ealing Council expressed their gratitude to the staff members that supported them during the pandemic.

“My carer has done an excellent job without worrying about herself.”

“Very good care support received. As a very vulnerable, disabled, housebound person, thank you.”

DIGITAL TECHNOLOGY AND SOCIAL CARE:



The chart above shows that, out of 65 individuals, 35 believed the reliance on digital technology had slightly (n.24, 37%) or significantly (n.11, 16%) affected their ability to access social care information or their social care support. Furthermore, analysis of the 53 responses from Ealing Council beneficiaries showed that only 14 out of the 53 have not faced any difficulties in accessing social care services or information digitally. The findings therefore indicate that while some have been able to use digital technology to access their care and even found it beneficial, a more person-centred approach could support those that require digital training or in-person support.

“The walk-in appointment was changed to virtual; much appreciated the digital services.”

“Due to usage of technology, I can connect to my support worker at any point.”

“I learned new skills over the pandemic to use the devices, extremely helpful.”

FOOD:

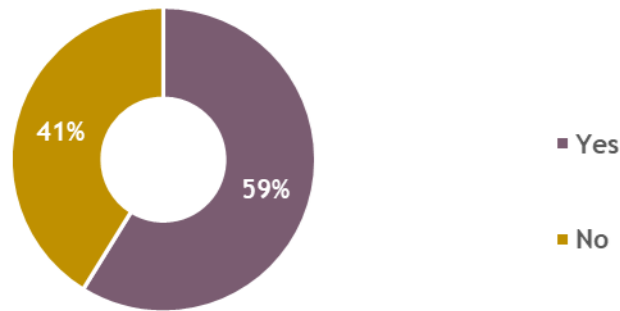
Although not directly related to an individual’s social care, 28 out of the 68 individuals stated that they had at least some difficulty in obtaining food during this period with 10 (15%) of these individuals suggesting that they had experienced significant difficulty. The support that individuals received in obtaining food appeared to be largely dependent on their personal circumstance. For instance, while one participant stated that, “My carer arranged the food for me as I’m unable to order online” another suggested that they “Starved almost half of the lockdown as I’m unable to cook because of the mobility issues.”. Once again, these findings suggest that there is still work to be done in order to achieve consistency in the overall care given to disabled individuals, even when it comes to basic provisions, like food.

Section 3: Access to Healthcare

GP SERVICES:

Q12. During the pandemic, have you experienced difficulties in booking appointment with your GP?

68 responses



As seen in the chart above, a large percentage of participants experienced difficulties in booking GP appointments during the pandemic. Further analysis indicated that most issues around appointment booking related to an inability to get through to their GP on the phone.

“I was not able to see my GP or get through over the phone. The phones would ring, and no one would answer. I do not know how to use the internet, so things were very difficult for me.”

“It was extremely difficult to get through on the phone lines.”

On the other hand, some participants praised the virtual appointment method, suggesting that the conversations over the phone were sufficient in meeting their healthcare needs with one participant stating, *“I had 3 or 4 phone consultation that were fine. My GP offered a call back service already, so I was used to a phone chat with them.”* Additionally, other participants who had been able to attend appointments for a face-to-face appointment were appreciative of the support they received:

“Fortunately, I got to see my doctor on the second chance during the busy times.”

“Slightly apprehensive about accessing health services due to the uncertain nature of the virus but always felt safe and supported.”

However, the difficulties in accessing care during the pandemic for this cohort seem to outweigh the positive experiences. Participants’ responses highlighted that the one size fits all approach to healthcare can be potentially damaging to individuals’ health and mental wellbeing as it can cause feelings of anxiety, frustration and hopelessness:

“No face-to-face availability. Daughter had to try and take photos of sores inside the mouth and send to GP. Not easy or satisfactory.”

“I was experiencing suicidal nervous breakdowns and severe depression. Could not see my doctor at all especially when I was told my husband was suffering from prostate cancer”

“Having to phone which I can't as I do not hear on phone”

“Phone appointments only, I don't always feel confident.”

“GP did not seem interested in my situation as an elderly person.”

“Having to phone and long waiting to speak to someone at reception to get medical advice was depressing.”

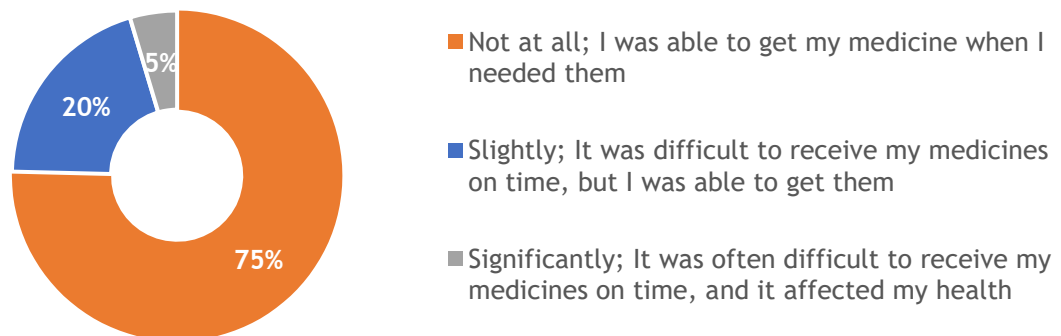
“They cancelled my daughter's regular cognitive therapy without any prior information.”

“My hearing test appointment was first delayed due to the pandemic in 1st phase of lockdown and now the 2nd phase over still didn't get an appointment.”

PHARMACIES:

Q13. Has your ability to access your prescribed medication or other medicines been affected during the course of the pandemic (since March 2020)?

68 responses



For the most part, participants indicated that they were able to obtain their medication during the pandemic. Only 5% of participants (n.3) indicated that they had experienced significant difficulties with this aspect of their healthcare. Although there weren't many, comments made about Ealing Pharmacies' service delivery were positive with one participant describing them as *“brilliant”* throughout the pandemic and another stating that *“the pharmacy staff delivered it (their prescription) the next day. It was relieving.”*. Interestingly, while one individual stated that they experienced sufficient support over the phone from their GP in receiving their prescription, another participant stated that the prescription process over the phone proved difficult for them and that *“...if it wasn't for my support worker and would not get my medication on time.”*

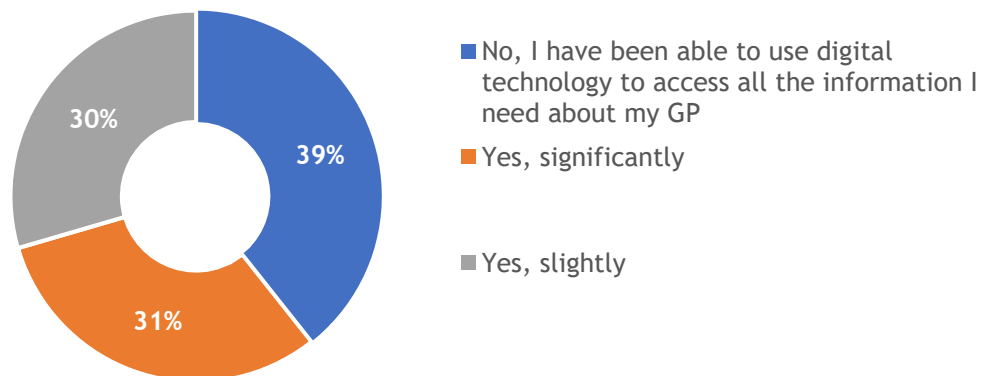
HOSPITAL APPOINTMENTS:

Out of the 69 participants, 28 (41%) had experienced a delay or cancellation in their treatment. The analysis showed that of these individuals, 25 (89%) have since attended or rebooked their hospital appointment. This demonstrates effective and efficient delivery of treatment and care by the Hospitals who are supporting Ealing residents and suggests that despite mounting winter pressures and the continued strain put on Hospital services by the pandemic, disabled individuals are being adequately supported.

DIGITAL TECHNOLOGY AND HEALTHCARE:

Q16. Has the reliance on digital technology during the COVID-19 pandemic affected your ability to access information about your health care (GP, Pharmacy, Hospital, etc.) during the COVID-19 pandemic?

62 responses



In relation to the virtual approach to healthcare, 61% (n.37) of individuals indicated that their ability to access healthcare information and services during this time was at least somewhat impacted by the reliance on digital technology, with 31% (n.19) of participants indicating that the shift to a predominantly virtual model of healthcare has had a significant impact.

As highlighted in the detail provided by some participants, oftentimes the difficulties experienced don't simply result in not being able to speak to a doctor, but also in a deterioration in their physical health, feelings of being forgotten, a distrust in services, a negative impact on their mental wellbeing and a knock-on effect to other areas of the healthcare system that are already overwhelmed.

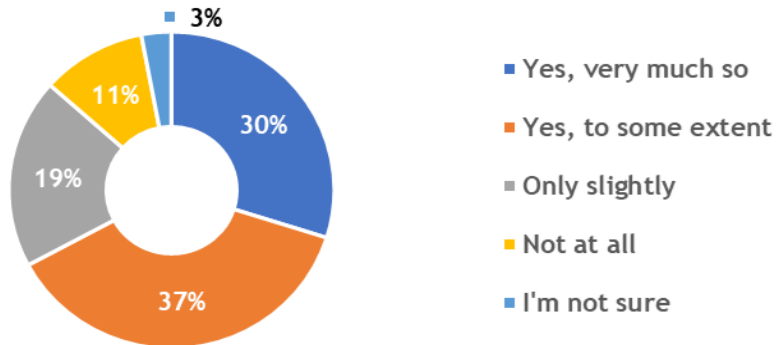
“Unable to get appointments and relied on A&E. Telephone diagnosis was available but I prefer to see GP”

“No face-to-face appointments. Care from accident and emergency only.”

Section 4: Your Mental Health Wellbeing

Q17. Do you believe that your mental wellbeing was affected due to the pandemic and resulting national lockdown (i.e., have you experienced loneliness, social isolation, psychological stress, feelings of unhappiness?)

