

Information needs of vulnerable people during the COVID-19 pandemic

May 2020



I found it difficult to assess
whether my asthma was mild
and therefore whether it
increased my risks.
The guidance on the
website (which I heard
about from the doctor
on the radio) is
complex when you
have to select your
medicines and hence
potential risk category

Comment from respondent





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Who are Healthwatch Nottingham & Nottinghamshire?

Healthwatch Nottingham & Nottinghamshire is an independent organisation that helps people get the best from local health and social care services. We want to hear about your experiences, whether they are good or bad.

We use this information to bring about changes in how services are designed and delivered, to make them better for everyone.

Why is it important?

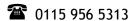
You are the expert on the services you use, so you know what is done well and what could be improved.

Your comments allow us to create an overall picture of the quality of local services. We then work with the people who design and deliver health and social care services to help improve them.

How do I get involved?

We want to hear your comments about services such as GPs, home care, hospitals, children and young people's services, pharmacies and care homes.

You can have your say by:



www.hwnn.co.uk



Facebook.com/HealthwatchNN

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Join our mailing list

We produce regular newsletters that feature important national health and social care news, as well as updates on local services, consultations and events.

You can sign up to our mailing list by contacting the office by phone, email or by visiting our website.



In order to understand the impact of COVID-19 on vulnerable people in Nottingham and Nottinghamshire, and to inform local and national responses, Healthwatch Nottingham and Nottinghamshire (HWNN) carried out a short survey between 17th April and 4th May 2020 to find out:

- Whether people knew if they were in the highest risk or increased risk group when read the NHS definition
- Whether those in the highest risk group received an NHS letter on 'important advice to keep you safe from Coronavirus' letter
- Whether people surveyed understand official COVID-19 information
- What are the unmet information needs of people surveyed
- Whether GP and hospital appointments had been cancelled or changed

HWNN made contact with vulnerable people via community groups, Facebook, existing contacts and through our volunteers. A total of 435 people from Nottingham and Nottinghamshire responded to the survey - 383 via an online survey and 52 were reached through phone calls. The breakdown of the people we reached is shown in table 1 below.

Vulnerable Group	Number of responses
People with long term conditions	193
People with one or more disabilities	142
People over the age of 70	135
People in the highest risk group	111
People who are Black, Asian, Minority Ethnic and Refugees (BAMER)	48
People who are lesbian, gay, bisexual, transgender or questioning (LGBTQ+)	44
Young people with mental health issues	11

Table 1 Source all responses (n=435) NB total is higher because some respondents fitted into 2 or more groups



Summary of findings

Findings across all those surveyed are summarized below. Summaries by each group are provided in the Appendices.

Highest risk group

- 12.6% (n=14) out of 111 people did not know they were in the highest risk group
- 28% (n=30) people in the highest risk group had not received a letter and 5 were unsure. Of those who had not received a letter or were unsure, 13 people did nothing, 11 followed it up themselves and 10 didn't know what to do

Increased risk group

- 9.3% (n=20) out of 213 did not know they were in the increased risk group
- People aged 70 and over were least likely to realize they are in the increased risk group

Clarity of information provided

36 people described what was unclear about the general government information. Some of their experiences are described below in their own words:

'My mother has dementia and now refuses to sleep upstairs as she's afraid of an invasion by virus, there's nothing for her from the Prime Minister, nothing from GP, nothing about prescriptions, no support.'

'I am 86 and live alone, family are not close by, conflicting info as to what I am allowed to do regards shopping'

'I just had a baby 2 weeks ago. So now I am in low risk group? Are newborns in A low risk group? 2 weeks ago I was in increased risk group. My birth was long I actually feel worse than I felt during pregnancy.'

'My daughter has a learning disability and I have mental health issues and I don't drive, we have very little support'

'The guidance about what is and is not essential was unclear, meaning people have been witch hunted in their local communities and a lot of people are very scared.'

