

People's views and experiences of how Covid – 19 has affected them



**Coronavirus
(COVID-19)**

healthwatch
Sandwell

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healthwatch
Sandwell



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Introduction

Healthwatch Sandwell (HWS) are the independent voice of the public in health and social care services. We collect feedback from people using health and social care services in Sandwell about their experiences and use that feedback to work with service commissioners and providers to look for ways to improve services.

One of the ways that we do this is to carry out engagement activities that focus on particular services or groups of people living and using services in Sandwell.

On this occasion we wanted to find out people's views and experiences of how Covid – 19 had affected them and how HWS might be able to signpost people to further information or services.

Background

COVID -19, also known as Corona Virus, was declared as a pandemic by the World Health Organization on 11 March 2020, which required a global co-ordinated effort to stop the further spread of the virus.

It is believed to have spread to the United Kingdom in late January 2020, the UK government imposed a lockdown¹ (a situation in which people are not allowed to enter or leave a building or area freely because of an emergency) on the evening of 23 March. Restrictions were initially put in place for a period of three weeks, until 13 April, but were later extended.

The routes of transmission of COVID - 19 were unclear at the outset, but evidence from other coronaviruses and respiratory diseases indicates that the disease may spread through large respiratory droplets and direct or indirect contact with infected secretions human-to-human transmission is occurring.

The UK were advised to begin social distancing² (avoid close contact with anyone who you do not live with), self-isolating³ (staying at home because you have or might have coronavirus) and shielding⁴ (a description of how to protect those at highest risk of severe illness if they catch coronavirus by minimising all interaction between a person and those who are most at risk). All these measures were put in place to help stop the virus spreading to other people.

Methodology

Telephone survey

Telephone calls were made/received by HWS staff to members of the public during this time frame. HWS are continuing to speak to local people, about their health and social care issues during the COVID - 19 pandemic. See appendix one for survey. The telephone survey engaged with 31 telephone people made between 30 March - 30 May 2020.

¹<https://dictionary.cambridge.org/dictionary/english/lockdown>

² <https://www.nhs.uk/conditions/coronavirus-COVID-19/social-distancing/what-you-need-to-do/>

³ <https://www.nhs.uk/conditions/coronavirus-COVID-19/self-isolation-and-treatment/when-to-self-isolate-and-what-to-do/>

⁴ <https://www.healthwatch.co.uk/advice-and-information/2020-03-26/coronavirus-what-does-shielding-mean>





Online survey

An on line survey was utilised (courtesy of Warrington Healthwatch). This survey was publicised using our social media platforms: Facebook, Twitter, Instagram and also on HWS web site. See appendix two for survey. 37 surveys were completed between 30 March - 30 May 2020.

In total HWS engaged with 68 people, the findings from both surveys have been amalgamated for this report. All data gathered adhered to the General Data Protection Regulation (2018). For the purpose of this report, all feedback is anonymous.

Findings

The questions and answers from both surveys have been amalgamated and grouped into themes:

- Information
- Experience of COVID – 19
- Experiences of accessing medical advice or care related to COVID - 19
- Coping and concerns during lockdown
- Mental health
- Getting help with healthcare for any existing health conditions
- Getting help with new symptoms that are NOT COVID - 19 related
- Assistance with daily living
- Signposting
- Volunteering

4.1 Information

Information about COVID - 19 was key to understanding what is happening and how to keep safe during the pandemic. Respondents were asked whether the information that they had was accessible, clear and understandable.

97% responded positively and collectively the majority of respondents stated that they had ample, easy to understand and accessible information. One person whose first language was Somalian stated that the information was accessible as they could read English. However, it is important to note that deaf people struggled to access information that was on TV.

'I am a deaf British Sign Language User and there have been no interpreters on the BBC daily briefings. I have had to rely on charities to produce the information in BSL, but this is brief clips only'

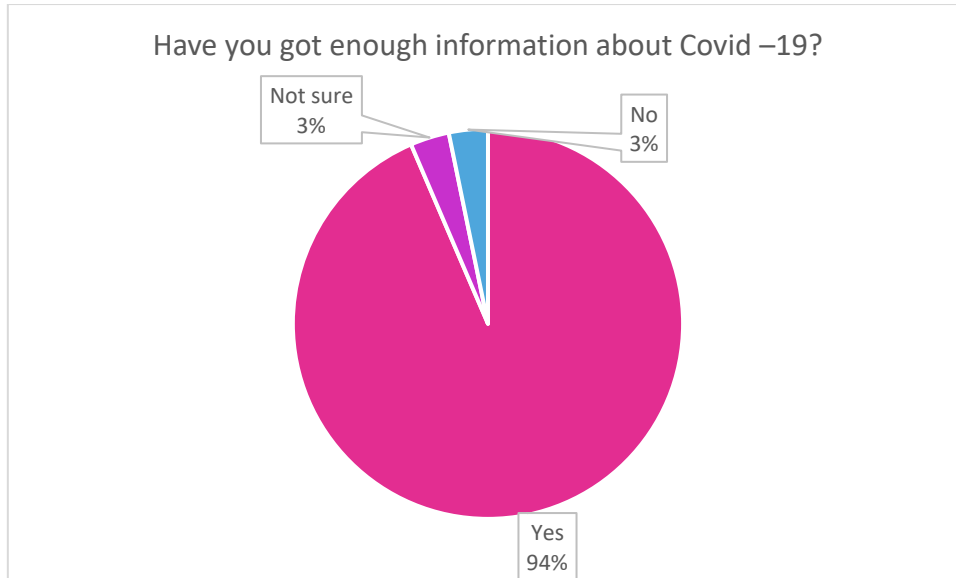
'Also, Sandwell Council leader videos on their website have no BSL or subtitles'