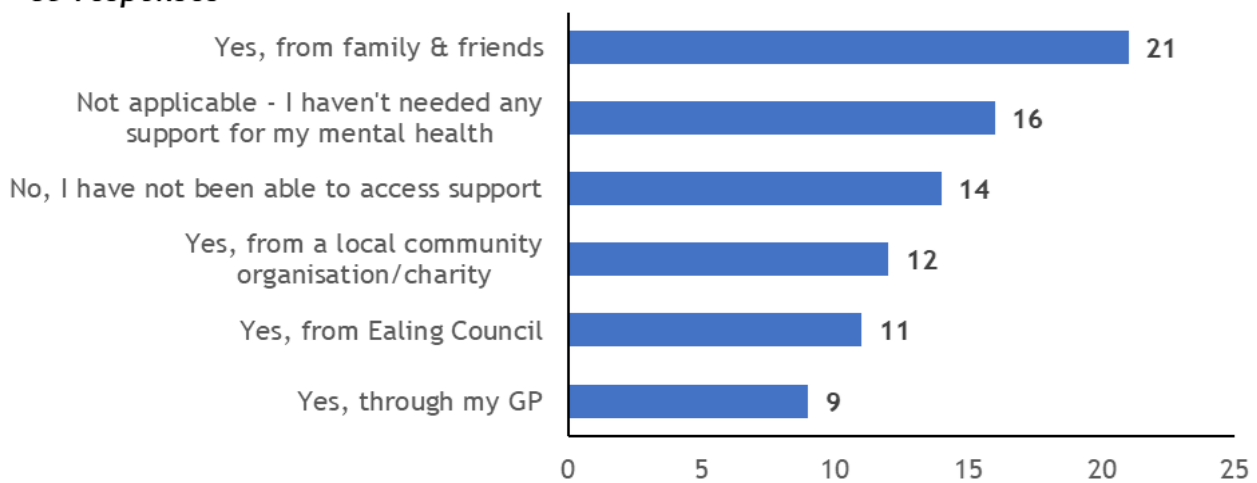
66 responses



As seen in the chart above, 44 out of 66 (67%) indicated that their mental wellbeing had been impacted by the pandemic with 20 (30%) of these individuals suggesting that the effect was significant. In addition, a further 13 (20%) individuals answered *Only Slightly*. These findings show that while the impact of the COVID-19 pandemic on the mental wellbeing of the entire population is clear, those who are living with a disability have been indiscriminately affected.

Q18. Have you been able to access mental health support during the pandemic (please tick all that apply)?

83 responses



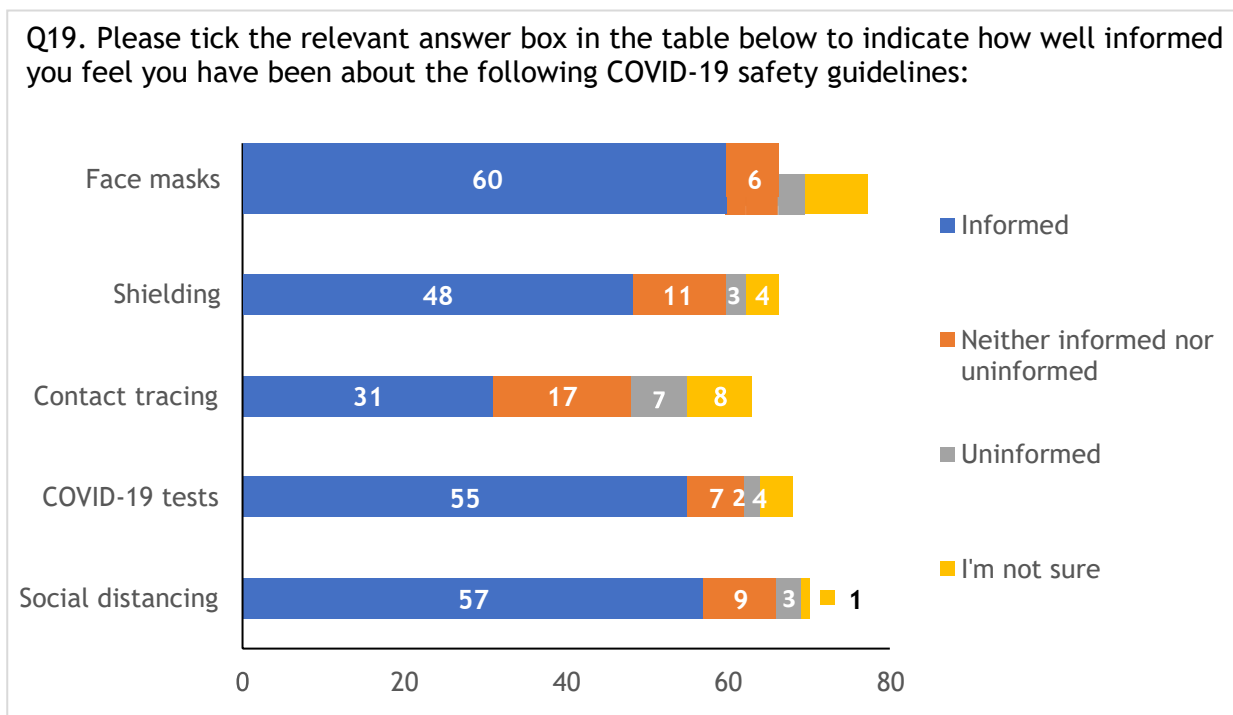
The findings from this research on the current level of access to mental health support suggest that more can be done by statutory and community organisations in this area of treatment and care. As seen in the chart above, out of 69 individuals, 14 (20%) indicated that they had not been able to access mental health support, during the pandemic. One individual commented that they were not able to access any mental health support for adults with autism and another stated that no one had provided them with a way of accessing any mental health support services. The issue with access is also a result of

service capacity as a third individual stated that although they had managed to speak to someone about therapy services to help their mental wellbeing, they were told that the waiting times for therapies can be up to two years. In addition to those who didn't access any formal mental health support, 15 (22%) out of the 21 individuals who selected *Yes, from family and friends* indicated that they received informal support from family and friends only and no additional, formal mental health support. The value of support from loved ones cannot be overstated. However, the current data suggests that this is not sufficient in meeting the mental health needs of disabled individuals and that more professional support is required to deal with the impact of the pandemic on their wellbeing.

Section 5: COVID-19 and the Vaccination

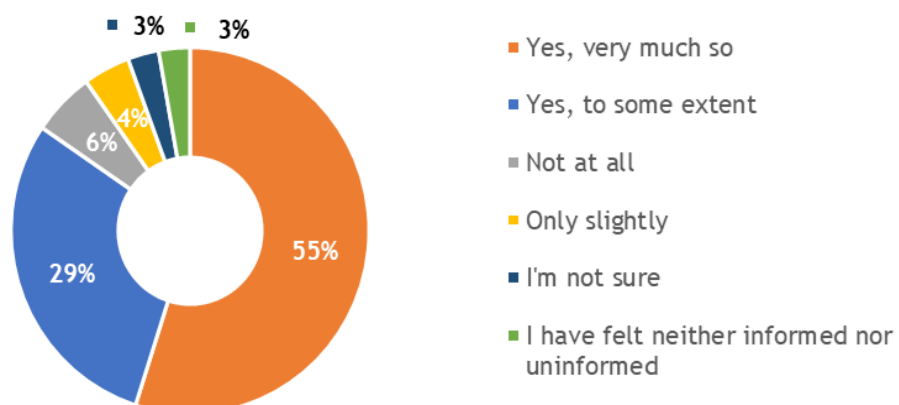
At the time of this research, 68 (94%) out of 72 participants had received both doses of their COVID-19 vaccination.

Q19. Please tick the relevant answer box in the table below to indicate how well informed you feel you have been about the following COVID-19 safety guidelines:

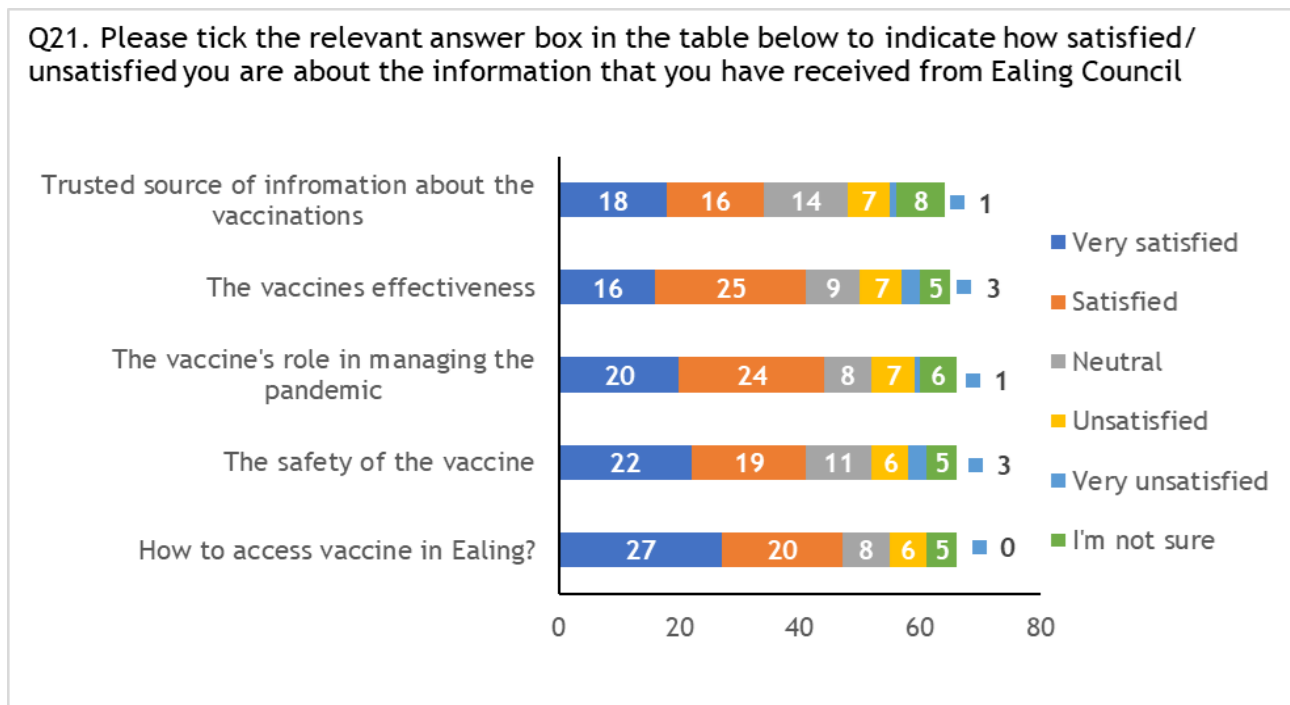


Q20. Have you felt informed about the COVID-19 Vaccination programme, since the start of the roll out on the 8th of December 2020?