Information needs

• 42.3% of people (n=184) had unmet information needs as outlined in the table below

Are there any COVID-19/CORONAVIRUS related topics you have not been able to get clear information or advice about?	Responses
About managing existing health conditions	40
Accessing repeat prescriptions	32
About how to access mental health services	27
Advice for carers/family members caring	21
How to access additional care support	17
Advice on infection control	13
Support for vulnerable (not high risk)	6
About accessing dental services	6
Information for people who do not use the internet	5
Whether routine appointments have been cancelled	5
About how to access GP services	5
Information about testing	4
What to do if need changes to medication	4
Advice for carers	3
Lack of information in other languages	3

Changes to appointments

- Of the 56.8% (n=247) who said their routine appointments had been changed or cancelled, 71 had their appointment delivered by phone call, 130 had their appointment cancelled, and 36 had their appointment postponed.
- 13.6% (n=59) had changed or cancelled their appointment themselves. Five of these did so because they feared contracting Coronavirus, 6 because they felt the NHS was too busy and 3 because they were shielding

Findings by group

- More than a quarter of people in the highest risk group had not received an NHS letter 'important advice to keep you safe from Coronavirus'
- Carers of people living with a disability asked for advice and additional care support
- People over the age of 70 are most likely to need advice as a carer
- People in the LGBTQ+ group were most likely to need information on how to access mental health services
- Young people with mental health conditions were most likely to ask for more information on infection control.

Conclusions

We found that a significant proportion of people did not know if they were in the highest risk or increased group for COVID-19. This indicates that the messaging about who falls into which group has not been sufficiently clear, so that people failed to identify the risk factors which apply to them. As 28% (n=30) people in the highest risk group did not receive an NHS letter 'important advice to keep you safe', this indicates messages are not getting through consistently.

Some people 9.2% (n=40) did not receive support on how to manage existing conditions while they are shielding or isolating. This may have caused their conditions to deteriorate or may have been a cause of anxiety. This is of particular concern where those conditions are known risk factors for developing more severe symptoms of Covid-19, or make managing their daily lives more difficult to control their exposure to the coronavirus.

Nearly half of the people who responded to the survey 42.3% (n=184) had unmet information needs, particularly around managing existing health conditions, accessing repeat prescriptions and accessing mental health support.

As 13.6% (n=59) of people who responded to the survey cancelled or changed their routine appointment themselves, this may imply that the message the NHS is open was perhaps not getting through.

Recommendations

Local health and care system

- Ensure that people receive information about how to manage existing health conditions, access repeat prescriptions and access mental health support;
- Publicise more effectively how people who are at highest risk and increased risk should keep themselves safe and access additional care and support during the COVID-19 pandemic.

National health and care system

- Provide greater clarity to explain the difference between the groups of 'highest risk' and 'increased risk';
- Clarify for the over 70s and other increased risk groups the additional precautions they need to take, over and above those of the general population, to keep themselves safe during the pandemic;
- In a future pandemic, prioritise access to mental health support from the outset.



Analysis by target group - Long Term Conditions

'How do I get my asthma preventer medication as the chemist has no stock as it comes from Italy?'

A total of 193 people said they had a long term condition

- Of these 65 thought they or the person they care for were in the highest risk (shielded group) and 87 in the increased risk group. After being given the definition of the groups 81 were in the highest risk group and 90 in the increased risk group
- Of these, 22 people in the highest risk group had not received a letter and 5 were unsure. Ten people did nothing about not getting a letter, eight followed it up themselves, and eight did not know what to do.

When asked how clear other official Coronavirus (COVID-19) information was, about how to keep safe during the Coronavirus (COVID-19) pandemic, the responses were:

Very unclear	Unclear	Neither clear nor unclear	Clear	Very clear	Haven't seen information
5	15	21	72	75	5

'I cancelled a follow up COPD appointment as my surgery was not able to do a telephone assessment which meant I would need to visit the surgery.'

