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WHAT WE KNOW NOW

What people with health and care needs experienced during the first wave of COVID-19

A rapid review of data from over 66,000 responses to National Voices members' surveys





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National Voices members' surveys*

Research and report by Fiona Weir on behalf of the National Voices coalition

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We want to thank Fiona Weir, an independent researcher and consultant who has previously worked in senior roles in NHS England, local government and charity and community sectors, and who has lived experience of managing long-term health conditions. She has carried out this work for National Voices *pro bono*. We could not have done this work without her and are very grateful for her professionalism and generosity. We are also thankful that National Voices members pooled their data and collaborated in this way – we can achieve so much by working together. Finally, a heartfelt thank you goes to everyone who filled in a questionnaire and told us about their experiences. We are listening. And we won't rest until you are heard by those who can make a difference.

Summary

This report is published by National Voices, the coalition of health and care charities in England.

We undertook a rapid review to analyse surveys carried out by our members during the ‘first wave’ of the epidemic in March-July 2020, reflecting the experiences of over 66,600 individuals with long-term health and care needs, including carers. Our findings show that many people experienced substantial harm and distress, in large numbers and across all groups and conditions. The NHS, government, local government and non-profit sector responses to COVID-19 in early 2020 were extraordinary and unprecedented, and so we can say without blaming anyone that *we must do things differently next time*.

We therefore present insights into people’s experiences that offer some system-wide learning, and that might help us to mitigate risks and fix problems now we are into the second wave of the epidemic and as 2020/21 winter pressures kick in.

The most widespread issues for people with long-term health and care needs were:

- **Wellbeing** – all surveys showed negative impacts, including increased anxiety and loneliness
- **Access to medication** – all surveys reported some problems getting medicines, including essential medications such as insulin and anti-psychotics
- **Getting food** – almost all surveys showed negative impacts such as trouble getting food and people going hungry
- **Access to healthcare** – almost all surveys showed negative impacts, including cancelled appointments necessary to manage health conditions
- Other issues and concerns – a majority of surveys also showed: Problems with **work** (for those working); Problems with getting or understanding **information**; Problems with **shielding**; Problems with **mental health** (when reported separately from wellbeing); Problems with managing symptoms and/or **deteriorating health**; Problems accessing **social care**; **Financial** concerns; and Impacts on **carers**.

Some effects are likely to be long-term; some compromised people’s independence and ability to self-manage their conditions; and some were potentially life-threatening. Some impacts clearly have wider implications for health inequalities and our wider society and economy. Crucially, it seems clear that **NHS capacity to deal with COVID-19 was found (at least in part) by removing capacity from the health and care of those with long-term conditions**.



Key recommendations supported by our findings are:

- **Do everything possible to avoid shutting down the health and care services** that people with long-term health conditions rely on, since risks and harm appear significant.
- **Listen to people** and understand their experiences of shielding, lockdown and service shutdown better, in order to minimise risks and protect from harm that we did not know about before.
- In the event of further national advice to keep those vulnerable to COVID-19 safe, provide **much better information and support** for vulnerable and shielded individuals and their families – recognising that they will be more affected by service closures and reductions.
- Keep charities, and the people with health and care needs they work with, at the centre of future planning and responses.

1 Background

1.1 About this paper

This rapid review report is published by National Voices, the coalition of health and care charities in England. It presents an analysis of the findings of surveys carried out during April-July 2020 by and on behalf of 11 health and care charities in England, which collectively reached at least 66,600 individuals with long-term health and care needs. It is intended primarily for anyone who needs to understand how to support people during a second wave and beyond, our 160 member charities, and anyone leading health and care design or delivery.

1.2 National context

The COVID-19 virus has disrupted the way we all live our lives. Extraordinary and unprecedented measures by government and services have affected the whole country, including our member organisations and the people they work with and support.

Around 15 million people in England have a long-term condition¹ which is managed with medications and/or other ongoing treatment, such as diabetes, chronic obstructive pulmonary disease or heart disease. Of these, 2.2 million are now identified as ‘shielded patients’² due to being clinically extremely vulnerable and therefore at high risk from COVID-19 infection. Also, around 7 million people in England are carers³, providing unpaid care for people with long-term health and care needs. **Our member organisations therefore represent around one in three adults**, including those who most use health and care services.

COVID-19 inevitably had major impacts on NHS delivery, shifting the focus to emergency hospital treatment and away from non-emergency and community care. The NHS declared a level 4 national emergency at the end of January and responded by diverting ‘maximum possible’ resources to deal with the epidemic⁴. A national ‘lockdown’ then began on 16 March 2020. Also in March, the Coronavirus Act suspended some parts of the Care Act, including temporarily suspending local authorities’ duties to assess social care needs and to meet needs beyond human rights requirements. This was partly a response to the increased pressures on local authorities, as people with health and care needs found there were fewer available health services.