71 responses



The charts above show that Ealing Council’s communication with this demographic regarding COVID-19 and the vaccination has been largely effective. Most individuals indicated that they felt *Informed* around the use of face masks (n.60, 87%), COVID-19 tests (n.55, 81%) and social distancing (n.57, 81%). In addition, a large proportion of individuals also felt informed about the COVID-19 vaccination rollout (n.60, 84%) with the majority of these answering *Yes, very much so* (n.39, 55%). On the other hand, many remain uninformed about contact tracing (n.32, 51%) and shielding (n.18, 27%).



In relation to Ealing Council’s distribution of information on the COVID-19 vaccination, the findings show that more individuals were satisfied than unsatisfied. Out of 66, 71% (n.47) were satisfied (41%, n.27 *Very Satisfied*) with the information that they received from Ealing Council on how to access the vaccine, 67% (n.44) were satisfied (30%, n.20 *Very Satisfied*) with the information they received regarding the vaccine’s role in managing the pandemic and 63% (n.41) were satisfied (25%, n.16 *Very Satisfied*) with the information that they received from the Council regarding the effectiveness of the vaccination.

“No problem at all, received all the information about the guidelines.”

“My care provider sent me newsletters having all the information.”

“Ensured our safety. My care coordinator provided all information virtually.”

“They informed me about the COVID-19 tests as I was doubtful of getting infected.”

“Received information from the Ealing Council about the dates of (my) vaccinations. Got text messages about the vaccination centre and bookings.”

Interestingly, the effectiveness of the vaccination was also the area in which individuals expressed the most dissatisfaction with the information that they received as 15% (n.10) stated that they were *Unsatisfied* or *Very unsatisfied*. Areas in which individuals expressed

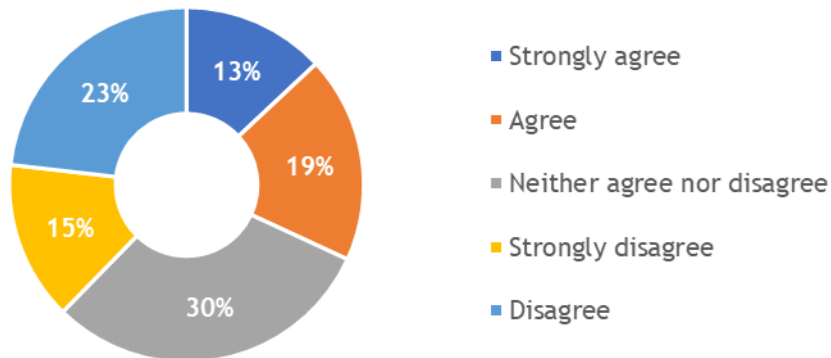
the most uncertainty and/or neutrality were Trusted Sources of Information About the Vaccine (47%) and the Safety of the Vaccine (38%), with the two most likely interrelated.

“Lot of vaccinations made me confuse due to lack of proper information.”

The final question pertaining to COVID-19 asked participants whether they agreed or disagreed with the following statement: “Since the government restrictions were reduced on the 19th of July 2021, I feel safe going out”.

Q22. To what extent do you agree or disagree the following statement “Since the government’s COVID-19 restrictions were reduced on the 19th July 2021, I feel safe going out”.

69 responses



Out of 69 individuals, only 32% (n.22) agreed or strongly agreed that they felt safe to go out after the 19th of July. Although not surprising, these findings show that there is still work to be done by the health and social care and community organisations in the borough to communicate effective explanations of exercising safety precautions and the information on the effectiveness of the vaccine to reinstate confidence in disabled individuals who have most likely been in a chronic state of worry during this time.

Findings & Analysis:

Focus group responses

During the two discussion forums at the Deaf and Hard of Hearing Women’s Group at Neighbourly Care (n.4) and the Ealing Power Group at the Dare to Dream service in West Ealing (n.14), a total of 18 individuals told us about their opinions about and experiences of care during the pandemic. This section outlines the main themes of the discussions.

Q1. Which of the following best describes your health problems or disabilities? (Please tick all that apply)

18 responses



LACK OF COMMUNICATION

During the discussions, the most referenced and pervasive issue was the lack of communication - and subsequently, the lack of trusted information - attendees felt they received from health and social care services. This related to the changes that were made to their care as well as the rules and restrictions that related to COVID-19 and the national lockdown.

“Adapting to the changing COVID-19 rules has left me feeling frustrated and worried to step outside even after the easing of lockdown.”

“A lot of people got virus even after getting vaccines. It made me feel scared and I wasn’t sure of taking a vaccine.”

“There are a lot of varieties of the COVID-19 vaccinations. It is confusing and I’m not sure which one to take and which one will be more effective.”

Further still, almost all attendees agreed that there was a lack of information regarding how they could obtain their COVID-19 vaccination. In fact, two of the attendees at the Ealing Power Group discussion forum and 3 attendees at the Hard of Hearing and Deaf Women’s Group forum stated that they had decided not to receive the COVID-19 vaccinations. These individuals suggested that insufficient communication and lack of trusted information sources played a part in their decisions. The opinions and experiences of these individuals indicates that the standard of communication from health and social care providers needs a further review.

One particularly worrying theme that was brought to light during the discussions was the lack of support and access to care services during the pandemic for those who are hard of

hearing. Attendees who are hard of hearing highlighted that a lack of sign language interpretation on television news programmes and a lack of subtitles on other online sources of news (including Social Media channels) caused persistent difficulties in the acquisition of effective and trusted information, making the ever-changing landscape of the pandemic “*extremely confusing*”.

In addition, adaptations to day-to-day social interactions that were forced upon the population by the pandemic were the most referenced factors that contributed to this lack of access and support for individuals who were hard of hearing. Interactions with healthcare professionals were made difficult as mandatory face masks meant that individuals were unable to lip read. One attendee also stated that they felt helpless after “*staff at reception ignored me because she was unable to understand sign language.*”. Furthermore, while telephone appointments or enquiries may work for other people, they were simply not an option for those that are hard of hearing. All hard of hearing attendees felt that these obstacles were not appropriately addressed by healthcare professionals and left them feeling discriminated against - “*They ignored my queries because I’m unable to understand what they say because of the face masks, and it made me worried and anxious.*”. This oversight is something that needs to be urgently addressed.

SOCIAL CARE SUPPORT:

Out of the total number of discussion forum attendees (n.18), 13 receive social care support from the Ealing Council. A further 3 individuals who are hard of hearing are actively seeking social care support. All the discussion forum attendees who receive support felt that their social care decreased significantly during the pandemic with one attendee reporting that support staff did not turn up for a week and they were, therefore, left alone to care for themselves. Additionally, for some, the knock-on effect of staff shortages was realised, as it was not only their health that was affected, but the health of family members that cared for them.

“Lack of staff due to infection made it difficult for vulnerable parents caring for me”

“My support worker was shielding that made my vulnerable parent stressed and worried.”

“Support worker got sick it messes up the entire support process.”

Crucially, some discussion forum attendees stated that their social care provider did not supply them with essential equipment during this time such as Mobility Chairs, Hearing Aids and vibrating equipment for hard of hearing individuals as well as transportation for essential travel. This resulted in feeling unsupported and ill-equipped to leave their home during the pandemic which attendees suggested negatively impacted their mental wellbeing.

In conjunction with this decrease in care that attendees experienced, an insufficient level of communication from social care providers was also regularly highlighted. The uncertainty that this lack of communication caused appeared as one of the most common themes during both discussions.

It should be noted that attendees at the Ealing Power Group were incredibly grateful to the staff and volunteers at the group who regularly called them, with some stating that they received one of these check-in calls every day.

“I suffered a lot during the pandemic due to the damage of my hearing aids. My sister-in-law tried ordering a new one but couldn’t get through.”

ACCESS TO HEALTHCARE:

The general feeling from attendees relating to GP services was one of disempowerment. Individuals suggested that the reliance on loved ones attempting to book appointments for them was “*frustrating*”. One attendee who was hard of hearing stated that it made them feel “*disempowered to take away my own decisions to see my GP, I have to depend on my son to book an appointment for me.*” Another attendee with learning difficulties stated that “*My mother called several times to book an online consultation with the GP for my health check but due to long waiting over the telephone, she got frustrated and dropped the phone.*”

Attendees were also frustrated with the lack of follow-up on delayed or cancelled health care appointments. In total, 11 out of 18 attendees had an appointment with their GP or the hospital postponed. These appointments included routine check-ups, physiotherapy hearing tests and blood tests. At the time of the discussion forums, none of these individuals had received any indication that these appointments will be rescheduled.

“Sad due to missed GP appointment”

“Did not get GP appointment I wanted. Only phone consultation, not face to face”

“Long waiting time to see GP”

PHARMACY:

Attendees agreed that, during this time, pharmacies had demonstrated service delivery to the highest standard with individuals wanting to thank them for their efforts during the pandemic.

“Delivered medicines at my doorstep in one ring only, fantastic service.”

“The pharmacies take good care of my repeat prescriptions.”

MENTAL WELLBEING:

Unsurprisingly, all the attendees at both forums felt that the pandemic had affected their mental wellbeing. Individuals referenced the inability to meet with family and friends due to the shielding rules as a key contributor to this as well as the “*stress, anxiety and worry*” that came with trying to keep up with the persistent changes to the COVID-19 restriction guidelines. As previously mentioned, for those with hearing difficulties, lack of available interpreters during in-person appointments, a lack of sign language or subtitles on news channels and social media channels and the general use of face masks and telephone appointments left them feeling “*extremely confused*”, “*disempowered*” and “*scared*”.