94% stated that they had enough information. However, there was a general feeling that there was too much information, someone described as being *'overloaded'* with information. Some people found it hard to understand especially as there was a lot of medical terms used.

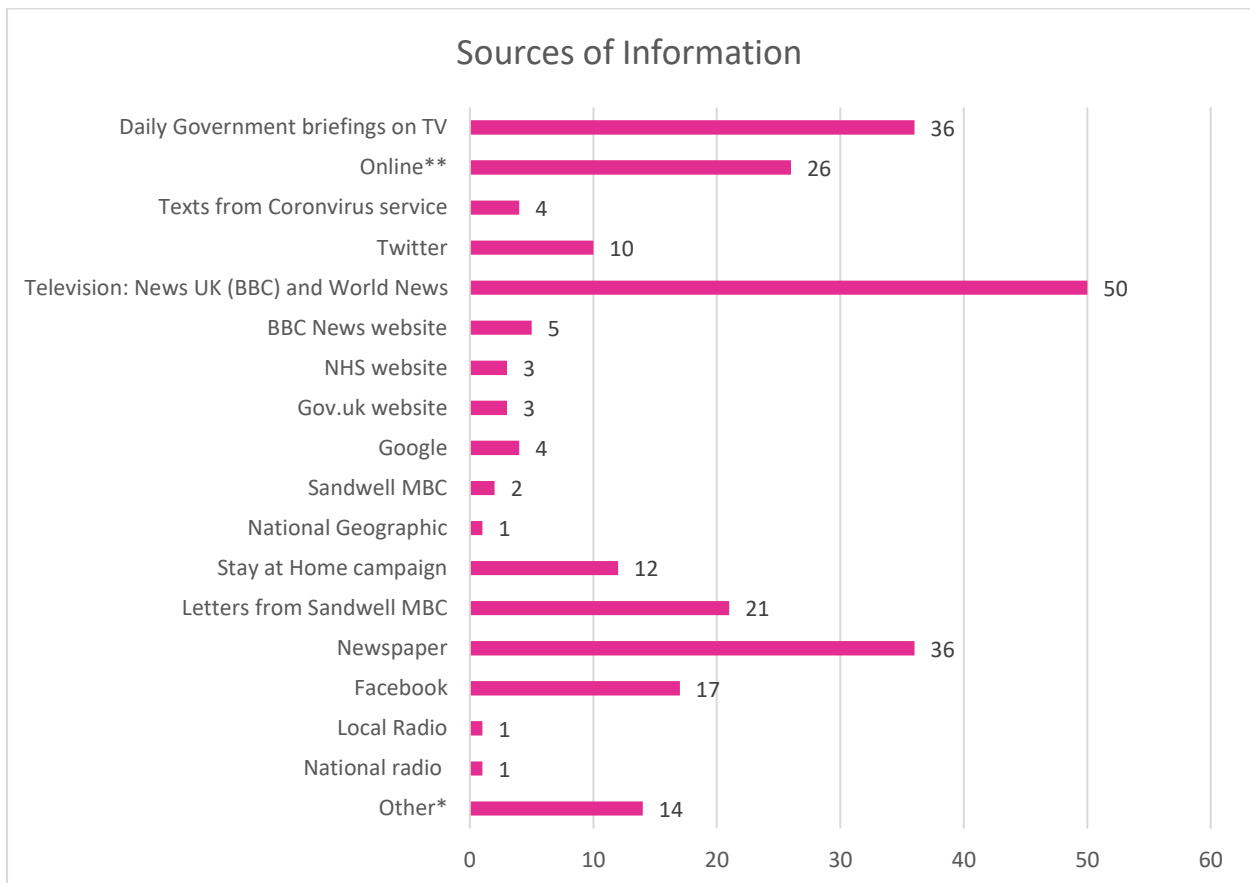
It was stated that the information kept changing and was at times contradictory, conflicting and not accurate. Examples were cited about the reasons when they could leave the house. Someone described it as :

'at times I dislike being under house arrest!'





Respondents were asked where did they obtain COVID - 19 information from, they identified more than one source. It transpires that The News on the television was main source of information.



