



COVID-19 How are we coping?

Week 6th-12th April 2020 Results

Overview of Week 1

In week one of the survey we saw a surge in public responses within a very short space of time that has not previously been seen in our localised survey work. As the weeks follow the number of responses continue to increase currently moving towards the 1,500 mark.

This can be interpreted in numerous ways, but the general feeling inferred from the responses, was that people wanted to vent their frustrations and fears of life under the grip of a global pandemic, whilst sharing warmth, compassion and community spirit in equal measure.

The aim of the work is to follow the population over time and understand whether their beliefs and behaviours change. During the first week, 6th to 12th April, the feedback demonstrated key features which included:

- A concern above all else for those who were vulnerable and weak.
- A concern for peoples own wellbeing and that of their families and loved ones.
- Frustration at mixed and negative messages being given through fake news, media and local and government sources.
- Frustration and concern about the impact on new or existing health and care issues outside of COVID-19.
- Frustration and concern for the lack of support systems within primary care, secondary care and mental health.
- Mixed tolerance levels for how the community is reacting to lock down restrictions and how they are being enforced.

These features will be monitored in the coming weeks to assess any significant changes which will support community infrastructure organisations, both local and national both in the here and now, but also in the future.

Background and Rationale for the Research

Healthwatch continues to deliver its core function of gathering public and patient feedback across health and care services impacting Lincolnshire patients.

A 13 week campaign to track how people are feeling week on week during the COVID-19 pandemic started on the 6th April 2020. The focus of the campaign is to understand how people are coping at different stages of the lock down period, what people find helpful, but also what their biggest concerns are.

The overall findings will be shared with the system and other interested partners whose services underpin the Lincolnshire and UK health and care infrastructure, this information will be crucial for future learning. The public voice will help them listen, understand and develop future crisis planning.

In week one 340 responses were received, and on the 29th April the total responses received stood at 1,411 increasing daily. The feedback is being analysed weekly to enable a comparison on a week by week basis as the situation in the UK continues to change in response to the pandemic.

Methodology

Week one of the survey was launched digitally on the 6th of April 2020 with responses captured through Survey Monkey. The survey is distributed every Friday afternoon through the Healthwatch network to members and stakeholder organisations. In addition, Facebook advertising has been utilised to target the wider Lincolnshire population.

The survey consists of 12 questions including 5 demographic questions, 3 of the questions provide an opportunity for the respondents to give more detail about their experiences through free text comments, some of which are shared within this document.

The questions posed are given below:

Questions from the survey

- Q1. Have you had coronavirus/COVID-19? Multiple choice
- Q2. What best describes how you are feeling today? Multiple choice
- Q3. Have you found it easy to find clear and understandable information about what to do to keep yourself and others safe during the coronavirus/COVID-19 pandemic? *Multiple choice*
- Q4. Do you feel the information and advice given around COVID-19 has helped you adapt to the changes imposed on your day to day life? Multiple choice
- Q5. Do you feel that you or your loved ones quality and safety of care (not related to COVID-19) is being affected? Multiple choice with free text comment field
- Q6. What are your three biggest concerns? (Please select 3 ONLY) Multiple choice

- Q7. Tell us what 'action' local or national, would most help you at this time with those concerns *Free text comment field*
- Q8. Please include your Email address as we would like you to complete this survey weekly Free text comment field
- Q9. What is your age? Multiple choice
- Q10. Gender What gender group are you in? Multiple choice
- Q11. What was your employment status before the Coronavirus (COVID-19) pandemic? *Multiple choice*
- Q12. What district area do you live in? Multiple choice



Results from the Survey

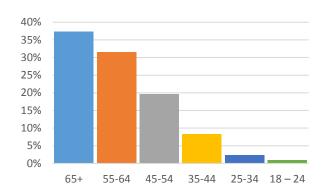
The following section reviews the results of the survey and draws out the key features within the narrative and where public free text comments are relevant, these have been included to add depth and richness to the data.

340 responses between 6th April and the 12th April 2020.