Are there any COVID-19/CORONAVIRUS related topics you have not been able to get clear information or advice about?	Responses
About managing existing health conditions	14
Accessing repeat prescriptions	9
About how to access mental health services	7
How to access additional care support	5
Support for vulnerable (not high risk)	5
Advice for carers/family members caring	4
About accessing dental services	3
Advice for carers	3
Information about testing	3

Have any of your routine healthcare appointments been changed because of COVID-19 / CORONAVIRUS?

Yes	No	Not sure	Not relevant
138	32	13	10

^{&#}x27;I have had to buy equipment to monitor my health at home so I can give my stats to the doctor over the phone because normally the doctor would take those measurements regularly at the surgery.'

Yes	No	Not sure	Not relevant
51	114	0	28



Analysis by target group - Disabled

'My daughter has a learning disability and I have mental health issues and I don't drive, we have very little support'

A total of 142 people - 32.6% of respondents said they lived with one or more disabilities.

- Of these 35 thought they or the person they care for were in the highest risk (shielded group) and 74 in the increased risk group. After being given the definition of the groups, 43 were in the highest risk group and 82 in the increased risk group
- Of the 43 people in the highest risk group, 14 people had not received a letter and 3 were unsure

When asked how clear other official Coronavirus (COVID-19) information was about how to keep safe during the Coronavirus (COVID-19) pandemic, the responses were:

Very unclear	Unclear	Neither clear nor unclear	Clear	Very clear	Haven't seen information
5	11	16	56	50	4

'Leaving the house more than once a day as a result of being autistic and needing to.'

Are there any COVID-19/CORONAVIRUS related topics you have not been able to get clear information or advice about?	Responses
About managing existing health conditions	8
Accessing repeat prescriptions	7
Advice for carers	6
About how to access mental health services	5
How to access additional care support	4
What to do if need changes to medication	3
Whether routine appointments have been cancelled	3

^{&#}x27;There is an absence of British Sign Language interpreters leaving many deaf/hard of hearing people in the dark.'

Have any of your routine healthcare appointments been changed because of COVID-19 / CORONAVIRUS?

Yes	No	Not sure	Not relevant
98	25	8	11

Yes	No	Not sure	Not relevant
37	85	0	20



Analysis by target group - 70+ year olds

'My mother has dementia and now refuses to sleep upstairs as she's afraid of an invasion by virus, there's nothing for her from the Prime Minister, nothing from GP, nothing about prescriptions, no support.'

A total of 135 people - 31% of respondents said they were aged 70+.

- Of these 33 thought they or the person they care for were in the highest risk (shielded group) and 82 in the increased risk group. After being given the definition of the groups 24 were in the highest risk group and 110 in the increased risk group.
- Of these 24 people in the highest risk group, 6 people had not received a letter and one was unsure.

When asked how clear other official Coronavirus (COVID-19) information about how to keep safe during the Coronavirus (COVID-19) pandemic, the responses were:

Very unclear	Unclear	Neither clear nor unclear	Clear	Very clear	Haven't seen information
4	6	11	59	54	1

'I am 86 and live alone, family are not close by, conflicting info as to what I am allowed to do regards shopping'

Are there any COVID-19/CORONAVIRUS related topics you have not been able to get clear information or advice about?	Responses
About managing existing health conditions	9
Advice for carers	7
Accessing repeat prescriptions	6
Advice on infection control	3

^{&#}x27;My respite break will not be available to me as the Care Home my husband was going to is now closed until further notice.'

Have any of your routine healthcare appointments been changed because of COVID-19 / CORONAVIRUS?

Yes	No	Not sure	Not relevant
66	46	5	15

^{&#}x27;My Mum is partially deaf and has early signs of dementia which makes telephone consultations impossible for her'

Yes	No	Not sure	Not relevant
22	90	0	24



Analysis by target group - Highest risk

'I now have an appointment in August that should have been in March, I have had two appointments in April cancelled and a medication review with my GP cancelled and an asthma check-up done over the phone.'

