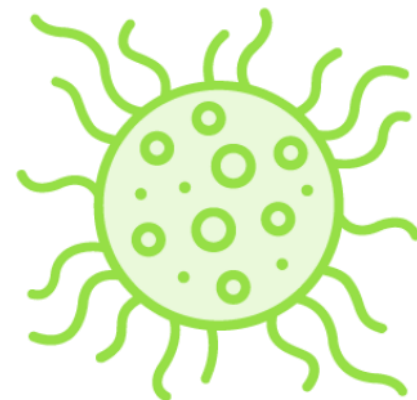


A SNAPSHOT REPORT

Are you living with a disability or a long term condition during the Coronavirus Outbreak?

May 2020



38

Total Responses

Date Created: Thursday, May 07, 2020

Complete Responses: 38

BACKGROUND AND METHODOLOGY

During the corona virus outbreak Healthwatch Wigan and Leigh received enquiries, comments and feedback from members of the public within Wigan Borough which indicate that some people with long term conditions who are isolated and/or shielding are having experiences which may not affect the general population.

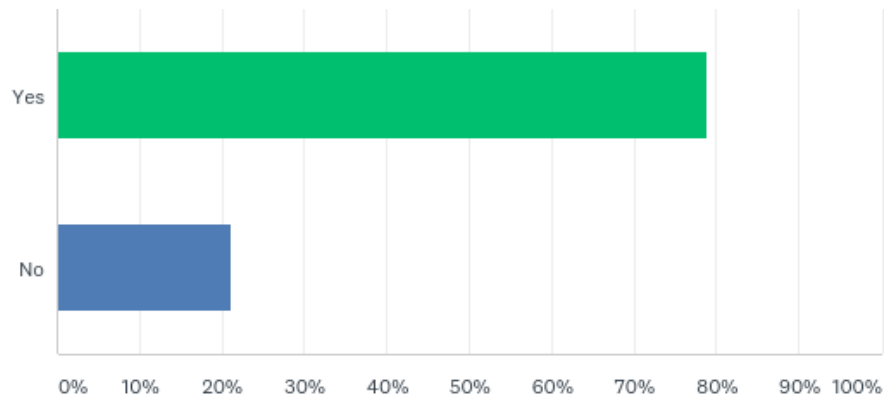
In response to COVID-19, we are aware that health and social care services have had to drastically change the support they offer the public. It is therefore important we understand how these changes are working for people so that we can inform health and social care services and support how they plan and deliver services in the future.

We ran an online survey shared through our mailing lists, social media and networks in the Borough with the aim of collecting experiences of local people to inform the health and social care system in the Wigan Borough to support their planning and delivery of services.

Q1: TELL US ABOUT YOU

Do you consider yourself to be at high risk from COVID-19/coronavirus?

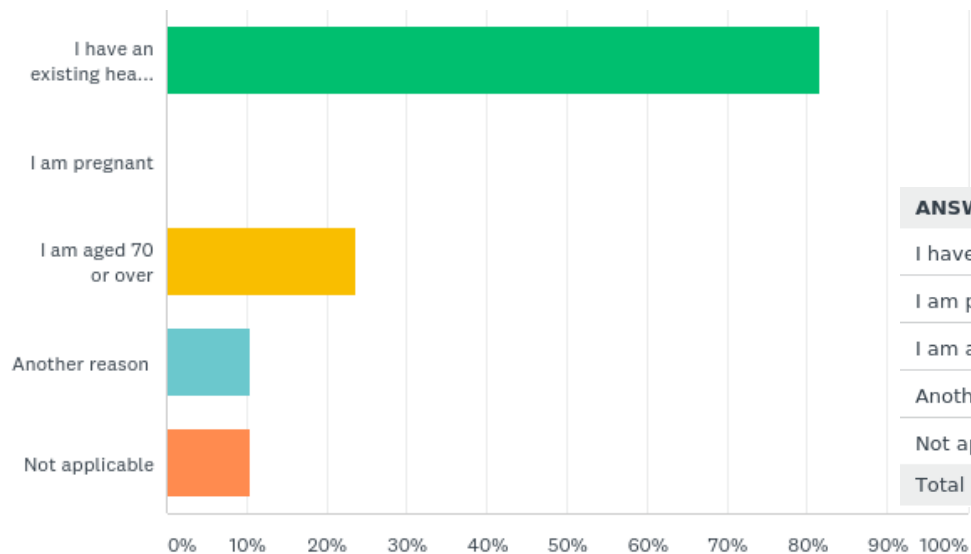
Answered: 38 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	78.95%	30
No	21.05%	8
TOTAL		38