**online:

This included: Medscape, Gov.uk, NHS.uk, World Health Organisation and Video bloggers on YouTube

*Other: this category included:





Letters/emails from the Government, Local Authority, General Practitioners and employer(s), Information from friends, neighbours and family.

Respondents were concerned that there was confusion about how people were interpreting the information, especially in relation to the 'rules', this added to people's frustration and confusion:

'some people are not taking any notice of the rules'

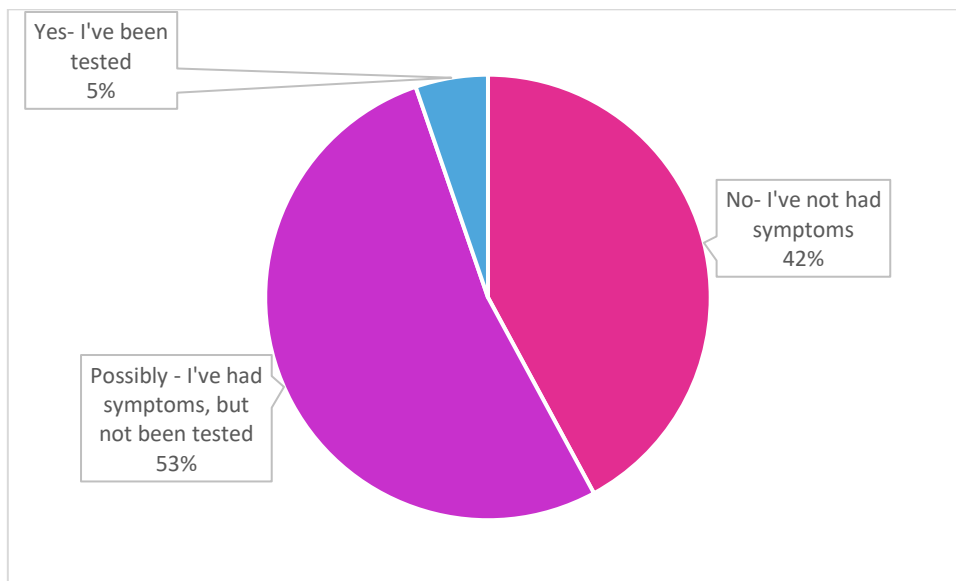
'bit more unclear now, because I see more people than before visiting friends and neighbours , in fact nearly everyone on the street is visiting and being visited and some have gatherings 4 or 5 homes sitting in deck chairs together, even a teacher and health worker nurse so that makes it confusing, I stay in and don't go out as I think the rules should be stay in , the 'r' is not low enough, not worth the risk and doesn't help NHS who have been so busy'

Information about services

Some patients had received letters and/or text messages about access to Primary care e.g. General Practitioners. When patients had rung GP practices some had heard an automated message what they needed to do if they had COVID - 19 symptoms and other health needs.

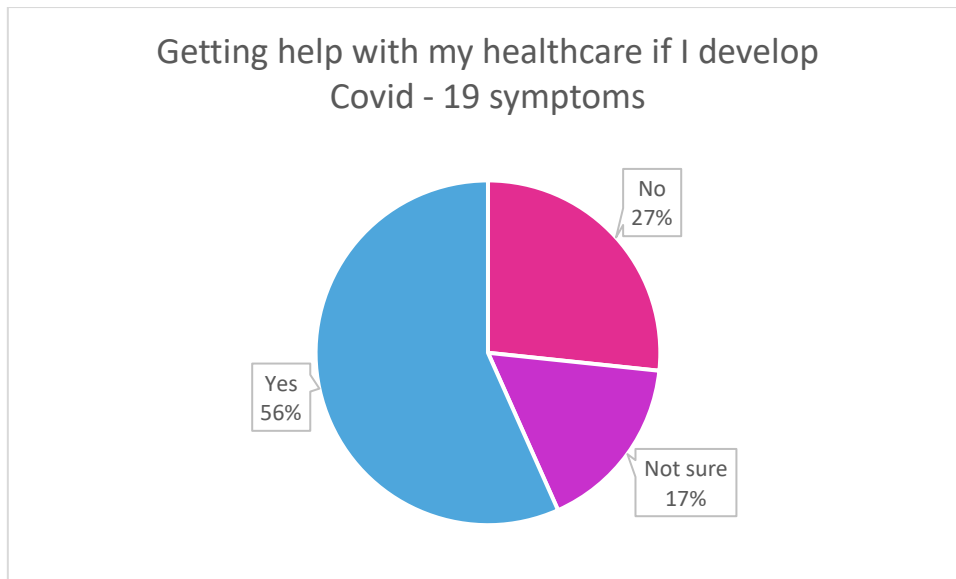
4.2 Experience of COVID – 19

Respondents were asked if they had had COVID – 19, at the time of this survey, there were only 5% who had a test to confirm if they had the virus, however there were a large number of people with symptoms but had not been tested (53%).