A total of 111 people said they were in the highest risk group

- Of these 73 people had received a letter and 6 were unsure. Thirteen did nothing, 12 followed it up themselves and got a response, 12 did not know what to do.
- 32 people said the letter did not make sense

When asked how clear other official Coronavirus (COVID-19) information about how to keep safe during the Coronavirus (COVID-19) pandemic, the responses were:

Very unclear	Unclear	Neither clear nor unclear	Clear	Very clear	Haven't seen information
1	5	9	49	46	1

Are there any COVID-19/CORONAVIRUS related topics you have not been able to get clear information or advice about?	Responses
About managing existing health conditions	6
Accessing repeat prescriptions	5
About how to access mental health services	4
Advice for carers	4
How to access additional care support	4
Advice on infection control	3

Have any of your routine healthcare appointments been changed because of COVID-19 / CORONAVIRUS?

Yes	No	Not sure	Not relevant
82	18	6	5

'Radiotherapy reduced from 15 to 5 sessions'

Yes	No	Not sure	Not relevant
33	65	0	13

^{&#}x27;I usually have a ketamine infusion to manage my pain every 3 months. I have not been able to have these because of the outbreak. I have had to start taking opioid medication to combat my pain again'



Analysis by target group - BAMER

'I just had a baby 2 weeks ago. So now I am in low risk group? Are new-borns in low risk group? 2 weeks ago I was in increased risk group. My birth was long, I actually feel worse than I felt during pregnancy.'

A total of 48 people said they were from a Black, Asian, Minority Ethnic and Refugee groups

- Of these 12 thought they or the person they care for were in the highest risk (shielded group) and 13 in the increased risk group. After being given the definition of the groups 12 were in the highest risk group and 17 in the increased risk group.
- Of these 12 people in the highest risk group, ten people had not received a letter and four were unsure.

When asked how clear other official Coronavirus (COVID-19) information about how to keep safe during the Coronavirus (COVID-19) pandemic, their responses were:

Very unclear	Unclear	Neither clear nor unclear	Clear	Very clear	Haven't seen information
1	3	4	29	10	1

Are there any COVID-19/CORONAVIRUS related topics you have not been able to get clear information or advice about?	Responses
About managing existing health conditions	2
Accessing information in other languages	1
About how to access mental health services	1
Accessing primary care	1
Accessing repeat prescriptions	1
Guidance for new mums	1
How to access additional care support	1

'Information for people who do not use the internet and who are digitally illiterate'

Have any of your routine healthcare appointments been changed because of COVID-19 / CORONAVIRUS?

Yes	No	Not sure	Not relevant
22	19	1	6

'Delay to start of exercise class for breathing difficulties'

Yes	No	Not sure	Not relevant
9	25	0	10



Analysis by target group - LGBTQ+

'I need information on 'transgender surgeries and if the NHS will continue to fund them all? Advice for loneliness and how to find friends?'

A total of 44 people said they were LGBTQ+

- Of these 11 thought they or the person they care for were in the highest risk (shielded group) and 22 in the increased risk group. After being given the definition of the groups 16 were in the highest risk group and 14 in the increased risk group
- Of these 16 people in the highest risk group, nine people had not received a letter

When asked how clear other official Coronavirus (COVID-19) information about how to keep safe during the Coronavirus (COVID-19) pandemic, the responses were:

Very unclear	Unclear	Neither clear nor unclear	Clear	Very clear	Haven't seen information
2	7	6	13	15	1

Are there any COVID-19/CORONAVIRUS related topics you have not been able to get clear information or advice about?	Responses
About how to access mental health services	7
What to do when in an increased risk group	2
Accessing repeat prescriptions	2

Have any of your routine healthcare appointments been changed because of COVID-19 / CORONAVIRUS?