Q2: Please tell us why (tick all that apply)

Answered: 38 Skipped: 0



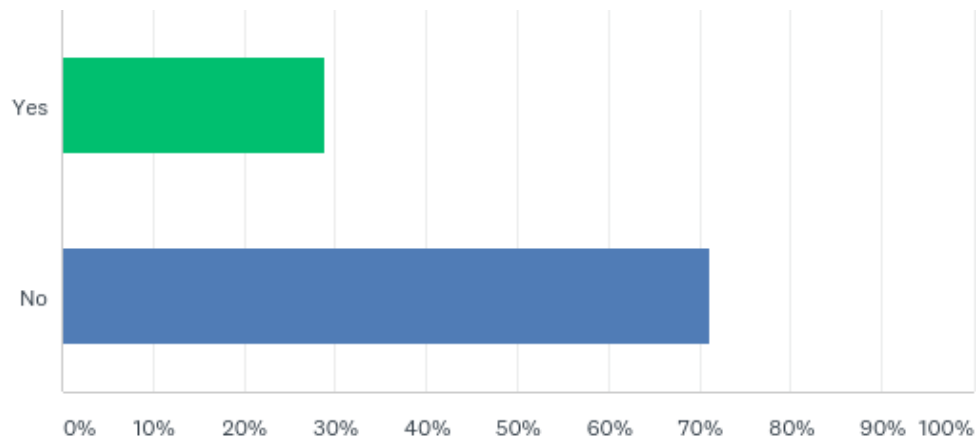
ANSWER CHOICES	RESPONSES	
I have an existing health condition	81.58%	31
I am pregnant	0.00%	0
I am aged 70 or over	23.68%	9
Another reason	10.53%	4
Not applicable	10.53%	4
Total Respondents: 38		

Q2: Comments

- I have various health issues - primarily Crohn's Disease for which I take immunosuppressants
- Diabetes 2, chronic kidney disease , ischemic heart disease, blood pressure, anal fistula, sepsis, arthritis
- I have Diabetes, COPD, Atrial Fibrillation and kidney problems
- I have asthma & high blood pressure
- Tachycardia & bradycardia, heartblock, pacemaker, and functional neurological disorder
- Severe COPD
- I have mental health not physical health
- Recovering cancer patient
- Bronchiectasis/Asthma/Pulmonary Aspergillus Disease
- Down's syndrome and epigastric hernia
- I am an organ transplant recipient
- I have chronic arthritis and take serious painkillers with serious side effects
- I have spasmodic CP with asthma
- My son has cerebral palsy, an ileostomy, gastrostomy ,gut dysmotility and autism
- I'm not a worrier, and was surprised a while ago to learn that such people tend to be more healthy
- Asthma, heart problems
- I am over 65 and had cancer
- Tracheotomy; overnight ventilation; metabolic disorder
- Previous bowel cancer; chronic fatigue; over 60
- I have a few of the conditions that we are told makes us more susceptible to complications of Covid 19 - asthma, hypertension, diabetes, autoimmune disease, heart issues
- I have a chronic neuroimmune condition
- I have Type 1 Diabetes

Q3: Have you received a text or letter telling you to shield yourself?