Demographics

Q9 - Age

18 - 24	0.89%	3
25-34	2.37%	8
35-44	8.31%	28
45-54	19.58%	66
55-64	31.45%	106
65+	37.39%	126



The volume of respondent's week on week are deemed to be satisfactory with respondents coming back week after week and the rate of responses staying stable. This is a positive level of response with opportunity to obtain a real time view of any behavioural shift. However that said, it is recognised that the younger respondents are not representative in number of our whole population at this time.

Q10 - Gender

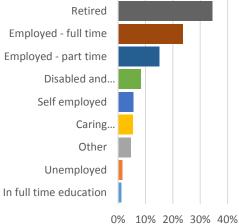
Male	16.8%	56
Female	83%	278



From the data, there is a significantly disproportionate amount of female responses compared to male. This is a frequent pattern seen locally however more will be done to target the male population and encourage them to share their experiences and views over the coming weeks.

Q11 - What was your employment status before the Coronavirus (COVID-19) pandemic?

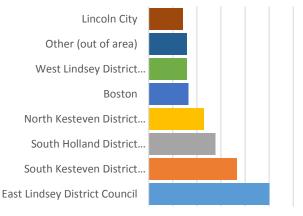
Retired	34.42%	116
Employed - full time	23.74%	80
Employed - part time	15.13%	51
Disabled and unable to	8.31%	28
work		
Self employed !	5.64%	19
Caring responsibilities !	5.34%	18
Other	4.75%	16
Unemployed	1.48%	5
In full time education	1.19%	4



This data was collected so that a review of whether the respondents status in terms of activity; employed, not employed, furloughed, carer etc. had any impact on their views and behaviours. Whilst this will be considered weekly the generated result is most likely to have greater consequence in weeks to come when there will be more data,

Q12. What district area do you live in?

East Lindsey District	25.07%	85
Council		
South Kesteven District	18.29%	62
Council		
South Holland District	13.86%	47
Council		
North Kesteven District	11.50%	39
Council		
Boston	8.26%	28
West Lindsey District	7.96%	27
Council		
Other (out of area)	7.96%	27
Lincoln City	7.08%	24



0% 5% 10% 15% 20% 25% 30%

The data shows a larger proportion of respondents from the East Lindsey district. As a result, targeted advertising in coming weeks is hoped to create a more even distribution of Lincolnshire localities.



The following section provides an overview of the main body of questions where public feeling is evaluated.

Q1 - Have you had coronavirus/COVID-19?

Yes - I been tested	0.90%	3
Possibly- Has symptoms, but not been tested	17.31%	58
No - Not had symptoms	81.79%	274

Question 1 was asked in order to understand if the views of the public were different depending on the level of exposure they had to the virus, whether that as a patient, family or loved one, carer or key worker. However at this time the sample size of those who had tested positive is too small to draw any robust analysis.

Q2 - What best describes how you are feeling?

This question aimed to understand how people were 'feeling', what was their core focus and noting particularly any areas that may, over the coming weeks, highlight continuing trends for ongoing concerns that aren't being met. The majority of people surveyed across Lincolnshire said they were most concerned for people who were perceived as vulnerable or weak as lockdowns and closure of life as they knew it, was forcing people to isolate themselves or carry on in an uncertain world.

It is worth noting that this high level of concern for others and the much wider views of people responding is significant. As the NHS noted the dramatic reduction in people presenting for health care, they asked people to take care of themselves and to seek medical help if needed, this was evident in Week 1 by the concern about peoples 'own' health and care coming 4th on the table of importance.

What is known from patient feedback is, that in addition to the concern for others, concern relating to catching the virus, putting a burden on the health system and a level of uncertainty about how ongoing conditions were being managed all add to reducing numbers seeking non-COVID related care.