Yes	No	Not sure	Not relevant
30	8	5	1

'I can no longer access counselling.'

Yes	No	Not sure	Not relevant
12	29	0	3



Analysis by target group - Under 25 years with mental health issues

'I am unable to have my regular counselling appointments at my college. It has meant transferring to adult services is difficult and longer.'

A total of 11 people said they were young people with mental health issues.

- Of these two thought they or the person they care for were in the highest risk (shielded group) and four in the increased risk group. After being given the definition of the groups three were in the highest risk group and three in the increased risk group.
- Two had received a letter.

When asked how clear other official Coronavirus (COVID-19) information about how to keep safe during the Coronavirus (COVID-19) pandemic, the responses were:

Very unclear	Unclear	Neither clear nor unclear	Clear	Very clear	Haven't seen information
2	1	1	7	0	0

Are there any COVID-19/CORONAVIRUS related topics you have not been able to get clear information or advice about?	Responses
Advice on infection control	3
Accessing repeat prescriptions	2
About how to access mental health services	2
About managing existing health conditions	1

^{&#}x27;Language too vague and info conflicts over time as well as it not being very accessible in terms of understanding'

Have any of your routine healthcare appointments been changed because of COVID-19 / CORONAVIRUS?

Yes	No	Not sure	Not relevant
8	3	0	0

Yes	No	Not sure	Not relevant
2	8	0	1



Area	Number	Percentage
Nottingham City	87	19.2%
Bassetlaw	80	17.6%
Gedling	77	17%
Rushcliffe	57	12.5%
Newark & Sherwood	47	10.4%
Ashfield	32	7%
Mansfield	31	6.8%
Broxtowe	21	4.6%
Outside of Nottinghamshire	19	4.2%
Not answered	3	0.7%
TOTAL	454	100%

Age	Number	Percentage
16-24	19	4.4%
25-34	26	6.0%
35-44	40	9.2%
45-54	59	13.6%
55-64	97	22.3%
65-69	45	10.3%
70+	133	30.6%
Not answered	16	3.7%
TOTAL	435	100%

Gender	Number	Percentage
Female	314	72.2%
Male	111	25.5%
Non-binary	3	0.7%
Prefer not to say	3	0.7%
Not answered	1	0.2%
TOTAL	435	100%

Employment status	Number	Percentage
Retired	193	44.4%
Part time	77	17.7%
Full time	64	14.7%
Unable to work	46	10.6%
No	35	8.0%
Student	12	2.8%
Prefer not to say	5	1.1%
Not answered	3	0.7%
TOTAL	435	100%

Ethnicity	Number	Percentage
White	393	90.3%
Asian	19	4.4%
Prefer not to say	7	1.6%
Mixed/Multiple ethnic	6	1.4%
Black	2	0.5%
South Asian	2	0.5%
Other (Chinese)	1	0.2%
Not answered	5	1.1%
TOTAL	435	100%

Sexuality	Number	Percentage
Heterosexual	287	66.0%
Homosexual	23	5.3%
Bisexual	18	4.1%
Asexual	16	3.7%
Prefer not to say	61	14.0%
Not answered	30	6.9%
TOTAL	435	100%

Are you a carer?	Number	Percentage
Yes	75	17.2%

Nationality	Number	Percentage
British	370	85.1%
Polish	17	3.9%
Pakistani	9	2.1%
Irish	3	0.7%
American	1	0.2%
Australian	1	0.2%
Swedish	1	0.2%
Portuguese	1	0.2%
Eastern European	1	0.2%
Not specified	31	7.1%
TOTAL	435	100%

Disability status	Number	Percentage
A long-term health condition	187	43.0%
Mental health illness	85	19.5%
Physical impairment	80	18.4%
Hearing impairment	57	13.1%
Visual impairment	26	6.0%
Learning impairment	15	3.4%
Social/behavioural problems	13	3.0%
Prefer not to say	0	0.0%

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