Respondents were asked if they believed they would get help with Covid – 19 symptoms



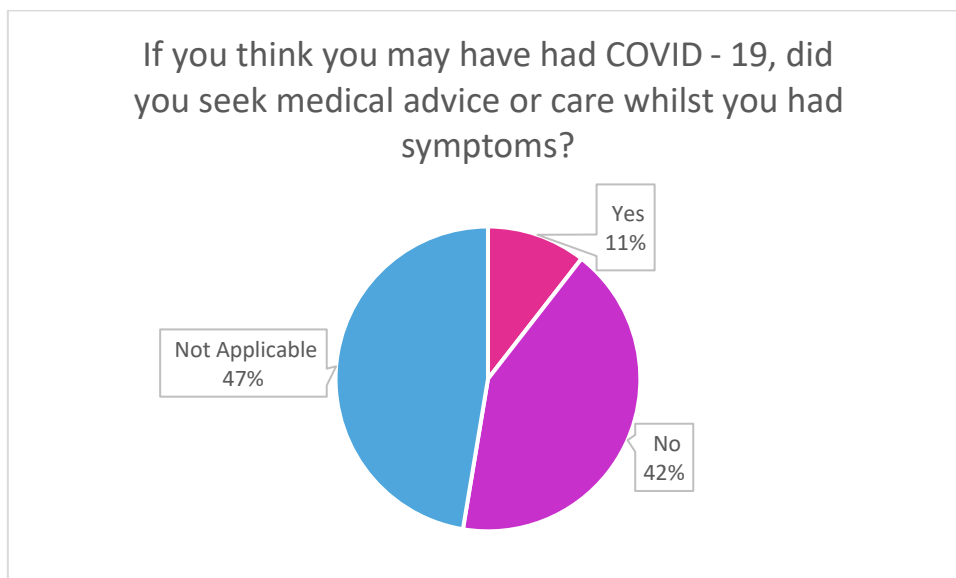


Interestingly 17% were not sure if they would get help with symptoms if they developed symptoms. 56% said they thought they would get help, but some were concerned especially as they find it hard to get through to 111. Some were unsure and stated that they thought that their age and vulnerability would limit their chances of help:

'I don't believe I'll get a ventilator due to my age'

Some people were concerned about the availability of nurses at local GP Surgery or needing to go to an alternative non-local GP Surgery as well as being unable to get referral via GP for home visit.

For those people who thought they may have had COVID - 19, 42 % did not seek medical advice or care for their symptoms.



4.3 Experiences of accessing medical advice or care related to COVID - 19

People reported varied experiences in accessing medical advice:

'I found it very easy, but I tend to research everything'

In relation to GPs, people spoke to GPs directly via telephone for advice. Alternatively, respondents reported that it was difficult to access their GP:





'Doctors refused to speak to me... NHS 111 were very helpful. Could not get Drs appointment and at the time(early February) Doctors were only interested in people who had come into contact with anyone from Wuhan or visited an infected area'

Respondents described being misdiagnosed as their systems could have been COVID – 19:

'After weeks of a bad cough and flu symptoms and a tight chest I had malaria. This was not treated promptly because health care workers including myself were convinced, I had COVID – 19'

'Symptoms were before COVID - 19 was supposed to be in UK - it now appears COVID was in the UK when I had symptoms'

The symptoms for COVID - 19 was extended in March by the Government , but people who had the added symptoms prior to March did not make the connection with COVID - 19 and did not isolate:

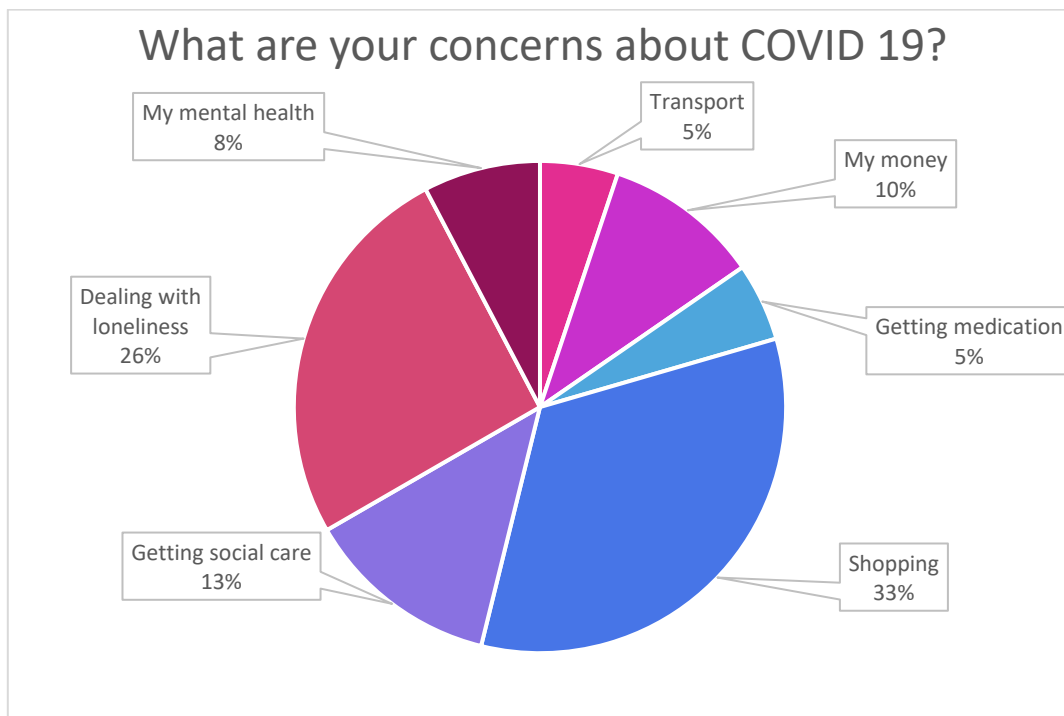
'I had the coronavirus symptoms in January there was no medical advice available at that time'