Concerned for those who are vulnerable or weak	53.14%	183
Curious about how this is impacting the world	28.7%	97
Inspired by how people are adapting	27.8%	94
Anxious about my health	26.9%	91
Happy to spend time with family	24.6%	83
Hopeful to see how the environment is improving during this time	23.7%	80
Lonely	13.9%	47
Impatient to get back to normal life	13.3%	13
Angry about the restrictions on my freedom	3.0%	10

The majority of respondents (53%) who said they were concerned for those who are weak and vulnerable shared some of their personal feelings, circumstances and situations below.

"Worried about my husband's health as he cannot have urgent surgery to treat bowel cancer and in the meantime he has a tumour causing pain and worry"

In addition were there was concern about peoples own individual health with 27% saying they are anxious. They shared some of the following perspectives including that of a nurse on a COVID ward.

"Concerned by the lack of support for those who live on their own - including those not classed as vulnerable. Having been ill with this and it initially having quite a significant impact on my breathing I was very aware I was on my own and, if something happened, would not be found."

"Scared as been made to work as nurse on Covid ward in a different hospital within my trust no support"

"Irrationally depressed with trivia but grateful healthy"

Q3. Have you found it easy to find clear and understandable information about what to do to keep yourself and others safe during the coronavirus/COVID-19 pandemic?

Yes	95.81%	298
No	4.18%	13



96% of respondents said they found it straight forward to find clear and understandable information about how to keep themselves and others safe during the COVID-19 pandemic.

Despite the positive 96% response, there were also a significant numbers of people who found that mixed messages were being shared and they were unsure where to go for trusted information.

"Mixed messages. We are over 70 and have to stay at home for 12 weeks but it's unclear if we can take a daily exercise or not, we have had no letter saying we are high risk. Also we don't know how to contact any of the volunteers if we need help to help"

Common themes from the feedback were:

- **Trust** Feelings that there was too much false information being shared.
- **Mixed messages** At times people were confused and felt advice was conflicting.
- **Centralised Messages** Communications from Government or other statutory organisations was not always clear and distributed effectively.
- **Blocked Access** Support telephone lines were blocked or felt that strong messages were given for people not to contact them.
- Vulnerable people with serious health conditions There were many comments stating people were concerned because they had not received a shielding letter to say they were vulnerable, this affected their health, ability to access support and in some cases people were made to go back to work in situations where they felt they were at risk.



If you are unsure where to go for information to keep safe through the COVID-19 pandemic please check out https://www.gov.uk/coronavirus

Q4 - Do you feel the information and advice given around COVID-19 has helped you adapt to the changes imposed on your day to day life?

Yes	89.43%	296
No	10.57%	35



89% of respondents felt the information and advice given around COVID-19 has helped them adapt to the changes imposed on their day to day lives.

Q5. Do you feel that you or your loved ones quality and safety of care (not related to COVID-19) is being affected?

Yes	37.91%	127
No	61.19%	205



The question sought to understand how people felt their health and care was being affected outside the COVID medical condition. The question gave respondents an opportunity to share how they felt the care for themselves, their family and loved ones was being impacted by the pandemic. 38% of respondents felt their loved ones quality and safety of care has been affected negatively during this time.

The core reasons for this negative impact on everyday health and care are summarised below, most of the experiences and opinions fell under the following categories, however the majority fell within the first 2 bullet points:

- Cancelled/postponed healthcare including: surgery; chronic condition reviews; ongoing treatments for chronic conditions; initial appointments with specialists; diagnostic procedures and investigations.
- Primary care: difficulty accessing advice and appointments; as well as a reluctance to access advice and care - due to 'not wanting to bother them' OR concern for personal safety in healthcare environments
- Concern around the implications of receiving a shielding letter as well as concern about not having receiving a shielding letter when they think they should.
- Dealing with a family member/loved one who don't have capacity to understand the current circumstances and the changes being imposed

The following shared a number of relevant comments shared by the public under the categories above:

Cancelled/postponed healthcare including: surgery; chronic condition reviews; ongoing treatments for chronic conditions; initial appointments with specialists; diagnostic procedures and investigations.