DIGITAL TECHNOLOGY:

Most of the attendees stated that they found the use of digital technology for their health and social care very difficult. This includes the challenges that individuals who were hard of hearing faced due to the reliance on telephone conversations.

Interestingly, the use of digital technology was difficult for almost all attendees due to the lack of devices available during the first lockdown. Two attendees stated that they missed online college classes during this time. However, attendees at the Ealing Power Group stated that during the 2nd lockdown, Ealing Council provided them with laptops and tablets to share. The staff and volunteers at the group were subsequently able to support individuals, either remotely or during a once a week in- person session, by teaching them how to use the devices to attend online classes from home, access news websites for COVID-19 rules and manage their own health care matters, if appropriate. Attendees praised the staff and volunteers at the Ealing Power Group for this level of support.

Unfortunately, some attendees who did not obtain device access stated that they really struggled to cope during this time:

“Missed my studies my mom doesn’t have a mobile or laptop.”

“Couldn’t book my online vaccine appointment as I don’t have a device and I can’t phone them either.”

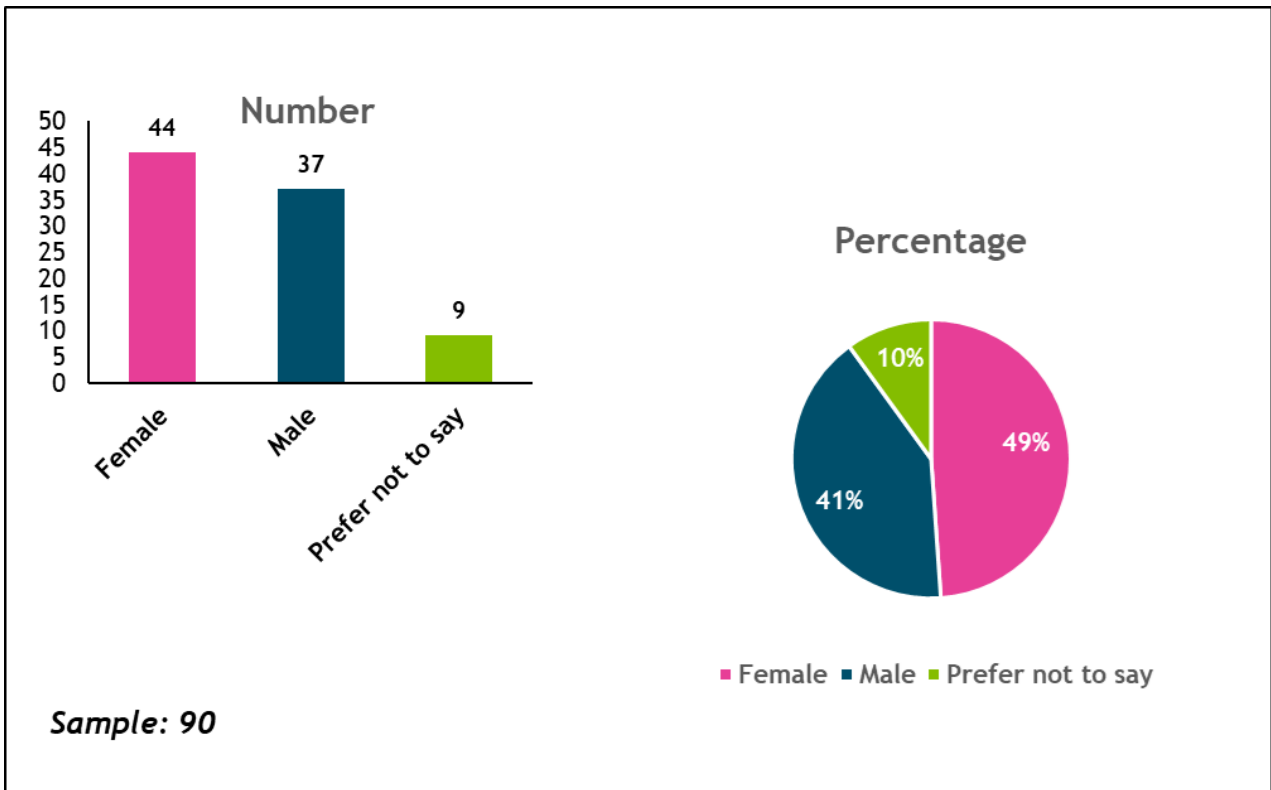
“I don’t know how to use it (digital technology), so I have had to learn.”

Monitoring information

The charts below show a breakdown of the demographic information that we collected from participants who are living with a disability or disabilities (n.90). This piece of work did not capture the demographic details of the informal carers who provided their feedback.

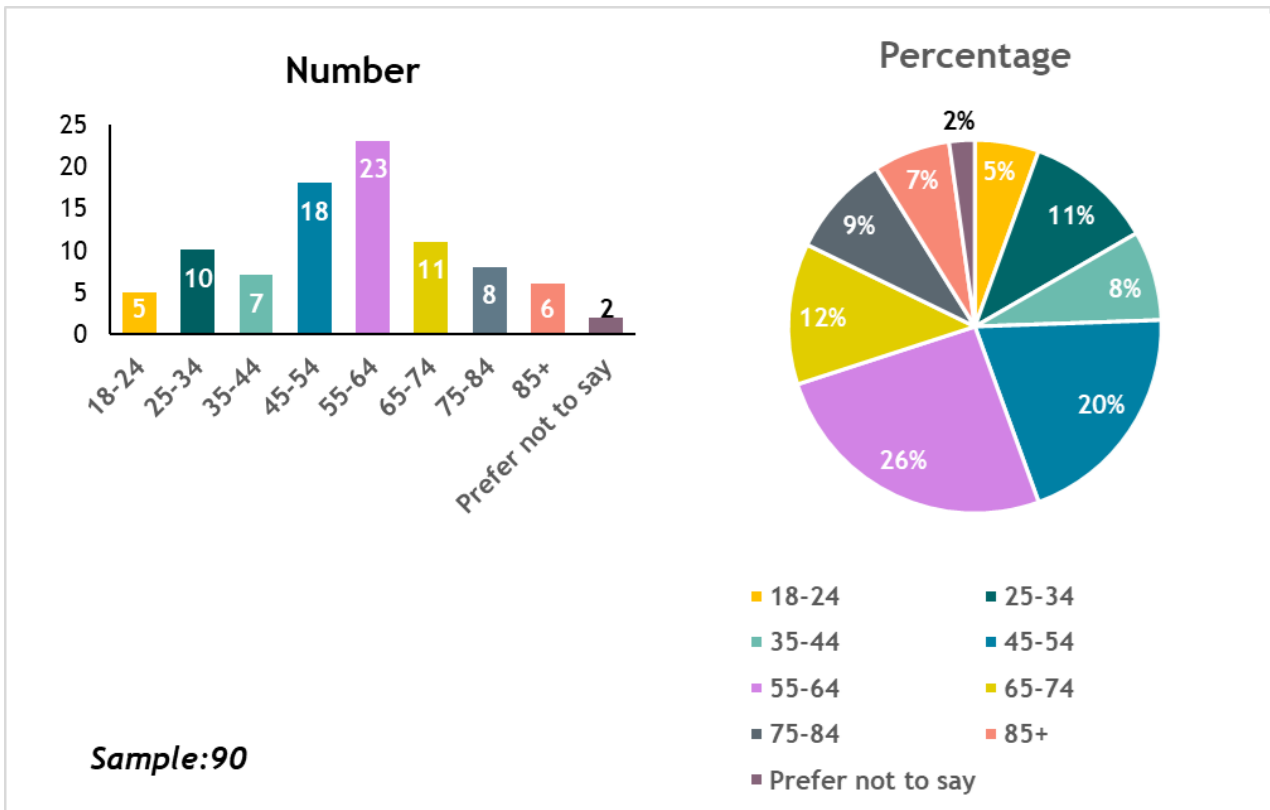
Gender

During this research we heard from a slightly higher proportion of disabled residents who were female (n.44) compared to males (n.37).



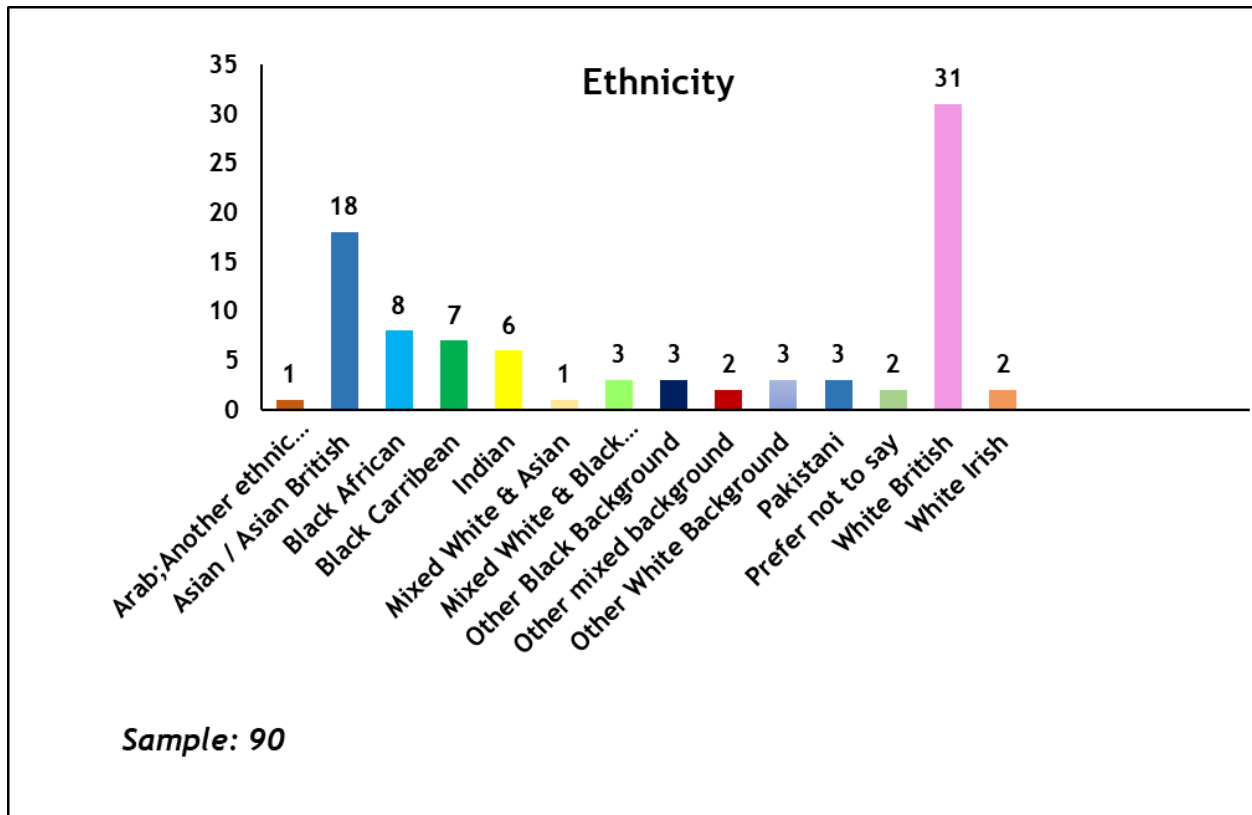
Age

Below is a breakdown by age group of the participants who chose to disclose their age. The top three age groups that we heard from were aged between 55-64 (n.23, 26%), 45-54 (n.18,20%) and 65-74 (n.11, 12%).