4.4 Coping and concerns during lockdown.

People were asked if they coping, 86% said they were and that they have all the supplies they needed and were getting support from the family and the community.

The majority of respondents were coping well and were being resilient. There was a sense that everyone was in the same situation and were doing their best. The people who said they were not coping were signposted to various support agencies (see section 4.9) and HWS continued to offer telephone support.

Respondents were asked to identify their concerns, section 4.5 has focussed on mental health, loneliness and isolation, the other concerns are addressed in section 4.8





4.5 Mental health

People identified that they were concerned about their mental health and the well-being of their relatives with existing mental health conditions. When asked further about this, 54% stated that their mental health and wellbeing been affected by COVID - 19 pandemic.

Respondents, this included people who were shielding and self-isolating as well as others, described how their mental health had been affected by COVID – 19, this section has been divided into themes:

Emotions and Behaviour

Emotional swings, anxiety and panic attacks and return of mild depression during lockdown plus finding it difficult to sleep were listed.

'I have had days when I have been very anxious'

'Feeling much more anxious being in all the time'

'Missing family so I cry a lot'

People described lacking in self-motivation and not being to socialise with friends as they live alone.

Relationships

People described how relationships were affected, families living in one household described how fractious things were getting due to all being together for long periods of time.

'I am not on the priority list for groceries and worry about sending my partner out for food'

Loneliness and Isolation

Respondents described how bored they were and how they would love to go out for a car ride. Being away from friends and family added to the sense of loneliness and isolation. Additionally, parents described how hard it was to entertain children and cope with 'home-schooling'

It was stated that due to self-isolation and /or shielding, people were missing family (birthday celebrations etc) and this was impacting on their mental health.

'The lack of guidance in sign language has increased my already high anxiety and depression. I feel social excluded more as my groups and activities have closed'

'Not being able to do any outdoor activities and not able to purchase the food items I like the most is frustrating. For example, I haven't had my hands on packet of flour. Essential items are finished quickly. Even going to buy groceries is such a challenge because some people are not habitual of keeping the distance on mind. We just get carried away as this is all new system for us'

'I am shielding, I am finding it difficult to stay in the house, my garden is not adequate replacement'

Respondents expressed their fears and worries:

'Anxious about passing the virus to my mum who is vulnerable'

'Worried about access to food and my income'

'I worry about decreased job security'





'Worry about an already failing economy and the lack of healthcare that will result from the effects of COVID - 19 shutdowns, lack of medical personal. ...the people are already so poor and the knock on effect of COVID - 19 means so many will die of other diseases like malaria TB HIV cholera'

'Financially we will all suffer, and it will take so long for any normality'

'People will get desperate, thievery will increase and so will unrest. The government does not have the capacity to cope with it all there will be unrest I am sure'

'I am a student nurse and feel guilt from not being able to help'

On a positive note respondents, who were embracing the situation and were able to adapt and be resilient, described they were filling their time with gardening, socialising using digital technology e.g. Facetime.

'I had been in isolation at home two to three weeks before this started so have found it very easy to follow'

'Still able to go out on the canal tow path and that's away from traffic....it has helped me to appreciate nature'