¹ Office for National Statistics 2020

(<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/adhoc/s/11478peoplewithlongtermhealthconditionsukjanuarytodecember2019>)

² NHS Digital 2020 (<https://digital.nhs.uk/data-and-information/publications/statistical/mi-english-coronavirus-COVID-19-shielded-patient-list-summary-totals/latest>)

³ 2011 census figures showed there were then 5.4 million carers in England. Projections for 2019 estimated around 8.8 million carers in the UK as a whole, with approximately 83% of these in England (Carers UK 2020: https://www.carersuk.org/images/Facts_about_Carers_2019.pdf).

⁴ NHS England 2020a (<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/urgent-next-steps-on-nhs-response-to-COVID-19-letter-simon-stevens.pdf>)



Charities in turn began to experience increased demand. The National Voices coalition reported impacts on member charities and the individuals they support, and anecdotally became aware that people with long-term health and social care needs were experiencing a variety of problems – including with daily living and with being able to meet particular health and care needs.

1.3 Preliminary insights

In April/May, National Voices worked with the Arthritis and Muscular-Skeletal Alliance (ARMA) and the Neurological Alliance to survey members and [report issues more formally](#). Forty organisations responded, and more than three-quarters reported an increase in demand for services and support, without a corresponding increase in resources. National Voices also launched [Our COVID Voices](#), an online ‘portal’ for individuals to report their own experiences at this time (the portal is publicly searchable).

From this early data, some common issues and themes for individuals seemed to emerge, including:

- Lack of information
- Issues relating to shielding
- Problems with access to food
- Problems with access to NHS services and essential medicines
- Loneliness and emotional wellbeing, including confusion and fear
- Other mental health impacts
- Care and support
- Employment issues
- Financial concerns and problems accessing benefits and other financial support.

There is a risk that emergency changes in health and care services may lead to long-term or permanent problems for people with health and care needs and the charities that support them. This rapid review has been carried out specifically to gain insight into early impacts, which might help us to learn lessons, mitigate risks and fix problems, as we enter the second wave of the epidemic and winter pressures.

2 Research Design

2.1 Scope

This rapid review sought to identify:

- The impacts on people with long-term health and care needs, using and systematically checking preliminary insights
- Common themes and key findings that might help us to learn lessons, mitigate risks and fix problems as we enter the second wave of the pandemic and 2020/21 winter pressures.

2.2 About the data

We reviewed data from these organisations: Asthma UK and the British Lung Foundation, British Heart Foundation, Carers UK, Diabetes UK, Kidney Care UK, Mind, Multiple Sclerosis Society, Neurological Alliance, Parkinson's UK, Rethink and Sustainable Care. In order to get a wider and more reliable picture, we deliberately sought data from a range of NV member organisations. Our strength is our diversity, our collaboration increases our reach.

The data provided responses from at least 60,600 individuals. Because some organisations sent out more than one survey to individuals and/or wrote separate themed reports on the same survey information, there were a larger number of responses than individuals. All survey data from each organisation was grouped and reviewed together, in order to avoid replicating findings.

Some significant groups of people with long-term health and care needs are not specifically included in the data sets – particularly, older people (1 in 5 of all patients in England⁵) and those with muscular-skeletal conditions (1 in 4 of all patients in England⁶). This is because research by the major charities representing these groups is ongoing; data will be available later and will cover a longer time period. However, older people and those with muscular skeletal problems are obviously included in all the other survey groups – so their experiences are represented here, but not focused on separately or specifically.

The data sources included: raw data sets (2); survey reports (28); other information sources (6). In all but one case, survey data was self-reported responses to surveys carried out by or on behalf of these organisations. One organisation worked with the University of Sheffield to carry out secondary analysis on the Longitudinal Household Survey data; this was treated separately and was not part of the thematic review, because questions are pre-set and responses did not include any free text. Instead, the information was used to sense-check and contextualise the thematic analysis findings.

⁵ NHS England 2020c (<https://www.england.nhs.uk/ourwork/clinical-policy/older-people/improving-care-for-older-people/>)

⁶ NHS England 2020d (<https://www.england.nhs.uk/ourwork/clinical-policy/ltc/our-work-on-long-term-conditions/musculoskeletal/>)

Table 1 provides a summary of all the data reviewed.

Table 1: summary of data reviewed (N = number of)

N responses	N individuals	N data sources	N discrete data groups for review	N orgs/partnerships
94455	60641	36	11	11

2.3 Methodology

The data was reviewed using the following stepped methodology:

Step 1 – defining the framework: Keywords and themes were defined for the thematic analysis, relating to the anticipated common issues and themes from the information already collected and described by National Voices in April/May (see above). These are shown in Appendix 1.

Step 2 – rapid review: A rapid review of all the data sources received, in order to confirm themes and keywords, describe the data sets and group them for thematic analysis.


Step 3 – thematic analysis: All the findings in the submitted data were reviewed to look for the keywords, using Adobe or MS Word document search tools. (The keywords were searched in order until one was found. If none was found, the issue was recorded as ‘not found’. Only the *presence* of keywords is reported, not the number of instances, since that could have reflected writing style or length of report rather than the importance or frequency of the issue).

Step 4 – further insight: Summary findings were collected from the data groups for each theme.