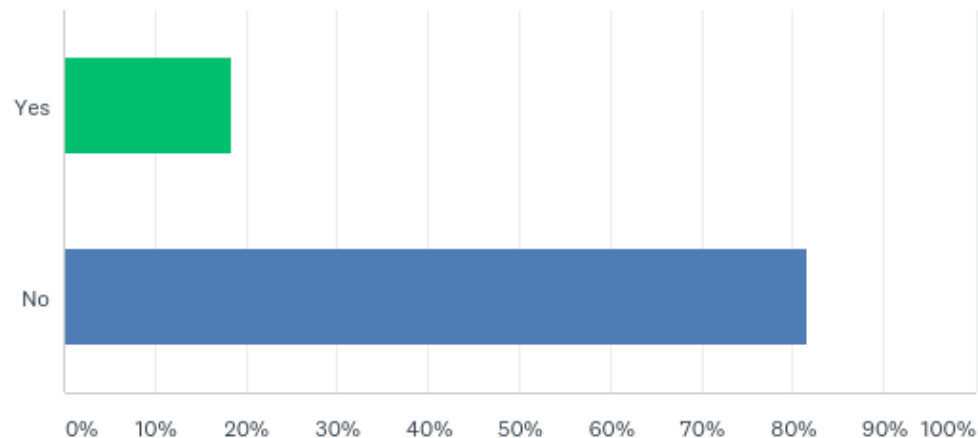
Answered: 38 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	28.95%	11
No	71.05%	27
TOTAL		38

Q4: Do you have any additional communication needs?

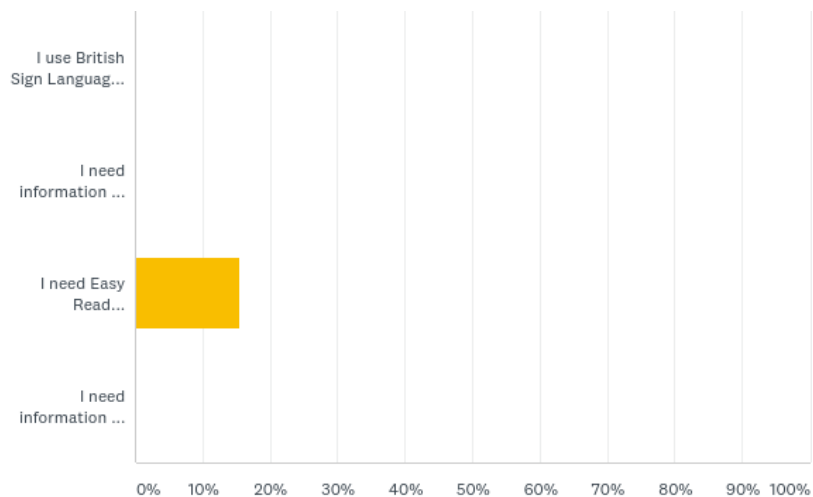
Answered: 38 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	18.42%	7
No	81.58%	31
TOTAL		38

Q5: If yes, can you tell us more? (Please tick all that apply)

Answered: 13 Skipped: 25

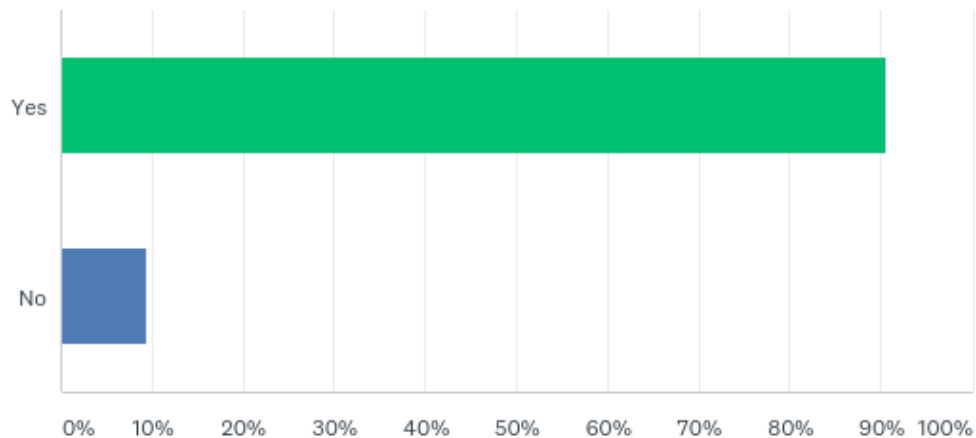


ANSWER CHOICES	RESPONSES
I use British Sign Language (BSL)	0.00% 0
I need information in braille, audio or large print format(s)	0.00% 0
I need Easy Read Information	15.38% 2
I need information in other language(s)	0.00% 0
TOTAL	13