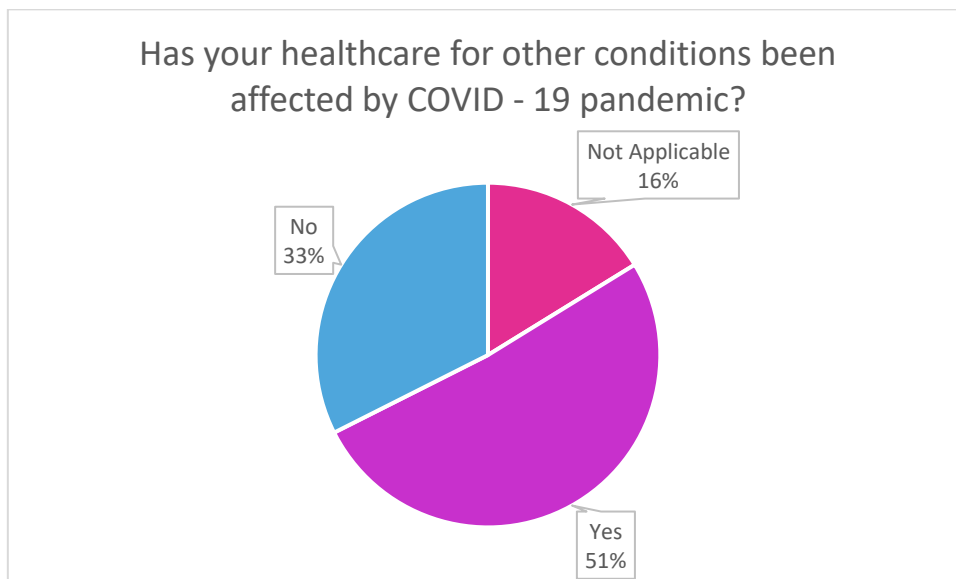
'Increased time in garden/natural light & not watching the news....now getting much better'

'Things don't seem as bad when you compare the situation that some countries have regarding resources'

'I've been very busy looking after other people. As Jehovah's Witnesses globally we implemented protection for older ones a week before the Government and stopped meetings before the ban on large gatherings...it has been a very time ensuring all are looked after'

Respondents described how helpful having telephone calls from volunteers and the Local Authority.

4.6 Getting help with healthcare for any **existing** health conditions



51% said that getting help for existing conditions during COVID 19 had been affected.





People described postponements of treatment/consultation/ appointments/operations which had affected their health and well-being. People were frustrated that they had already waited a long time to get these appointments in the first instance.

People described routine surgery being postponed and was concerned how long it would be to get back to normal as they were concerned that their symptoms would worsen e.g. cataracts.

Appointments for physio therapy, hearing tests, foot health and lymphoedema treatment, MRIs, heart consultant , knee replacement operation check-up, sleep apnoea check-up were listed as postponed. Appointments with audiology at the Lyng had been disrupted, however they sent batteries for aids in the post.

Concern was expressed about receiving care for their mental health, cancer symptoms (diagnosis) as well as cancer treatment, wound dressing, urine tests and physio therapy.

Some respondents described that they are unable to access GP surgery as it is engaged but spoke well of pharmacy services and District Nursing services that were still accessible. However, some respondents described effective telephone consultations with their GP.

People expressed concerns about their relatives who had existing conditions, heart bypass, breathing issues and children who were coeliac disease.

One person described the situation as:

'It's a worry'

Respondents have struggled to obtain medication:

'I am shielding due to bronchiectasis, asthma and heart issues. I have had to keep my nebuliser longer as cannot go to the hospital to exchange it'

'I have not been able to have my B12 injection'

'I take warfarin but as the anti-coagulation clinic prescribe it by post the prescription hadn't arrived when I needed warfarin and it was difficult to get an emergency supply as it is not on my repeat'

Due to postponements some people experienced discomfort:

'I got way sicker from malaria than I should have....I was refused treatment by a private hospital. I was treated 3 days later than I should have been'

There was also a sense that even though some people had other conditions/symptoms they didn't want to go to a hospital setting:

'I'm not really feeling like I want to be in hospital right now....as I view it as a much riskier place'

Some shielded category patients, including those with sickle cell, were very concerned about attending hospitals and being put on wards where is COVID - 19 is present.

67% stated they were not sure or believed they wouldn't get help and stated:

'I believe my other conditions will be given a back seat in the current crisis'

People described not feeling safe and neglected:

'Haven't made appointments for health checks that are due, as don't feel safe going into medical environment unless an emergency also I don't want to put pressure on NHS'





'Felt absolutely abandoned as not able to get tested, other symptoms not listed and unsure of the long term effects of having contracted the virus'

4.7 Getting help with **new** symptoms that are not COVID – 19 related.

A minority of people were concerned about getting help with new symptoms that are NOT COVID - 19 related. However, if there were diagnosis of new conditions, people were concerned about the process of referrals to hospital for further consultation with specialists.

One person was concerned about back pain was not being a priority at this time, although the patients was in a lot of pain and discomfort. Some described feeling vulnerable but stated that 111 had been useful. Other described administering 'self-care' as they were unable to access advice.

4.8 Assistance with daily living

This section will address people's concerns identified in section 4.4

Getting social care

People's experiences were varied, domiciliary carers had continued to visit which was appreciated. One person was concerned whether carers would bring the virus into her home, so her son moved in to care for her.

One person was being assessed in a residential care home, but it was unclear what was going to happen due to COVID - 19, however the family were in contact with Adult Social Care, who were helpful.

One parent of a 19 year old with mental health difficulties would have appreciated some contact to see how he was, but no one had been in touch.

Shopping

The majority of people were coping well with shopping which included home delivery from super markets also relatives were assisting. Some respondents spoke highly of the volunteers (through SCVO) and the Local Authority delivered food parcels.