"Lots of appointments for my daughter have been cancelled which we have waited 2 years for my husband struggling with his anxiety and can't see anyone"

"I have heart disease as I had a heart bypass 7 years ago. I am currently under investigation as my GP found a heart murmur and following a chest x-ray I also have fluid around my heart. I'm waiting for an echocardiogram to see what's going on with my health and yet haven't heard a thing. I'm concerned but don't want to

go to a hospital either. My new problems started a few weeks before lockdown so I understand the wait. Still feel scared waiting."

"My former wife has had her outpatient appointment to remove a cancerous tumour from her nose cancelled and only a message to say will be rescheduled at some future date. As she was informed this tumour could be one that is spreading elsewhere it is of concern. She understands situation and would not wish to attend hospital at this time but does raise anxiety which is already high."

"I am afraid that should I need medical care for something other than Covid-19 it will be extremely difficult to get. Before this it was almost impossible to get a doctor's appointment. I was due for a diabetes check-up over a month ago and that hasn't happened, so my diabetes could be completely out of control and nobody seems to care."

"Mum's important surgery (pacemaker replacement) cancelled. Son recovering from major brain injuries and multiple fractures sustained in 2018 had surgery and reviews postponed for several months, also neuro appts."

"My sister in law has a heart condition and is finding it difficult to get advice"

Primary care: difficulty accessing advice and appointments; reluctance to access advice & care - due to 'not wanting to bother them' OR concern for personal safety in healthcare environments

"It makes you reluctant to contact GP as they are under pressure. So other health issues may get side tracked."

"I have had ongoing pain inflammation and swollen glands in mouth and throat. There are no dentist provisions for urgent dental care where I live. I have had a telephone appointment with a doctor who asked me to diagnose myself. I have been given antibiotics but dubious if this will work as no one has been able to check my throat, glands etc. I am scared going to work as my immune system is obviously low."

"Not being able to physically visit the GP is worrying. My husband has heart problems and is anxious in case he can't get the care he needs."

"Patients are scared to seek medical help when they need it as the messages from GP surgeries are very aggressive and off putting. Patient's ailments are getting worse and they are not presenting soon enough, this is resulting in critical situations and in some cases death. More needs to be done to tell patients they can and should seek medical help."

Concern around the implications of receiving a shielding letter as well as concern about not having receiving a shielding letter when they think they should.

"Mixed messages. We are over 70 and have to stay at home for 12 weeks but it's unclear if we can take a daily exercise or not, we have had no letter saying we are high risk. Also we don't know how to contact any of the volunteers if we need help to help"

"No letter from GP or consultant about self-isolation or shielding"

"I have Sarcoidosis which has caused scarring on my lungs. I take medication to help with my breathing I'm 69yrs I try to keep myself as fit as can but I'm restricted as to how my lungs and breathing are from day to day. The government have said we should receive a letter because we are at risk with Covid19 never received one. Rung the doctor because my chest was tight and I had upset tummy and sore throat he said they didn't class Sarcoid as high risk and my systems would suggest self-isolating for 7days I was fed and worried after talking to him on the phone."

"I received an NHS letter telling me I am vulnerable and should isolate for 12 weeks. I have no idea why. My GP practice can't enlighten me either."

Dealing with a family member/loved one who don't have capacity to understand the current circumstances and the changes being imposed

"My mother who is blind disabled and has early dementia lives with me I am not medically trained and I'm not a carer We have been muddling through but not been offered any advice on what the f we do if one of us gets covid19 or any other illness My mother is vulnerable but no one has contacted me because she lives with me regardless of the fact I'm not her carer but her Daughter"

"My grandmother was medically fit for discharge from hospital but couldn't go home as insufficient carers available to restart care package. She now has tested positive for Covid-19, caught in hospital"

"Assessments have been cancelled meaning my step mum is dealing with a frail old man who is suffering from dementia and Parkinson's while she recovers from a fractured hip and waits for a replacement pacemaker. My older son 26) was recovering well from a serious brain injury and multiple fractures, appointments cancelled, surgery cancelled. Mental health worsening by the day. My younger son (almost 22) is terrified he has severe learning disabilities and physical disabilities too there's no support available until I cannot cope. How does one (I have disabilities too), deal with isolating to protect the vulnerable but have to shop for 5 people with restrictions on amounts? How does one stand in queues knowing that it will be impossible to walk around the supermarket before pain becomes unbearable?"