This approach built up a picture for each charity, and all the charities collectively, of:

- (a) Whether or not a theme was reported
- (b) Whether or not the impacts were clearly negative or uncertain/possibly negative, and
- (c) Highlights and trends across the group of charities.

Note that it was not possible to collate and directly compare charities’ findings, because different surveys used different methodologies, different questions and reported in different ways. This alternative approach, using a framework for thematic analysis, does not necessarily present a *complete* picture of issues facing people with health and care needs, but it does present a systematic, comparable and repeatable analysis. It also provides a tool



for any other organisation with survey findings to use to evaluate their own respondents' experiences, and to find out to what extent they are typical.

We are exploring a more coordinated approach to collecting data from our communities as we enter the next phase of the pandemic. We would be interested to partner up with organisations or researchers on this.

3 Key Findings

The thematic analysis showed that the **most widespread issues** affecting individuals with long-term health and care needs during COVID-19 are:

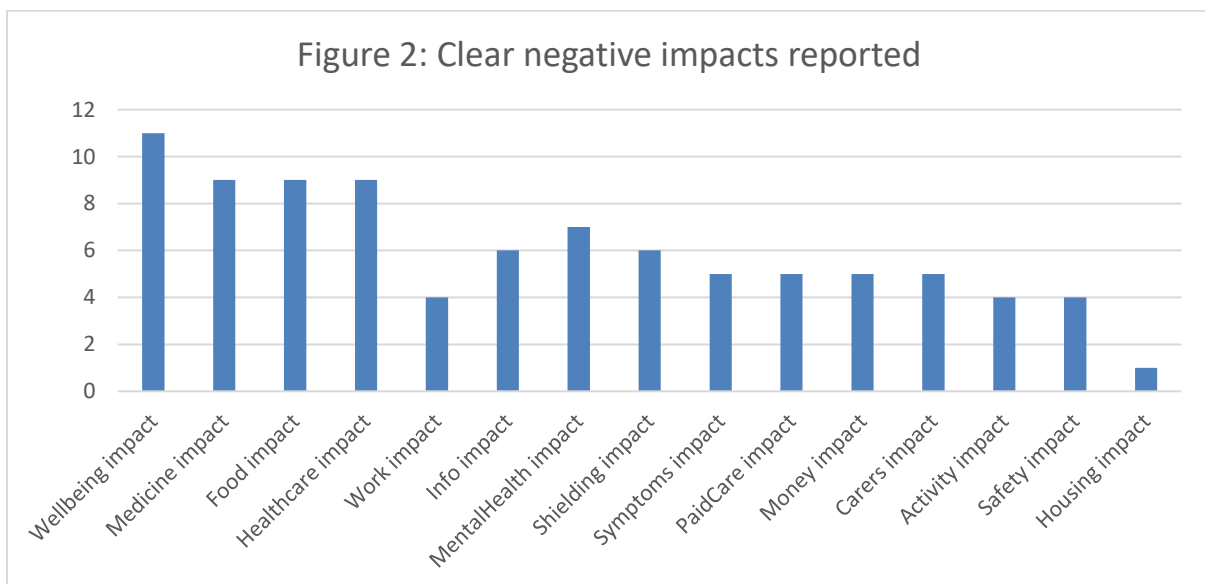
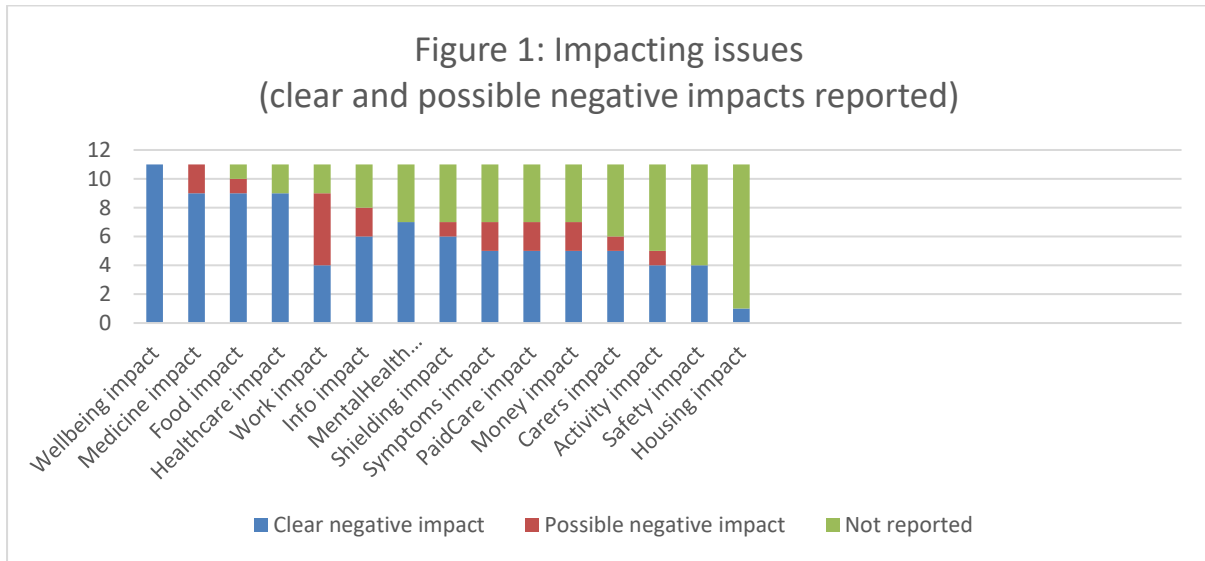
- **Wellbeing** – all 11 data groups showed clearly negative impacts on wellbeing, including increased anxiety and loneliness
- **Access to medication** – nine showed clearly negative impacts and two showed possible impacts; all groups reported some problems getting medicines, including essential medications such as insulin and anti-psychotics.
- **Getting food** – nine showed clearly negative impacts and one showed possible negative impacts, including trouble getting food and going hungry
- **Access to healthcare** – nine showed clearly negative impacts, including cancelled appointments necessary to manage health conditions.