- Dyslexic
- I have Alzheimer's
- Can't read or write. Have difficulty understanding
- Autism
- No communication needs
- I am non-verbal, though I sign yes and no, and I understand everything that is said
- I am deaf

Q6: Have you been able to find the information and advice in the format(s) or language(s) that you need?

Answered: 32 Skipped: 6



ANSWER CHOICES	RESPONSES	
Yes	90.63%	29
No	9.38%	3
TOTAL		32

Q7: If you have experienced changes to your health care due the coronavirus outbreak, could you tell us a little bit about this? e.g. which service, if there were appointment changes etc. was the communication clear and timely, did it cause issues due to your shielding or isolating?

Routine Care

Individuals with a long term condition are concerned that their routine care has been cancelled or postponed, particularly:

- Physiotherapy
- Diabetic retinopathy and routine bloods
- Podiatry
- COPD care
- B12 injections

Continence Service

Individuals who usually attend a day centre are concerned that the continence service is not accommodating the change in circumstances and refusing to provide or deliver additional pads

Digital and Telephone Care

Mainly positive comments about digital and telephone care. Individuals using the AskmyGP app and having video consultations with services, including video calls from CAMHS

Communication

Individuals commented on their experience of excellent communication between services and themselves and services working together to avoid an individual in having to attend the hospital for aspects of care.

Others praised services on their care and obvious safety measures when they had attended a service, particularly the Thomas Linacre Centre

Q7: Comments

- There where appointment changes because I had an appointment at the job centre, and it got cancelled because of the coronavirus
- GP support with Mental Health
- I have been able to get my prescriptions as normal (although my husband is now picking them up from the chemist.) I had a telephone appointment with my GP but have not been able to get treatment for a blocked ear - I suspect the clinics aren't running but I was advised to continue using olive oil. I had to get some routine blood tests done which was quite worrying for me as I hadn't left the house in over a month. Safety precautions were taken, and the waiting room was empty when I arrived. This was different to previous times I visited the Thomas Linacre Centre when it was extremely busy. I was seen promptly - PPE was in place for the nurse and it went as smoothly as it could.
- Sepsis and needed 3 courses of antibiotics. fistulotomy cancelled. cataracts appointment on hold
- None
- Appointment with GP cancelled, not re-arranged. I had to ring and request another appointment which was a telephone consultation
- I had a severe asthma attack and I have another chest infection. The ambulance was called out which sent my autism and OCD the through the roof!
- Yes, I was due a physio appointment but do not know if I will be taken off the list
- Pacemaker check-up cancelled
- It would have been nice if someone had contacted me to see if I was doing ok
- Visits stopped from housing support officer and no face to face with GP but a lot of telephone support
- Unable to attend vital Diabetic Retinopathy eye screening and blood tests
- Mental health issues
- No change
- Chest infection in February & March . Tried to speak to someone at the chest clinic at Wigan, not interested, passed back to GP
- Day Centre closed, attended four days a week, only one daughter rather than three provide my care. Incontinence service refused to provide any extra support. My family communicate things to me though I find it difficult to understand the situation and am very anxious. My daughter is completing this survey for me or it would not be accessible to me
- None
- Hospital appointments have been by telephone consultation. Limited communication from the hospital, I had to chase up what was happening regarding my appointments. Blood tests were also delayed for 5 weeks. I usually attend Salford Royal renal out-patients clinic at Boston House but have had to attend Salford Royal for blood tests
- Difficulty getting hospital appointment
- Appointment changes and appointment cancelled
- No issues

Q7: Comments continued.....