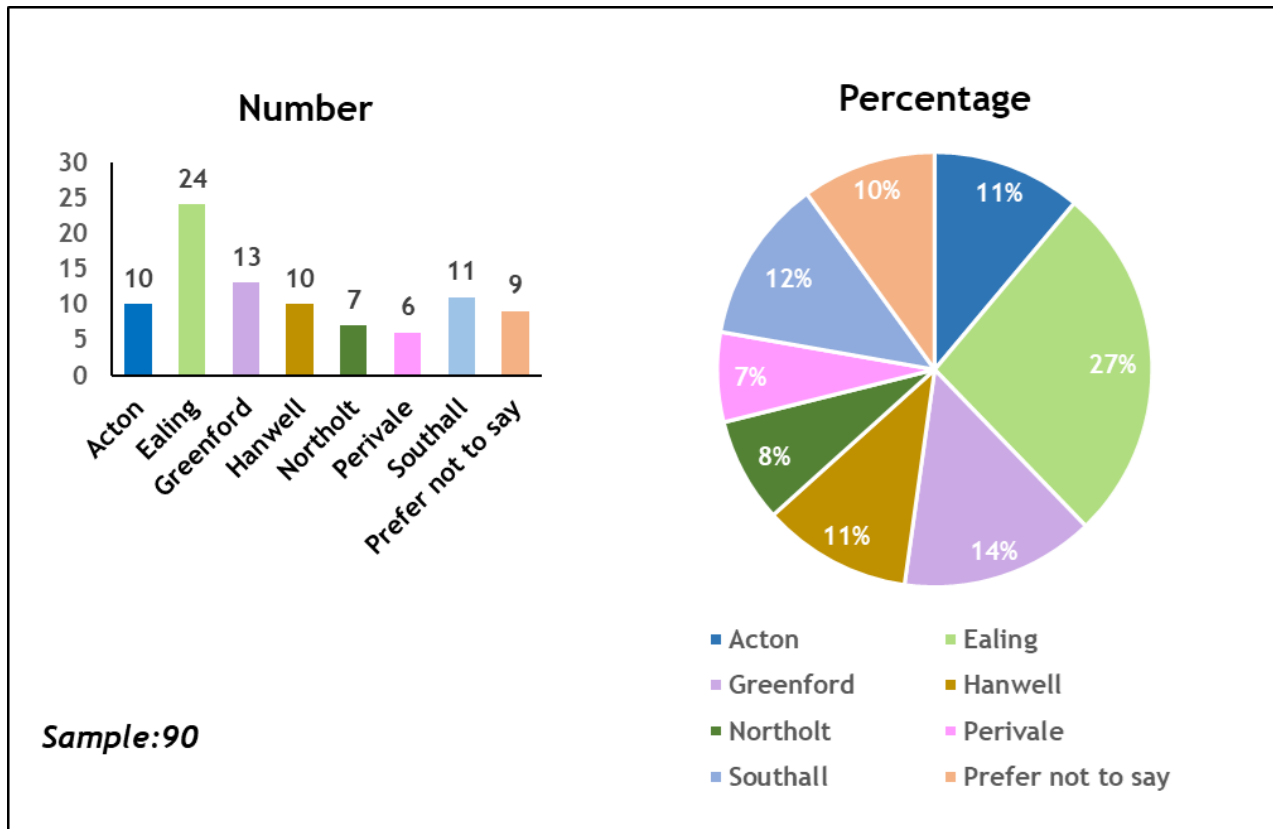
Ethnicity

Most individuals who participate in this research were from a Black or Minority Ethnic background (n.55). Individuals of White British ethnicity made up 35% of the population sample (n.31), with Asian/Asian British participants (n.18, 20%), Black African participants (n.9, 8%), and Black Caribbean participants (n.7, 8%) making up the most represented ethnicities.



Area of residence

Most respondents were residing in the Ealing locality (n.24, 27%) followed by Greenford (n.13, 14%) and Southall (n.11, 12%) The lowest number of respondents were from those residing in Perivale (n.6, 7%).



Findings & Analysis:

Family Carer Survey Responses

FAMILY CARER

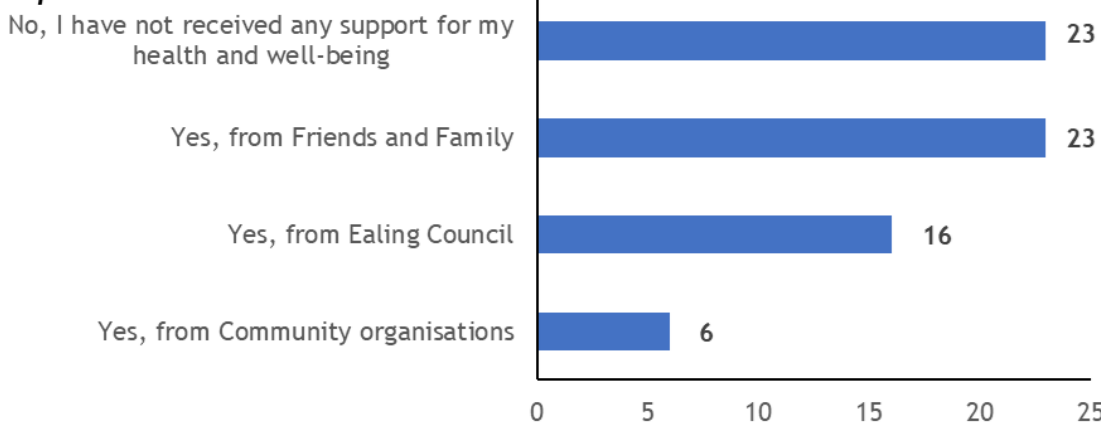
“Caring for my care during the pandemic was incredibly difficult. It took a huge toll on my health and wellbeing and when my care died it was devastating as I was not allowed to be with her due to the care home being overwhelmed and not communicating despite clear instructions as to her wishes. The whole process has been horrendous, and I know many other carers who are now on their knees - broken emotionally, financially and in poor health as a result of giving up work to be exploited as unpaid carers. We feel very strongly that there is no understanding of the fact that relationships, careers and hopes are dashed. Unpaid carers are COMPLETELY taken for granted.”

Section 6 of the Disabilities survey asked unpaid, family (or friends) how they would evaluate the social care that their loved ones received during the pandemic. Additionally, this opportunity was taken to ask carers what areas of care they believe could be improved and how their own health and wellbeing has been affected during this time. In total, 62 unpaid carers provided their feedback.

How do you feel:

Q28. Have you received any support for your own health and wellbeing during this time (tick all that apply)?

66 responses



When asked about their own health and wellbeing and the challenges that they faced during the pandemic, the feedback from carers was unsurprising. From the number of carers who responded, only 16 (24%) had received support from Ealing Council and just 6 (9%) had accessed support from a community organisation. Although a few carers commented that they were relatively unaffected, many individuals touched upon the significant physical, emotional and mental fatigue that they felt due to:

- *Trying to “juggle full time care with a job”*
- *Worrying about the number of COVID-19 related safety precautions that they had to ensure themselves and their loved one were abiding by.*
- *Feelings of neglect from services and distrust in the system with one participant stating, “Unpaid Carers feel we have been used and abused” and another saying, “I just wish there was more reward for the hard work we’ve done.”*
- *A lack of mental support for them and their own health having to “take a back seat”*
- *A lack of effective communication (both the lack of information and in one case, information overload) from paid care agencies, leaving family carers to provide “24/7 care” whilst being uncertain about the future and not having “an end in sight”.*
- *The guilt, fear and anxiety brought on due to “not being able to offer the right support and reassurance” to their loved one.*
- *Dealing with rude staff when reaching out for Primary Care support for their loved ones*
 - *“The receptionist sound rude and dropped the call without even hearing me completely.”*
- *A lack of support from social care services, with one individual highlighting that their own health is deteriorating - “We have not had much care or had support from them. But, at the moment, I am not well & I am their carer and their mother & I am having health problems. Need plenty of help.”*
- *No respite for carers with individuals stating it is “Emotionally challenging to keep the mood uplifted.” and that it’s “Physically draining to do all the caring alone” without “seeing my own friends and getting a break from care.”*

Care Received:

This feedback provided by family carers offers a unique perspective which will be integral to the improvement of social care service delivery for disabled individuals. Regarding the quality of care that loved ones with disabilities received, feedback was mixed; 16 individuals commented that the care that their loved ones received was “not good”, “not enough” or simply absent - *“There is no support, I am providing all the support.”* This becomes particularly disheartening when combined with feelings of being forgotten that these carers witness in their loved ones and experience themselves. One carer stated, *“We just have to get on with it, the state doesn’t seem to care about him.”*

On the other hand, many carers were happy with the formal care that their loved one received and expressed their gratitude for the role that the paid carers/ social care providers played during the pandemic. In total, 19 individuals were positive in their comments about the paid care that was delivered, stating that it was “*excellent*”, “*very helpful*” and “*essential*”. Other individuals indicated that care providers were successful in their adapted virtual approach to care with one individual stating that their loved one was “*lucky to have a fantastic group of carers got 1 or 2 calls from social services to ask how he was*”. Others expressed their gratitude, as well.