Other issues widely affecting individuals with long-term health and care needs during COVID-19, and reported as concerns by a majority of organisations/partnerships, are:

- **Problems with work** (for those working): nine out of 11 showed people who worked were having problems, including having to work away from home, although they had been told to shield.
- **Problems with getting or understanding information:** eight out of 11 data groups showed this as possibly or clearly impacting, including people who needed information about how to manage their own health while access to their usual healthcare was limited.
- **Problems with shielding:** seven out of 11 showed problems with shielding, including people not receiving shielding information, or not being able to shield although they were advised to.
- **Problems with mental health** (when reported separately from wellbeing): seven out of 11 reported adverse mental health effects, although not all surveys clearly differentiated mental health and wider wellbeing impacts.
- **Problems with managing symptoms and/or deteriorating health:** seven out of 11 reported people's health was impacted and/or deteriorating, including because they could not access the healthcare or medicines they needed.
- **Problems accessing social care:** seven out of 11 reported people had problems with their usual paid care, and/or that they needed extra help because of shielding and could not access it.
- **Financial concerns:** seven out of 11 showed people had financial concerns, including falls in income because they could not work due to shielding, and/or had reduced work hours due to additional care responsibilities.
- **Impacts on carers:** seven out of 11 reported a wide range of negative impacts for carers, including additional care responsibilities, knock-on effects on work and money, and impacts on wellbeing and mental health.

Other issues that were reported include: issues with lack of exercise/physical activity; safety concerns, particularly self-harm and substance abuse, and including issues relating to personal protective equipment; and concerns about housing and homelessness. It is harder to draw conclusions about these themes because they appear to be *possible* rather *clear* issues in a number of surveys, usually because there were a small number of responses, and/or responses were mixed or anecdotal.

Figures 1 and 2 below show the prevalence of different issues, and whether they were reported as clearly and/or possibly impacting negatively.



4 Further insight and discussion

4.1 Understanding the key impacts for people with health and care needs

This rapid review and thematic analysis can only begin to develop our understanding of the impacts of COVID-19 on people with health and care needs, and is perhaps best used to give pointers for further research. However, we can build a **robust basic understanding of impacts** relating to the four key issues, because they were reported consistently in most of the surveys (at least nine out of 11). As such, the findings here represent the experience of around 66,600 individuals with a diverse range of health and care needs, including carers.

Wellbeing


“My anxiety is heightened; it feels as if someone is trying to choke the very life out of me, as the walls close in.”

All surveys showed that many people’s wellbeing was affected by lockdown and service shutdown. Different surveys used different measures so the figures cannot easily be compared, but there were some large effects - with 30-45% of respondents generally affected - and 75% in one survey. **People shielding were likely to report lower wellbeing than those not shielding.** Lack of information and/or reduced access to services was, unsurprisingly, linked with increased anxiety. Loneliness was a key issue for many, with those living alone particularly affected. Carers had lower wellbeing than average, measured on the (validated) Warwick scale, and this was linked with reduced services for the cared-for person and an increase in caring responsibilities. Working and younger carers were more likely to be lonely. Women were also more likely to report lower wellbeing (although it is not clear whether this is independent of caring role). Some surveys measured wellbeing over time and found that it deteriorated.

Implications: Lower wellbeing, increased anxiety and loneliness are associated with poorer health outcomes, so there may be some future effects on physical and mental health. Social distancing continues, and some people with health and care needs are also continuing to shield, so these effects may continue. Charities and community organisations play a key role in supporting wellbeing, providing social connection and reducing loneliness, and could help mitigate and prevent some negative health outcomes. Social prescribing offers an effective way of linking charity and community offers and connections with formal health and care.

Access to medication

“While the government has put in place measures to provide food and medicine for those who are extremely vulnerable, for example people with certain cancers or severe asthma, what about vulnerable people who do not meet these medical criteria? I know that I am not the only person impacted by this.”