Medication

The majority of people had been able to access pharmacy services and online services, both with home delivery and getting prescriptions. People described having relatives to assist with collecting medication. There was uncertainty about prescription for children's medication (mental health medication).

However, there was one situation where a patient had travelled to his GP/pharmacist and it was operating from another geographical area (sign on the door) but this was not communicated to the patient which resulted in a wasted journey. Also, some people were frustrated with trying to get through on telephone to GP practices to order repeat prescriptions.

My money

From the respondents that were spoken to, people did not identify financial issues, although concern was expressed if they lost their jobs due to the COVID - 19.

Transport



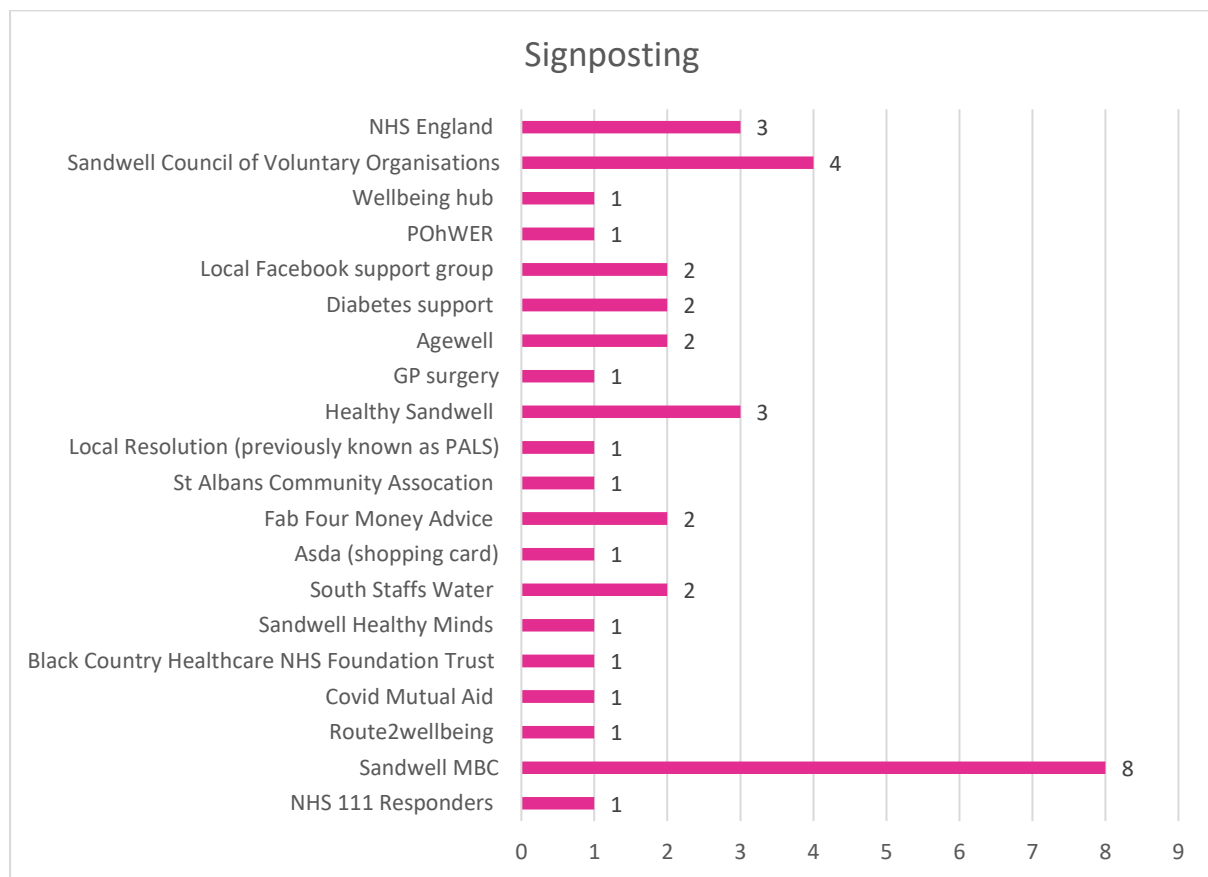


Transport was identified as an issue, anecdotally a respondent described how she drove herself to an alternative GP Surgery (Post breast cancer) and was accosted by Police as to purpose and warned could be fined next time for being out and about during lockdown.

Concerns were raised if different patients needed to go to a different GP Surgery or go to hospital appointments, especially using public transport or taxis (cost and not 2m social distancing). This was of particular concern for patients who are extra vulnerable re: immune-compromised, disabled or long term conditions such as Sickle Cell and Thalassemia. Other people described using taxis more to avoid public transport.

4.9 Signposting

The role of HWS is to signpost the public to resources that will help them, during this project, the staff have signposted to the following organisations:



4.10 Volunteering

The telephone survey asked people whether they would like to volunteer to help others with tasks such as:

- Delivering medicines from pharmacies
- Driving patients to appointments
- Bringing patients home from hospital
- Making regular phone calls to check on people isolating at home





Volunteers were needed to help the most vulnerable people (1.5 million in the UK) who have been asked to shield themselves from COVID – 19 because of underlying health conditions.