Q6 - What are your three biggest concerns?

Question 6 seeks to identify the main areas of concern for people and is closely linked with question 2 (What best describes how you are feeling?), due to the volume of information received the decision was taken in subsequent weeks to narrow the fields and to only ask for the 'top 3' biggest concerns, the free text option has been removed.

In question 2, the majority of respondents (53%) said they were concerned for those who are weak and vulnerable. In this question the overwhelming key concern related to their own and their families health and wellbeing, intrinsically linked with catching or passing on the COVID-19 virus.

Concern for own/families nealth and wellbeing	141
Catching or passing on COVID-19	90
People not following the rules	70
Concern for vulnerable people including keyworkers	51
Long term effects of COVID-19	51
Getting food / shopping	49
Economy/ local businesses	44
Access to Healthcare	42
Finances	37
Not being able to see friends / family	32
Concern about NHS coping	29
Length of the lockdown	29
Dying	26
Mental Health	26
Loneliness and isolation	24
Restrictions to day to day activities	19
Job / work	13
Testing	10
Information and advice	8
Education / School	7
Media messages	7
When there will be a vaccine	7
No Concerns	5

The most common responses were concern for their own and families' health and wellbeing, here are just a few ...

"Me and my family's health"

"Husband not getting surgery for bowel cancer"

"Safety of family and friends"

"My husband could get the virus and due."

"Worried about loved ones getting Covid 19"

Impact of ... "People not adhering to restrictions in lockdown"

Impact of ... "People not adhering to social distancing"

Q7 - Tell us what 'action' local or national, would most help you at this time with those concerns?

From these responses there was a very mixed variety of views, here are what stood out as those that had most impact on people.

- **More support** for vulnerable, for NHS staff and care workers, for families and all key workers.
- **Testing** feeling that much more of this could have been and needs to be done.
- Honesty feeling that information was being held back and not as transparent as it should be, and messages are confusing like the daily number of deaths are not representative of that day and exclude community deaths.
- **Positive messages** a definite feeling of fear and negativity was getting people down, it was felt more positive messages would help lift spirits.
- Lockdown Rules this was a mixture of people feeling stricter conditions and compliance needed to be a focus, whereas others wanted more freedom, particularly being able to drive round and sit in their car so they can get out and relieve pressure (mental wellbeing/ household resilience).
- Mental health concerns regarding how little support is being provided.
- **Media** a lot of negativity about how the media is portraying the current situation.
- **Exit strategy** feeling that this would help practically and mentally, this was linked in with positive messages and mental health.
- **Shopping** there were a significant number of comments relating to people's needs and challenges in being able to shop for what they needed.
- **Doctors and Primary Care** People asking when they will be able to get the support they need and a definite feeling of neglect for some.
- Police there was a mixed view in terms of police involvement in the pandemic, from a sense of needing to maintain public order and ensure compliance with the restrictions were upheld, whilst feeling that police powers were insufficient (interestingly there was no consideration for the limited numbers of police available daily to carry out these enforcements), and secondly an opposing view which felt the police needed to back off.

Finally

Week 1 of the campaign has provided an interesting insight into the perspectives and mind-set of some the Lincolnshire population, the limitations of the sample size are acknowledged and actions will be taken over coming weeks to try and bring some balance. The aim is to be able to identify and share where a mood and behaviour is at any given point, and report any notable changes which will support the whole community infrastructure meet the needs of Lincolnshire's residents.

Watch out for the highlights over the coming weeks and if you want to get involved you can do so by simply following this link to take part: https://www.surveymonkey.co.uk/r/VBTW2PB



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