All member surveys showed that some people had problems getting their regular medicines, including medications they rely on. Across nine surveys, between 7%-38% of people reported difficulties, with 11%-17% reporting serious concerns. These problems inevitably contributed to stress and anxiety. Some people had difficulty get essential medications such as insulin or anti-psychotic drugs, presenting a potential threat to life as well as health and wellbeing. **People shielding inevitably found it more difficult to get prescriptions, and so too did carers who were overstretched** by needing to provide more care. Volunteer schemes helped but did not always work. Two surveys showed uncertain effects, in one case with only 2% of respondents affected and the other improving over time.


Implications: Access to medicines appears to have improved for most people as lockdown lifted. However, being unable to get essential medication can be life-threatening, and so the potential impact of this problem must not be underestimated: another threat to supply of medications must be avoided. Volunteer schemes need urgent review to see whether they can be made to support better access to medication. Other possibilities could be explored, with people and communities, charities and the NHS working together to find new solutions - such as whether GPs could make use of practice records about carers and shielding individuals to help improve their access to prescribed medicines. National Voices also supports this shared call for improving patients' access to medicine:

<https://www.nationalvoices.org.uk/publications/our-publications/legislation-change-support-patient-access-medicines>.

Getting food

"I didn't get my Government shielding letter until 20th April and not being on the shielding database meant getting food and medication has caused real anxiety and worry. It took me two weeks after the official lock down to get a slot with a supermarket. It took several 4am attempts for success."

Almost all surveys reported food insecurity. Different surveys used different measures so the figures cannot easily be compared, but there were some large effects and common trends. Across 10 surveys, 24%-64% of people had difficulty getting food. There were particular issues for people with diabetes: 55% had problems with regular food supplies, including foods used to manage hypoglycaemic attacks. The supermarkets' schemes did not always work well, especially since they relied on shielding letters, which were not always sent to those that should have had them. Volunteer schemes helped but did not always work. Food insecurity contributed to anxiety and worsened existing mental illness. Many people reported spending more, which contributed to financial worries for some. Many people ate less healthily, some people went hungry, and food bank use increased. There is evidence that young carers, women and (in the one study that looked at this) black, Asian and other minority ethnic (BAME) families were seen to be especially likely to go hungry.



Implications: Many people in the general population experienced difficulties getting food, but the impacts can be more serious and more difficult to mitigate for people with health and care needs and their carers. Food insecurity has potential long-term as well as short-term impacts on physical and mental health and is likely to contribute to widening health inequalities. The volunteer and supermarket schemes need to be reviewed so they can be improved, with charities helping to ensure that the voices of people with health and social care needs are heard. Other possibilities could also be explored, with people and communities, charities, local government, the NHS and supermarkets working together to find new solutions; anecdotal evidence suggests that the very local schemes worked best, so local voices and local networks are key to improvement.

Access to healthcare

“I have had important medical appointments put off because of the virus and two serious appointments failed to happen because, it seems, COVID-19 issues were considered more important than my own life-threatening condition. A friend of mine has had a triple by-pass operation postponed.”

Between 27%-84% of people reported disruptions to their healthcare, with **people more likely to experience some difficulties as time went on, or if they had multiple needs**. Those who usually rely on regular healthcare to manage long-term health conditions were likely to experience most disruption. In many cases, the disruption was significant – for example, one in three people with Parkinson’s had their consultant and specialist nurse appointments cancelled; and two in five people with neurological conditions had consultant appointments cancelled with no alternative date offered; 7.5% of people with neurological conditions reported they had needed emergency care they did not receive. **Many people reported that problems accessing healthcare caused anxiety and some said it affected both physical and mental health**; one in three people with pre-existing mental health needs said their mental health deteriorated as a result. Community mental health support appeared to completely unavailable for some. Digital alternatives did not suit everyone, with older people and those with mental illness apparently more likely to miss out on healthcare entirely when face-to-face care was not available. Some people opted to cancel or postpone their own appointments because of concerns about coronavirus. Some carers reported they had to take on new responsibilities – for example, doing injections – because regular healthcare was not available.

Implications: It seems likely that **there will be long-term impacts from these healthcare disruptions, some predictable and some unpredictable**. Charities and the NHS are likely to want to try to monitor long-term impacts; not all will have the capacity to do so, but partnership arrangements may mean that larger charities can help smaller organisations to keep track. Crucially, it seems clear that the **additional NHS capacity to deal with COVID-19 was found by removing capacity from the routine healthcare of those with long term conditions**.

4.2 Understanding other important impacts for people with health and care needs

The surveys found a more mixed picture or smaller effects relating to some other issues. Often this was related to the different methodologies used by the different surveys, so that findings could not easily be aggregated or generalised. The findings in this section are therefore more tentative.

Work

“We may wish to work from home, and we would like that to be a right where possible. We may need retraining if our previous work role can’t be performed virtually. We would love it if working from home was not implied to be shirking. We would love everyone to remember how difficult ‘splendid isolation’ is to live in.”