“Received all the necessary things from the care services to keep me and my wife safe.”

“Great staff they always called me and sent wheelchair and stick to support my father’s mobility issues.”

Individuals who were neither overwhelmingly positive or negative expressed their understanding of the situation, commenting that the care that their loved one received was “*limited at times, but overall adequate*” and “*not great, but all have had to adapt*”. One individual stated that the staff at the care home that their loved one had to be moved to “*did their best*”, but that they were “*not prepared*” for the strain that the pandemic put their service under. The gravity of the situation is clear in this participant’s experience as they lost their relative during the pandemic. They commented, “*the failure (of the care home) to enable a last goodbye was unforgivable - but understandable*”

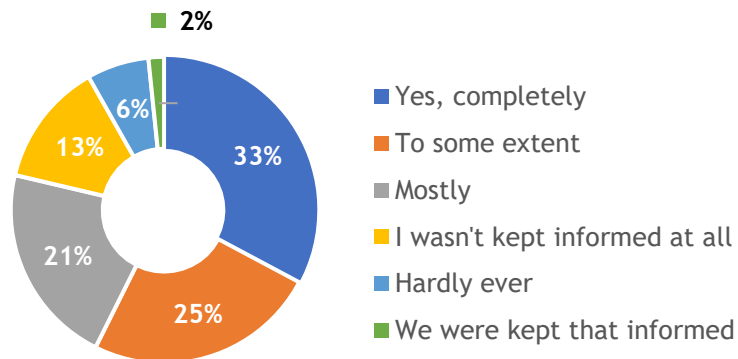
CASE STUDY

Thematic analysis showed that in combination with a lack of information, a lack of “partnership and communication” between all parties involved in a disabled individual’s care has led to the standard of care during the pandemic falling short. One carer suggested that while the care that their partner (a deaf individual who is going through Chemotherapy) received at a hospital was ‘wonderful’ the care provided by Ealing Council was insufficient as the method of contact the provider recommended was telephone but, would not allow the carer to speak on behalf of them - “...they wouldn't accept me using the phone in her name and there is nothing available for deaf people who cannot use a phone. When my partner complained about this saying that we could text or email instead, *she* got told that it is not possible.”.

A point worth noting is that this carer indicated that they themselves were over 70 and, therefore, even the basics such as buying food for them both during this time proved difficult. They had to recognise the risk that they were putting themselves under while making sure that their loved one was also safe.

Were you kept informed about the changes that were made to your relative/ friends social care during the pandemic (from March 2020)?

61 responses



Out of the 61 individuals who answered the question pertaining to how informed they felt about the changes being made to their loved one’s care from their social care provider, 20 (33%) felt entirely informed, 15 (25%) individuals felt informed *To some extent* and 12 (20%) individuals indicated that they did not feel informed. Therefore, out of the total number of carers who responded to this survey, 45% (n.27) were not adequately informed about the changes that had been made to their loved one’s care. Of the individuals that received care from Ealing Council, 16 (30%) of their informal carers indicated that they were not sufficiently informed about changes to their loved one’s care. As one participant stated, “...care providers are not providing enough support. No information on the schedules of carers. Never informed about their visits”.

Next Steps:

Carers also shared their opinions on what potential solutions could be actioned to alleviate some of the issues and challenges faced during the pandemic and going forward.

STANDARDS OF SOCIAL CARE SERVICE DELIVERY

Carers relatively frequently suggested that their loved ones paid care and support needs to be improved. References were, for the most part, related to the amount of time that their loved ones received paid care - “*The key is that the social care provides agreed and approved service by spending allocated time to complete the required care tasks.*”

In addition, one carer suggested that “...staff need to be trained well to deliver high standard of support. Assessments, regular supervision, peer to peer support for mental health wellbeing.”

Additionally, and somewhat associated with the delivery of care, was a comment from one family carer that they “*would be happier to know carers have been vaccinated...*”. They indicated that although they had consistently witnessed paid carers wearing the appropriate PPE, they questioned whether social care provider staff who use public transport were being regularly tested.

SOCIAL CARE PROVIDER COMMUNICATION

Carers suggested that communication and care could be improved through the implementation of a single point of contact for their loved one’s care needs. Feedback also indicated that regular telephone contact from care providers with both themselves and their loved ones should be incorporated into support care plans as a standard measure of care.

One carer recognised that a higher degree of integration between all stakeholders involved in their loved one’s care would help to alleviate some of the challenges outlined and that more regular and transparent lines of communication would help to facilitate this integrated care.

PERSON-CENTRED APPROACH TO CARE

Within this notion of more integrated care, carers agreed that the ‘one size fits all’ approach to care during the pandemic has contributed to the inconsistencies seen in individuals’ social care and the resulting decrease in care provided.

For example, one individual who supports a loved one who is hard of hearing highlighted the need for more B.S.L trained interpreters for healthcare services with another suggesting that as unpaid carers, they need to be much more involved in the care planning and organisation if their loved one cannot independently organise and manage their own care, due to their disability. This particular individual suggested that this could be done by “*visiting and assessing the genuine case required by the person.*”. Another individual suggested that while there is a place in care for online support, the “*appropriate and relevant services need to take place in person*”, in order to create a person-centred approach to care and provide sufficient and specific support.

FAMILY CARER RESPITE

To address the fatigue, exhaustion and ill-health that carers are experiencing, many mentioned that they should be supported with access some sort of short break, respite service.

There was an overall agreement from carers that the resumption of loved one’s day activities may help to partly address this issue, however, exploring ideas around longer respite should still take place, particularly if a similar scenario to the pandemic-related lockdowns should occur again.

Conclusion

Current national and pan-London data and the Council's agenda to improve inequalities in health and direct feedback received from disabled residents led Healthwatch Ealing to conduct research into the affect that the COVID-19 pandemic has had on the health and wellbeing of individuals living with disabilities as well as their unpaid carers. During this research we heard from 90 individuals living with a disability or disabilities. The research found that:

- For the most part, Ealing Council effectively communicated with recipients of their care, but this area of support still requires further improvement in order to consistently meet the needs of all recipients.
- Ealing Council were able to provide a large proportion of individuals with the same amount of care during the pandemic as they did prior to it, with recipients praising social care staff for the quality of support they received. Both the feedback on the standard of care and Ealing Council's communication are impressive given the context of the pandemic and the Council and service provider staff should be proud of the care that they have provided individuals with, during this time.
- However, some experienced a reduction in care provision, amount of time that carers spent with them and general quality of care. Again, this points toward the need for a concerted effort from care providers to ensure that the standard of care is consistently delivered for all recipients.
- There is space for more collaboration between social care providers and community organisations for the delivery of basic provisions including food and medication and other aspects of care and support such as transportation, equipment (including electronic devices) and digital training.
- Booking GP appointments was an area in which disabled individuals experienced a lot of difficulty with many expressing their frustration and turning to A&E services for support and others indicating that the method of appointment should be more person-centred. However, comparing this feedback to that which Healthwatch Ealing gathers from all residents on a quarterly basis, the findings suggest that disabled individuals were able to access care slightly easier. It would be interesting to understand GP management when it came to the treatment of disabled patients and those with long-term health conditions.
- Individuals praised the efforts of Pharmacies during the pandemic in delivering their medication.
- Unsurprisingly, a disproportionate number of individuals felt that their mental wellbeing was impacted during this time with some indicating that they had received no support for this issue.
- A significant proportion of the population sample felt that the reliance on digital technology for their health and social care needs had played a role in this impact on their mental wellbeing. This view was reinforced by the discussions that took place at both forums.

- Ealing Council’s communication with the public around COVID-19 were largely effective with most people very satisfied with the information that they received on safety guidelines and the vaccination programme.
- The discussion forums highlighted several key themes that corroborated with survey findings. Individuals agreed that a lack of communication from their social care provider was a major contributory factor to feelings of stress, anxiety, helplessness and neglect.
- Unlike the survey findings however, many discussion forum attendees were not pleased with the level of care that they received from Ealing council, with some highlighting the knock-on effect that the lack of support had on their vulnerable parent-carers.
- Attendees at the hard of hearing discussion forum highlighted a concerning gap within the delivery of their health and social care. Practical issues that they faced during the pandemic such as being unable to lip read or use telephone services and a general lack of interpretation/ subtitle support left them feeling “*extremely confused*”, “*scared*” and “*disempowered*”. This is an oversight that requires immediate action from all service providers.
- Individuals with learning difficulties were very grateful for the electronic devices that Ealing Council provided them with through the Ealing Power Group and, in turn, praised staff at the group for supporting them to learn IT skills they needed to access online college classes, COVID-19 related news and attend to their own health and social care needs.

In addition, the feedback from 62 unpaid carers highlighted:

- The overwhelming impact that the pandemic had on carers’ physical, emotional and mental wellbeing due to a range of issues and challenges including being responsible for round the clock care, trying to juggle these responsibilities with their own career, sacrificing their own health, feeling neglected and exploited, insufficient information on changes made to their loved one’s care and a lack of support for their mental health.
- Feedback from carers on the support that their loved one received from their providers was mixed, with some praising social care staff for their efforts and others suggesting that the care and the communication around their care was not enough.
- Carers agreed that in order to improve the wellbeing of their loved ones and themselves, services needed to address the inconsistencies in the quality of care and the communication pertaining to this care, largely through the utilisation of a more person-centred approach to care. In addition, carers highlighted the need to provide them with respite and reward that they deserve for their unwavering efforts during the pandemic.

The findings from this research provides an evidence-base for a set of recommendations that Healthwatch Ealing hopes that borough health partners explore how they can help to support the completion of these recommendations. Perhaps most importantly is that Healthwatch Ealing view this piece of research as the start of an ongoing, robust and collaborative health equality strategy. The aim is to continue to engage with disabled residents and unpaid carers to further explore the intricacies of the health inequalities that both groups face. The views and experiences shared by residents will help to build upon and evolve the recommendations that have come out of this initial piece of research.