The aim of this question was to provide information for those that wanted to volunteer, it was also a tool to help people (who were able) to improve their mental well-being by assisting others.

2 people were already volunteering, everyone else declined with no reasons given.

Conclusion

This project aimed to find out people's views and experiences of how Covid – 19 had affected them, this included access to information, care and support.

Information about COVID - 19 was key to understanding what is happening and how to keep safe during the pandemic. The majority of respondents stated that they had ample, easy to understand and accessible information. However, there was a general feeling that there was too much information, and that the information kept changing and was at times contradictory, conflicting and not accurate.

It transpires that the News on the television was the main source of information. It is important to note that deaf people struggled to access information that was on TV and this may have impacted on their knowledge about COVID - 19. Scotland provided this service throughout their television updates. The Equality Act 2010 requires providers of goods and services to the public to make reasonable adjustments to assist people with disabilities. In this situation for deaf people and hard of hearing people, reasonable adjustments should include providing communication aids, such as a British Sign Language interpreter (BSL).

5% of the respondents said that had a test which confirmed that they had COVID – 19, however over half of the respondents had symptoms but had not been tested. This low percentage may be because the Government prioritised key workers for the test⁵. 42 % did not seek medical advice or care for their symptoms.

Accessing medical advice varied, some struggled to access a GP but others were able to have telephone consultations, nevertheless, contacting surgeries by telephone proved to be difficult for some.

The majority of people were coping, and they had all the supplies they needed and were getting support from the family and the community. There was a sense that everyone was in the same situation and were doing their best.

Respondents were asked to identify their concerns, the main concerns were loneliness and isolation, getting shopping and receiving social care. There were concerns about getting help for existing and new conditions as treatment/consultation/ appointments/operations had been postponed and it was feared that symptoms could worsen. People also did not want to go to a hospital setting for fear of contracting COVID – 19.

HWS were able to signpost the public to support agencies and to give advice about their concerns.

⁵ <https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested>





This report has provided a snapshot of people’s views and experiences of how Covid – 19 has affected them. This report will be shared with commissioners and provider of health and social care services to assist with service delivery now and the future.





Appendices

Appendix One - Telephone Survey

Questions

Information

1. Have you got enough information about Covid –19?
2. Is the information easy to understand?
3. Is the information accessible e.g. in a language that you can access?
4. Where did you get the information from?

Care and Support

5. What are your concerns about COVID - 19?
 - 5.1 Getting help with my healthcare if I develop Coronavirus COVID - 19 symptoms
 - 5.2 Getting help with my healthcare for any existing health conditions
 - 5.3 Getting help with new symptoms that are NOT COVID - 19 related
 - 5.4 GP services access – have you been informed of:
 - any changes
 - alternatives
 - 5.5 My mental health
 - 5.6 Dealing with loneliness and isolation
 - 5.7 Getting social care
 - 5.8 Shopping
 - 5.9 Getting medication
 - 5.10 My money
 - 5.11 Transport
6. How do you feel you are coping?
 - 6a. If no
 - What do you need?
 - Shopping
 - Medication
 - A friendly phone call to check up on me
 - Other...please specify
7. Signposting





Local Resolution (PALS)	NHS England	SCVO	POhWER	Diabetes support
GP/ Practice Manager	Young carers	Wellbeing hub	SMBC (LA)	Agewell
Covid Mutual Aid	Route2wellbeing	HealthySandwell	Time2talk	Other

8. Volunteering

Being involved helping in the community.

Would you like to help others?

Delivering medicines from pharmacies	Driving patients to appointments
Bringing patients home from hospital	Making regular phone calls to check on people isolating at home





Appendix Two - COVID - 19 Survey

- Q1. Have you had coronavirus/COVID - 19?
- Q2. Have you found it easy to find clear and understandable information about what to do to keep
- Q3. Would you like to tell us more about this, and where you were able to find this information?
- Q4. If you think you may have had coronavirus/COVID - 19, did you seek medical advice or care whilst you had symptoms?
- Q5. Would you like to provide more feedback on your experiences accessing medical advice or care related to coronavirus/COVID - 19?
- Q6. Has your mental health and wellbeing been affected by the coronavirus/COVID - 19 pandemic?) For example, through increased anxiety, as a result of social isolation, or a lack of access to community groups and activities?)
- Q7. Would you like to tell us more about this?
- Q8. Has your healthcare for other conditions been affected by the coronavirus/COVID - 19 pandemic? For example, through cancelled operations or appointments, difficult obtaining prescriptions or medication, difficulty making GP appointments?
- Q9. Would you like to tell us more about this?
- Q10. Is there any other way that you feel your health, care, or wellbeing has been affected by the coronavirus/COVID - 19 pandemic that you would like to tell us about?

(Survey format courtesy of Healthwatch Warrington)





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