Many people with long-term health and care needs and/or carers do not work, and many more work part-time, so the surveys unsurprisingly found smaller effects. However, there are some potential implications for health inequalities, independence and the wider economy. Important findings that may need further investigation include:

- **Some people with long-term health and care needs are key workers**, and some of these were unable to stop working even if they were told to shield. This inevitably caused anxiety and other problems.
- Working presented safety issues for some people with health and care needs: **around one in three did not feel safe at work, and around three-quarters reported being unable to keep socially distanced.**
- **Shielders were apparently more likely to be on reduced income than non-shielders**, suggesting wider inequalities of wealth and health for people with the greatest health and care needs.
- **Carers often needed to take on further care responsibilities** during lockdown because of reduced availability of health and care services, and this led many to reduce their work hours. One in five working carers apparently permanently lost or gave up work as a result.
- In the one survey that looked forward in time, an overwhelming majority of respondents (83%) were concerned about going back to work after lockdown.

Information

“Admitting the unknowns of this pandemic and being transparent with how decisions are being made will do far more to build trust than pretending otherwise. The Government needs to recognise its failures in communication with the most vulnerable groups. It needs to listen to the concerns and worries of people who are isolated and for whom the future feels so bleak and uncertain.”

Not all surveys asked questions about access to information and those that did asked in different ways, so that the findings are harder to interpret. Findings that may need further investigation include:

- Many people wanted more and better information, especially about self-care and how to manage their own condition while they could not access their usual healthcare.
- Some charities reported large increases in requests for information; individuals who were asked generally found charity information helpful.
- People who were working wanted their employers to be given better information about their needs.
- There were many concerns about shielding information – see below.

Shielding


“I have no garden so I have only felt the sun on my face for those fleeting escapes. I can get some breeze from opening my windows, but it’s not the same. I heard this week that it looks like it will have been the sunniest spring since records began - feels like a cruel irony as I have missed it all.”

A minority of people responding to these surveys were shielding; despite the small population size, there were some important effects reported. Particularly, the **lack of clarity and sustained confusion, with many contradictory messages being given around shielding**, appears to have led some people to shield unnecessarily, which will have health, wellbeing and economic impacts. Important findings that may need further investigation include:

- **Some people shielding had problems accessing support**, including necessary and already-assessed care.
- **Some carers had to move in with shielding individuals** because usual care arrangements had broken down. This led to some carers losing/giving up work – see above.
- **Many people who expected to shield did not receive an official shielding letter.** This caused significant problems, for example meaning that they could not access supermarket delivery schemes.
- People who needed to shield were not told early enough: around one in five only received their letter after a month.
- Around half of those receiving shielding information found it unclear. Some received conflicting advice.
- **Many people with long-term health needs chose to shield even if they had not been told to.** One survey, for example, showed around half of respondents shielding but only one in ten had received NHS guidance to shield.

Mental health

“I had the letter to shield. I have two children at home, a husband who worked as a health care worker. He moved out to protect me. My depression worsened - I was not able to seek help from anywhere, my healthcare was non-existent. The world became more dark for me mentally and physically.”



Most surveys did not distinguish consistently between wellbeing and mental health. Some asked questions about combined impacts on ‘physical and mental health’. Important findings that may need further investigation include:

- Many people reported a deterioration during lockdown; **carers were more likely than non-carers to report an effect.**
- Most people with pre-existing mental health problems reported their mental health had deteriorated; **the effect was apparently greater for young people with pre-existing conditions.**
- People with pre-existing conditions often attributed their deterioration to **problems with accessing mental health support and/or medications.**

Managing Symptoms

“Daily life has become impossible and lockdown may not have been so hard if I was able to do more. However, I can only sit or lie down as it is so painful to stand or walk. I am so scared what the outcome of all of my health issues will be and worry about how long I can continue as I am.”

People responding to different surveys had different conditions, so the findings were inevitably different. Reports by individual charities provide more details. Common findings that may need further investigation include:

- 30%-40% of people reported deteriorating health or worsening symptoms.
- Problems accessing healthcare were reported as impacting both physical and mental health.
- Anxiety about accessing healthcare was also seen as an aggravating factor.
- Some people had symptom-managing treatments interrupted or stopped.
- People with asthma initially reported improvement which they attributed to lower pollution, but by July two in five people said their asthma was worse.

Accessing social care

“I can’t get my Powerchair out of the house, couldn’t change into the gear without help, would have been too exhausted to dress and get back.”

Most respondents did not normally use social care, so respondent numbers were small. However, findings that may need further investigation include:

- **Around half of those who did use care services before COVID-19, including carers, appear to have reported reductions in service.**
- **Many people said they needed more care than they were getting.**
- **Volunteer help was not seen as a replacement for social care.**
- **Carers** said care services they relied on were not running and this impacted their ability to work and their own health/wellbeing.

- Some people reported not being able to access care because their **social care assessments were cancelled**.

Financial impacts

“My partner and I both lost our jobs, as neither can be carried out in a COVID-Safe way.”