Recommendations

Based on the findings of this research, Healthwatch Ealing would like to make the following recommendations for improvement:

Recommendation Area 1: Communication

1.a. Ensure that changes made to an individual's care is communicated to them effectively, including family carers in conversations when appropriate.

1.b. Provide individuals and their family carers with clear instructions on the ways in which they can contact their provider for information, clarification or to make a complaint. Consider a single point of access for this, taking individuals' preferred methods of contact and any limitations around access into account.

1.c. Explore how social care providers and community organisations can collaboratively address mental wellbeing issues and social isolation through a comprehensive wellbeing check-up call programme.

If delivered by a community organisation there should be a clear line of communication with the individuals social care provider to ensure that any of their queries or concerns are appropriately relayed to their carer.

1.d. Consider what has made the COVID-19 communication strategy with these populations so effective and how this can be replicated throughout the recovery phase of the pandemic to provide further awareness around trusted sources of information on COVID-19 with a particular focus on Contact Tracing. This must include subtitles for any videos for hard of hearing individuals.

This communication can concurrently serve to increase the levels of trust and confidence within these particular demographics. In theory, this could also provide vaccine hesitant individuals with the information they need to revise their decision about not receiving the vaccine. As evidenced within this report, the absence of communication and access only diverts the delivery of care to a different area of the health and social care system.

Recommendation Area 2: Standard of Social Care

2.a. Exercise a person-centred approach to care that accounts for the best methods of health and social care appointments for individuals as well as ensuring that more nuanced and individualised support is provided to individuals. This could entail a ‘core offer’ with an outline of the extra provisions that are required by individuals, including level of digital access.

For example, the availability of interpretation services for GP surgeries who support hard of hearing individuals, face-to-face appointments where phone call appointments are insufficient and alternative methods of communication for those who do not have access to digital devices on a regular basis.

2.b. Ensure that mental health support services are widely and easily accessible for disabled individuals and their unpaid carers. Social Care services must collaborate with local mental health service providers to deliver effective and up to date communication around how individuals can access these services. It is worth exploring how supporting individuals to access these services could be worked into the provisions of paid carers.

2.c. Ensure that paid carers stay for the allotted amount of time. This should be monitored by obtaining regular feedback from recipients around the quality of the support and care that they receive.

2.d. Time in carers work schedules must allow for training and development sessions. These sessions should include refresher training on the use of Personal Protective Equipment as well as sessions on more general aspects of care that will help to make the high standard of care delivery more consistent.

2.e. The delivery of required equipment for disabled individuals should be reviewed to ensure that the assessment process, method of request and delivery of equipment is effective and efficient. Where possible, this should include the provision of digital devices to community organisations that support disabled individuals.

Recommendation Area 3: Healthcare Access

3.a. Address the inequalities in access experienced by individuals who are hard of hearing. This should include a systematic review of alternative methods of appointment and follow-up for these individuals, clear and easy access to B.S.L interpreters and a system-wide effort to include subtitles with any video communications.

3.b. Improve the level of consistency seen across GP surgeries' telephone contact by implementing the same telephone system across GPs in the borough as well as utilising a standardised GP follow-up model where capacity and resource allows. This model should include alternative methods of contact for patients who are hard of hearing.

3.c. Hear from GP surgeries about their patient management methods during the pandemic, paying particular attention to how they supported those with disabilities and/or long-term health conditions and whether this was standard across all surgeries.

3.d. Further work must be carried out in collaboration with both healthcare services and community organisations who provide mental health support to Ealing residents. This work must include reviewing how they are making their support accessible to disabled individuals and the family members that care for them. Given the impact the pandemic has had on the mental health of these populations, funding should be reviewed to explore whether financial support could be provided for mental health access improvement.

Recommendation Area 4: Access to basic provisions

4.a. Collaborative efforts between Ealing Council, community organisations and local supermarkets should take place to explore the development of an effective method of food delivery to those that need it most. Although this was an issue during the COVID-19 pandemic lockdown, disabled individuals may still benefit, and it would be a strategy that would then be in place were to any future lockdown to occur.

4.b. Collaborative efforts between Ealing Council and community organisation transport services to make sure that essential transportation is easily accessible for disabled individuals, including the distribution of physical copies of contact details.

Recommendation Area 5: Access to digital devices and skills training

5.a. Provide community organisations with the largest footfall from disabled individuals with electronic devices, where funding allows.

5.b. Explore the feasibility of a borough-wide delivery of digital skills trainings by the local voluntary community sector. One of the current trainings delivered by local organisations could be standardised and delivered across multiple communities by participating organisations.

5.c. Consideration should be given to the alternative methods of engagement and access that will support those who are digitally isolated.

Recommendation Area 6: Support for Carers

6.a. Work collaboratively with local organisations to drive the resumption of day activities that will give carers short respite from their caring responsibilities that they have not had during the pandemic. This should be supplemented by the exploration of more specific respite/short break options for informal carers. This should cover both a standard offer to informal carers as well as one-off celebrations of their efforts such as park walks, cinema trips or coffee mornings.

6.b. Ensure that the same mental health support services that are readily available for disabled individuals are available to carers as well.

Recommendation Area 7: Continue research in this area of health inequalities

7.a. Healthwatch recognises that this research is the start of Ealing borough's work on health inequalities experienced by disabled individuals and their carers and not the finished article. Work between Healthwatch Ealing and key health partners will remain a priority going forward to adapt and evolve these recommendations as required to ensure that they are successfully tackling the issues that we hear from residents.

7.b. Further analysis of current and future feedback is required as part of this continued work to identify any themes related to ethnicity, age, area of residence and/or level of deprivation to understand areas of care delivery that deserve prioritised focus.

Limitations

As our work in this area continues, we hope to work with partners to implement the above recommendations. However, in order to do so effectively, we must recognise the limitations of this report and understand where developments can be made to address these limitations in future research and engagement:

1. Due to the pandemic, conducting face-to-face engagement at community venues proved difficult. As seen during this research project, face-to-face engagement provides rich detail about the complexities of residents' issues that may be missed in more quantitative surveys. Future qualitative research should engage with communities who live with disabilities that may not be strongly represented in this report.
2. For the residents that we did not distribute a paper copy of the survey to and that are without access to digital means of communication, they may have not had access to our survey and/or may not have seen our online promotion of this research. This will include those that are not being supported by any kind of social care provider
3. Due to the research sample size, further research would be beneficial to provide a more robust evidence-base and confirm that the findings of this work are representative of population feedback.
4. Due to lack of digital access and, subsequently, a lack of promotion in some areas and communities the current data cannot be generalised to more deprived populations in the Ealing borough.
5. Whilst we successfully distributed 500 paper copies of our survey to gather feedback from those who are digitally excluded, more work should be done to capture the views of the digitally excluded who did not participate in this research and build on the offered recommendations.

Appendix - 1: Survey Questionnaire

The Experiences of Those Living with a Disability & Their Family Carers During the COVID-19 Pandemic

Thank you very much for agreeing to participate in this survey.

Healthwatch Ealing is the independent consumer champion for health & social care services for the residents in Ealing borough. We are conducting this survey to understand how people living with a disability have been affected by the COVID-19 pandemic, from March 2020.

The opinions and experiences that you share will be used by Healthwatch Ealing to write a report that will inform Ealing Health Partners of how care is being delivered in the borough and identify any areas which need further improvement. This report will be made publicly available on our website: www.healthwatchealing.org.uk

All the feedback that you provide will remain anonymous. Your responses will not be disclosed to your social care provider. Your feedback will be held in a secure database and deleted once the report is complete. You can ask for your feedback to be removed from this database at any time. Our contact details are as follows.

Telephone number: **020 3886 0830**

Email: info@healthwatchealing.org.uk

We are also looking for individuals who would like to tell us about their experience in more detail. If you would like to organise a one-to-one discussion with one of the Healthwatch Team, please leave your details at the end of the survey in the 'Contact Details' section.

Do you consent for this information to be used in this way?

Yes No

Section 1: Your health condition(s) and wider circumstances

1. Which of the following best describes your health problems or disabilities (tick all that apply)?
 - a) Visual impairment (e.g., blindness, partial sight)
 - b) Hearing impairment (e.g., deafness, partial hearing)
 - c) Mobility issues (e.g., difficulty walking short distances, climbing stairs. Lifting objects)
 - d) Learning difficulties
 - e) Autism
 - f) Social or behavioral disability (e.g., ADHD)
 - g) Mental Health needs
 - h) Breathing difficulties or excessive fatigue
 - i) Don't know
 - j) None of the above
 - k) Other (Please specify)

2. Please put a tick in the box next to the sentences that best describe your living situation since the start of the COVID-19 pandemic in March 2020 (tick all that apply):
- a) Shielding due to being in a 'high-risk' vulnerable group
 - b) Rarely or never left home due to my fear of COVID-19
 - c) Rarely or never left home due to withdrawn support as a result of the pandemic
 - d) Rarely or never left home due to unclear communication about the risk from COVID-19
 - e) I was able to leave home on a regular basis
 - f) Other (please specify) _____

3. What is your current state of employment (tick all that apply)?
- a) Studying
 - b) Jobseeking
 - c) Volunteering
 - d) Working full or part time
 - e) Unable to work because of disability
 - f) Retired
 - g) I lost my job during the pandemic

Section 2: Your Social Care Support

4. Who provides you with your social care support (i.e., your paid carer)?
- a) Ealing Council
 - b) A private social care provider (please specify) _____
 - c) I only receive support from family or friends
 - d) I am disabled, but I do not need any support from social care providers
 - e) I am disabled and in need of social care, but I do not receive any
 - f) None of the above
5. If Ealing Council provides your social care support, how you would rate their communication during the pandemic (i.e., informing you of any changes to your care or answering any questions that you had regarding your care):
- a) Very Good
 - b) Good
 - c) Neither good nor bad
 - d) Bad
 - e) Very Bad