COVID-19 has affected many people’s finances, but people with health and care needs, and their carers, have lower financial wellbeing than the general population, and may have fewer work and money choices. Findings that may need further investigation include:

- **Most people reported spending more money** – for example because of limited food choices and/or a need to buy more hygiene supplies. This may be sustainable in the short-term for some, but is likely to cause problems longer term. Around one in eight people (of those asked) expect long-term negative impacts.
- 20%-50% reported some financial concerns.
- Financial concerns seemed often linked to **shorter or lost work hours**. Working carers were almost twice as likely as non-working carers to report financial concerns.
- Many people linked financial concerns with **worsening mental health and wellbeing**.

Carers

“I live with and care for an elderly disabled parent, how can I return to work and put them at risk? The guilt I feel for this is almost unbearable, I am acutely aware many are faced with similar dilemmas, shielded or not.”

Surveys focusing on carers found impacts on all other areas of concern. Carers UK, Sustainable Care, Carers Week and Parkinson’s UK published reports that present detailed pictures of need. As well as the impacts included elsewhere, this rapid review found that:

- Reduced availability of health and social care services meant **increased responsibilities** for informal carers.
- Around seven in ten carers appear to have taken on extra responsibilities; some people have become carers for the first time.
- Many carers felt **overstretched**; around two in five felt this affected their own physical or mental health.

Further impacts

Smaller or less clear impacts were reported in some surveys. Important findings that may need further investigation include:

- 29%-54% people reported **struggling to stay physically active**. Many felt this impacted on their physical or mental health. Some who used physical activity to manage long-term health conditions reported specific effects, including increased pain, poorer coordination and poorer mental health.


- COVID-19 appears to have affected some people's **safety**. Around two-thirds of those working outside the home did not feel safe. Some people with mental health needs – especially young people - reported self-harm, substance misuse or other harmful behaviours. In one survey, around one in six people said they were unsure how to access care in an emergency. Some carers were unsure about being able to provide safe care beyond their usual roles. None of the surveys reviewed asked about domestic abuse, but this may be an area for further investigation.
- Two early surveys reported safety issues relating to **personal protective equipment (PPE)**, specifically that unpaid/family carers were concerned that third party carers did not always have appropriate PPE. One further survey reported that approximately one in seven people with long-term health conditions who continued to work did not themselves have access to appropriate PPE.
- Only one survey asked about **housing issues**. This found that 8.5% had housing concerns due to lockdown that made their mental health and wellbeing worse.

4.3 Understanding these findings in context – comparisons and caveats

These findings are 'snapshots in time': in other words, they describe experiences for particular groups of people with existing long-term health conditions at specific points between April and July 2020, during the UK epidemic. It would be interesting also to see how the experiences of these groups of people change over time, but these data sets do not provide us with such information. It would be useful to have a common set of questions as we go into the second wave of the pandemic – particularly relating to wellbeing and access to services, medication and food – which could be asked by different organisations and at different points, to track experiences over time.

It would also be useful to know how the experiences of these particular groups of people with long-term health conditions compare with experiences in the general population. Again, these data sets do not provide that information; but it may be available elsewhere, for example in ONS and government data and other population-level surveys that identify people's health and caring status. The government has announced funding for research into long-term health impacts for people hospitalised with COVID-19⁷, with a view to improving treatment options. It seems that it would be equally useful to fund parallel research into health impacts for people with existing long-term health conditions who have been affected by COVID-19 in more complex ways.

⁷ Department of Health and Social Care 2020 (<https://www.gov.uk/government/news/research-study-into-long-term-health-impacts-of-COVID-19-launched-in-the-uk>).



National Voices and our members are interested to explore how our impressive reach and ability to connect with people with often complex needs could be strengthened through collaborating with others who have more and stronger data capabilities.

5 Conclusions


This rapid review and thematic analysis showed that people with long-term conditions and their carers were adversely impacted by shielding, lockdown and service shut-downs in substantial ways that need to be more fully understood. The NHS, government, local government and non-profit sector responses to COVID-19 in early 2020 were extraordinary and unprecedented, and so we can say without blaming anyone that ***we must do things differently next time.***

We identified some common adverse experiences, issues and concerns, particularly relating to people's wellbeing, food security and hunger, access to healthcare and access to vital medications. There were also concerns relating to getting information, managing symptoms, work, finances and other issues. Many risks were substantial and some were potentially life-threatening. **There are likely to be some persisting effects from the 'first wave' – on individual health and wellbeing, on health inequalities and on our wider society and economy.**

Certain effects are likely to be repeated or increased as we enter the second wave of the pandemic, especially if these lead to further shielding, service shut-down and/or social lockdown. At the time that these measures were first introduced, the general assumption was that they would be temporary; we now expect that some may need to be ongoing. **We should not glibly assume that because most people were resilient through the 'first wave' of COVID-19, they can be as resilient again. Our findings about early impacts on people's mental health and wellbeing particularly raise severe concerns for the future.**

The impacts on **shielding individuals** are potentially greater, both because they are clinically more vulnerable and because shielding itself limits people's ability to 'self-serve' and meet their own daily living needs; they inevitably need more services and support. The impacts on **carers** will also inevitably have knock-on effects on the people they care for, and on mainstream services if they are unable to care. Impacts that affect people's **independence** – for example, their ability to work or their ability to manage their own health condition safely – are particularly important to mitigate, not only for individuals' own benefit, but also because services cannot manage the further demand that will result if/when more people lose their independence.

Crucially, it seems clear that NHS capacity to deal with COVID-19 was not found by improving efficiency or working magic, but by **removing capacity from the health care and social care of those with long term conditions**, and that people with long-term health and care needs experienced distress and harm as a result. Government, health economists and charities alike will want to understand more about the risks, harm and costs of the 'first wave', including long-term implications, as we move forward.



Charities in the National Voices coalition have had a key role in identifying issues. They will also have an ongoing key role in designing solutions, mitigating risks and preventing harm, alongside people with long-term health and care needs themselves, and their carers.


National Voices and our many members, large and small, national and local, condition-specific or focused on inequality groups, stand ready to help in this second wave and as we approach winter. But our sector too is struggling with depleted resources, loss of fundraising income, redundancies and exhaustion. We, too, are the so-called 'front line'. If we cannot hold or support a need, it will go elsewhere, often in unplanned ways. It is in the interest of the formal health and care system to maintain our ability to play our part. Collectively, we need to ensure that we continue to listen to people's experiences of shielding, lockdown and shutdown, in order to understand their ongoing needs as we head into this winter. Particularly, we must mitigate risks and protect people from harm that we did not fully understand before but have a better understanding of now.

6 Recommendations

- Do everything possible to avoid shutting down the health and care services that people with long-term health conditions rely on, since risks and harm appear significant.
- Listen to people and understand their experiences of shielding, lockdown and service shutdown better, in order to minimise risks and protect from harm that we did not fully know about before.
- In the event of further national advice to keep those vulnerable to COVID-19 safe, provide much better information and support for vulnerable and shielded individuals and their families – recognising that they will be more affected by service closures and reductions.
- Keep charities, and the people with health and care needs they work with, at the centre of future planning and responses.

Appendix 1: framework for thematic analysis

Theme	Description <i>An individual's...</i>	Keywords
Shielding arrangements	<i>Knowledge and understanding about whether or not to shield</i>	Shielding, shielded, self-isolating, cocooning, very vulnerable
Safety	<i>Experiences of impacts on personal safety</i>	Safety, danger, harm, violence, abuse, crime, victim, protective* (*NB: This was used to identify potential concerns about personal protective equipment (PPE).
Other information (access and understanding)	<i>Knowledge and understanding about other information important to their health and wellbeing during COVID-19</i>	Information, understanding, guideline/s, advice, unsure, confusion, confused
Food security	<i>Ability to get food and know that they will have enough to eat</i>	Food, eat, eating, hungry, meal/s, food delivery/ies, food bank
Medicines (access to)	<i>Ability to get their usual medicines</i>	Medicine/s, medication, prescription/s, prescribed, over-the-counter
NHS services or other healthcare (access to)	<i>Access to emergency healthcare; the healthcare they rely on to manage their long-term condition(s) and/or other healthcare</i>	Healthcare, medical, getting help (health), GP, long-term condition, hospital, consultant, appointment/s, nurse, rehabilitation, pharmacist, physio, therapist, treatment, PLUS keywords relating to specific conditions of people surveyed (eg: diabetes, arthritis, etc).
Physical health and symptoms	<i>Experiences of health effects, including worsening or improvement of symptoms</i>	Health, symptom/s, ill, illness, deterioration, deteriorate
Physical activity	<i>Ability to do enough physical activity, including structured and unstructured/informal exercise</i>	Exercise/s, physical activity, move, movement, outdoors, walk, swim, gym, play
Emotional wellbeing, including loneliness	<i>Emotional state or wellbeing, including loneliness</i>	Wellbeing, emotion/s, emotional, loneliness, lonely, isolation, fear, afraid, stress
Mental health	<i>Assessed mental health needs, and/or the mental health needs of those with an existing MH diagnosis</i>	Mental health, mental illness, depression, suicide, self-harm, psychiatric, admission, community MH, PLUS key words relating to specific conditions of people surveyed (eg: psychosis, PTSD)
Paid care needs	<i>Access to the social care they have been receiving, with or without assessment; or access to assessment of need</i>	Social care, assessed care, assessment, adult services, home care, domiciliary care, personal care, care needs, care worker, social worker, personalisation, independence, safety
Carers' needs	<i>Needs directly related to their informal caring responsibilities, whether assessed or not.</i>	Carer/s, caring responsibilities, carer support, short break, respite
Work	<i>Experience of impacts on work or looking for work (if relevant)</i>	Work, employment, job, job-seeking, furlough, working from home, adjustment/s



Financial security	<i>Experience of impacts on income and day-to-day finances</i>	Money, income, finance, financial, poverty, cash, spending, debt, loan, benefits, sanction/s
Housing security	<i>Experiences of impacts on housing, including homelessness</i>	Housing, homeless, homelessness, accommodation, refuge

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National Voices

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 160 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

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