- f) I'm not sure
g) Not applicable
6. To what extent was your paid social care affected during the COVID-19 pandemic?
- a) I received more social care during the pandemic compared to before
b) I received the same amount of social care during the pandemic
c) My social care decreased slightly during the pandemic
d) My social care decreased significantly during the pandemic
7. During the pandemic, was your paid social care delivered to a high standard (e.g., your paid carer regularly visited you, cared for your specific needs, stayed for the allocated period of time)?
- a) Yes, always
b) Most of the time
c) Only sometimes
d) Rarely
e) Never
f) Not applicable
8. Has the reliance on digital technology during the COVID-19 pandemic affected your ability to access social care information and services?
- a) Yes, significantly
b) Yes, slightly
c) No, I have been able to use digital technology to access all the information I need about my social care
9. Has your ability to access food changed over the course of the pandemic?
- a) Not at all - I was able to access food without problems
b) Slightly - Sometimes getting food was difficult
c) Significantly - It was often difficult to get food when I needed it
d) I'm not sure
10. How would you prefer to be contacted in future regarding your social care (please tick all that apply)?
- a) Email
b) Letter
c) Text
d) Phone call
e) Face to face
11. Use the box below to tell us anything else you would like to about the support from Social Care that you have received, during the pandemic:

- c) Only slightly
- d) Not at all
- e) I'm not sure

18. Have you been able to access mental health support during the pandemic (please tick all that apply)?

- a) Yes, from a local community organisation/charity
- b) Yes, through Ealing Council
- c) Yes, through my GP
- d) Yes, from family and friends
- e) No, I have not been able to access support
- f) Not applicable - I haven't needed any support for my mental health

Section 5: COVID-19 and the Vaccination

19. Please tick (ü) the relevant answer box in the table below to indicate how well informed you feel you have been about the following COVID-19 safety guidelines:

<i>Guidelines</i>	<i>Informed</i>	<i>I'm not sure</i>	<i>Uninformed</i>	<i>I'm not sure</i>
Social distancing				
COVID-19 tests				
Contact tracing				
Shielding				
Face masks				

20. Have you felt informed about the COVID-19 Vaccination programme, since the start of the rollout on the 8th of December 2020?

- a) Yes, very much so
- b) Yes, to some extent
- c) I have felt neither informed nor uninformed
- d) Only slightly
- e) Not at all
- f) I'm not sure

21. Please tick (*ü*) the relevant answer box in the table below to indicate how satisfied/unsatisfied you are about the information that you have received from Ealing Council regarding the following information:

<i>Information</i>	<i>Very satisfied</i>	<i>Satisfied</i>	<i>Neutral</i>	<i>Unsatisfied</i>	<i>Very unsatisfied</i>	<i>I'm not sure</i>
How to access the vaccine in Ealing						
The safety of the vaccine						
The vaccine's role in managing the pandemic						
The vaccine's effectiveness						
Trusted sources of information about the vaccine						

22. To what extent do you agree or disagree with the following statement:

“Since the government’s COVID-19 restrictions were reduced on the 19th July 2021, I feel safe going out.”

- a) Strongly disagree
- b) Disagree
- c) Neither agree nor disagree
- d) Agree
- e) Strongly agree

23. From the list below, which sources of information did you use to stay up to date on the latest COVID-19 safety guidelines and vaccination rollout updates (please tick all that apply)?

- a) Family/ Friends
- b) Traditional Media (Television, Radio, Newspapers)
- c) social media (Twitter, Facebook, Instagram)
- d) Newswebsites
- e) Ealing Council website
- f) National Government or NHS websites
- g) Letters or texts from the Government or NHS
- h) My social care providers
- i) My GP or other healthcare professionals
- j) Local/National charities

24. Have you been fully vaccinated for COVID-19 (both doses)?

- a) Yes
- b) No

25. If you answered ‘No’ to the previous question, are you hesitant to take the COVID-19 vaccine?

a) Yes

b) No

c) Not applicable

If 'Yes', please provide your reason(s) in the box below:

Section 6: Monitoring information

What is your age?

- 16-24 25-34 35-44 45-54
 55-64 65-74 75-84 85+ Prefer not to say

What is your gender?

- Male Female Prefer not to say?

What is your postcode? _____ **OR Town:** Acton Ealing Greenford
 Hanwell Northolt Perivale Southall Prefer not to say

What ethnicity do you identify as? (Please tick one box)

<p>White</p> <p><input type="checkbox"/> British</p> <p><input type="checkbox"/> English</p> <p><input type="checkbox"/> Gypsy or Irish Travelers</p> <p><input type="checkbox"/> Irish</p> <p><input type="checkbox"/> Scottish</p> <p><input type="checkbox"/> Welsh</p> <p><input type="checkbox"/> Other White background (specify if you wish)</p>	<p>Asian, Asian British, Asian English, Asian Scottish or Asian Welsh</p> <p><input type="checkbox"/> Asian / Asian British</p> <p><input type="checkbox"/> Bangladeshi</p> <p><input type="checkbox"/> Chinese</p> <p><input type="checkbox"/> Indian</p> <p><input type="checkbox"/> Pakistani</p> <p><input type="checkbox"/> <u>Other Asian background (specify if you wish)</u></p>
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<p>Black, Black British, Black English, Mixed Black Scottish, or Black Welsh</p> <p><input type="checkbox"/> African</p> <p><input type="checkbox"/> Caribbean</p> <p><input type="checkbox"/> Other Black background (specify if you wish) _____</p>	<p>Mixed</p> <p><input type="checkbox"/> White and Asian</p> <p><input type="checkbox"/> White and Black African</p> <p><input type="checkbox"/> White and Black Caribbean</p> <p><input type="checkbox"/> White and Chinese</p> <p><input type="checkbox"/> Other mixed background (specify if you wish) _____</p>
<p>Another ethnic group</p> <p><input type="checkbox"/> Arab</p> <p><input type="checkbox"/> Another ethnic group</p>	<p><input type="checkbox"/> Prefer not to say</p>

Section 7: To be answered by your family (or friend) carer.

26. Were you kept informed about the changes that were made to your relative/friend’s social care during the pandemic (from March 2020)?

- a) Yes, completely
- b) Mostly
- c) To some extent
- d) Hardly ever
- e) I wasn’t kept informed at all

27. Have you received any support for your own health and wellbeing during this time (tick all that apply)?

- a) Yes, from Ealing Council
- b) Yes, from Community organisations
- c) Yes, from Friends and Family
- d) No, I have not received any support for my health and wellbeing

28. Please describe how caring for your friend/relative during the pandemic has affected your own health and wellbeing (emotionally, mentally, physically, financially, etc.)

29. Please tell us about the biggest challenges that you have faced whilst caring for your relative/friend during the pandemic?

30. Overall, how do you feel the level of support and quality of care has been for your relative/friend from their social care provider, during the pandemic.

31. What suggestions do you have for the social care provider on how they can improve their service to further support you and the person that you care for?

Contact Details

Either you or your friend/family carer can fill in this section if either you wish to be contacted by Healthwatch Ealing to further discuss the care you receive.

Name: _____

Phone: _____

Email: _____

THANK YOU

Appendix - 2: Themes & Subthemes

<u>Theme</u>	<u>Subthemes</u>
Access to services	Convenience/Distance to travel
Access to services	Inequality
Access to services	Information and Advice
Access to services	Lack of
Access to services	General
Access to services	Patient choice
Access to services	Service Delivery/Opening Times
Access to services	Suitability of Provider (Individual or Partner)
Access to services	Suitability of Provider (Organisation)
Access to services	Waiting times
Administration	Admission Procedure
Administration	Appointment availability
Administration	Booking appointments
Administration	Commissioning and provision
Administration	General
Administration	Incident Reporting
Administration	Management of service
Administration	Medical records
Administration	Quality/Risk management
Care Home Management Registered Manager - Absence	
Care Home Management Registered Manager - Suitability	
Care Home Management Registered Manager - Training & Development	
Care Home Management Staffing levels	
Care Home Management Suitability of Staff	
Communication	General
Communication	Interpretation Services
Communication	Lack of
Communication	Community engagement and involvement
Communication	Response times
Continuity and integration of care	
Diagnosis/assessment	General
Diagnosis/assessment	Lack of
Diagnosis/assessment	Late
Diagnosis/assessment	Mis-diagnosis
Diagnosis/assessment	Tests/Results
Dignity and Respect	Confidentiality/Privacy
Dignity and Respect	Consent
Dignity and Respect	Death of a Service User
Dignity and Respect	Consent
Dignity and Respect	Death of a Service User (Mental Health Services)
Dignity and Respect	Equality & Inclusion
Dignity and Respect	Involvement & Engagement
Discharge	Coordination of services
Discharge	General
Discharge	Preparation

Discharge	Safety
Discharge	Speed
Facilities and surroundings	Buildings and Infrastructure
Facilities and surroundings	Car parking
Facilities and surroundings	Cleanliness (Infection Control)
Facilities and surroundings	Cleanliness (Environment)
Facilities and surroundings	Cleanliness (Staff)
Facilities and surroundings	Disability Access
Facilities and surroundings	Equipment
Facilities and surroundings	Food & Hydration
Facilities and surroundings	General
Finance	Financial Viability
Finance	Transparency of Fees
Finance	Lack of funding
Home support	Care
Home support	Co-ordination of Services
Home support	Equipment
Making a complaint	Complaints Management
Making a complaint	General
Making a complaint	PALS/PACT
Medication	Pharmacy Repeat Prescriptions
Medication	Medicines Management
Transport	Patient Transport Service (non NHS)
Transport	Ambulance (Emergency)
Transport	Ambulance (Routine)
Referrals	General
Referrals	Waiting times
Safety/Safeguarding/Abuse	
Staff	Ambulance Staff/Paramedics
Staff	Attitudes
Staff	Capacity
Staff	District Nurses/Health Visitors
Staff	General
Staff	Midwives
Staff	Staffing levels/Lack of
Staff	Suitability
Staff	Training and development
Treatment and care	Effectiveness
Treatment and care	Experience
Treatment and care	Quality
Treatment and care	Safety of Care/Treatment
Treatment and care	Treatment Explanation
Treatment and care	Lack of support