- GP/hospital appointments are important to my health
- Had to change my podiatry appointment, rescheduled for end of June
- Had to cancel appointment with wheelchair service, which means my outdoor powerchair is very uncomfortable but staying in anyway, so it is not 100% a problem. Hope to reschedule when safe
- My son was unwell but thankfully didn't need hospital, his mental health has worsened but finally has video calls fortnightly from his psychologist from Wigan CAMHS
- Yes. I was told that my GP and regular hospital appointments would be by phone. A district nurse is going to come and take blood for a test instead of my going to hospital and, separately, is going to insert my Zoladex capsule. I'm just hoping that my GP will have sent a prescription to the pharmacy and that they will deliver it to me in time
- I was due to have a heart valve replaced and possible bypass but the day before I had my pre op Wythenshawe Hospital had had its 1st case of the corona virus so I was told at the pre op that all elective surgery was cancelled so it was a waste of time and money going for the pre op
- Self isolating due to reasons given. Have in addition sleep apnoea. Had a bleed from my eye contacted, sleep clinic, spoke to them by phone - would normally have gone to see them. New different mask had to be sent out by taxi. They contacted Cardiology and Dr Arya telephoned and amended medication. Excellent service
- My manual lymphoedema treatment was cancelled. Communication was clear, but has left me in a lot of discomfort due to the build-up of fluids
- More anxious worrying about every little thing
- We haven't attended or wished to attend any appointments, all were cancelled
- Not been able to see my COPD team and not been able to get my B12 injection
- As yet, not applicable
- Changes to GP repeat prescription service - all ok
- Physio postponed scans not scheduled
- No appointment for footcare received, dental appointments cancelled, ENT appointment cancelled, no appointment with the practice nurse to discuss routine blood results despite being promised a telephone appointment so am unsure about my diabetic status and am assuming all is well. 12 monthly review for another condition - no plans to discuss treatment or diagnostics by GP
- I can no longer access my weekly physio treatments for pain and have had two surgeries cancelled. I also had a stroke last week and had to go to A&E. I have been referred to the stroke clinic but only for a telephone consultation, which is understandable but not as reassuring as seeing someone in person
- I haven't had any changes to my care, but I have spoken to my GP using the AskmyGP app about my concerns and anxieties around shielding the implications for my family
- No

Q8: If you receive care or support to help you carry out daily activities, have you experienced any changes to this care due to the coronavirus outbreak? Can you let us a little bit about this?

Day Centres

Individuals who usually attend day centres are not taking up the offer of care visits as they are vulnerable and high risk and taken the decision not to accept offers for help

Home Care

Some individuals have chosen to limit home care and prefer support from their family due to concerns around shielding and lack of confidence in the availability and appropriate level of PPE

Support

Some individuals say that although they need some support, it is being offered by their own families.

Some individuals comment that they have had no support and have had to cope alone. This may be due to the fact they have not received a letter advising them to shield or they have not been identified by their GP and so may not have been aware that help is available.

Q8: Comments

- I don't receive care or support to help me carry out daily activities, but I am looking into it for the future
- Only child daughter (teacher in enclosed school) unable to shop and visit due to fracturing her patella when pushed by a pupil
- None required
- I need support to encourage me to take my medication, attend to personal care, eat, drink It is my family that have supported me through this difficult time
- Yes! Lots, the staff that come and help me daily are having to be so careful and I am high risk, so they are only coming in when absolutely necessary and even then they are communicating at the bottom of my stairs and me at the top. (Flat I live in) this has been hard
- No
- Not applicable
- No one has checked if I had any needs
- No, I have received all my care
- No
- I have had to manage on my own. It has been very difficult
- No change
- I am receiving care from my partner
- Etherstone Day Centre which I attended four days a week closed four weeks after lockdown. Very limited visiting service offered and as I am vulnerable and high risk my family have not taken up this offer as yet. I have incontinence pads delivered. My daughter was dismayed that the service would not accommodate the huge changes due to coronavirus and deliver additional pads or earlier than usual
- Not applicable
- No day care support they are closed
- None

Q8: Comments continued.....

- No changes
- It took more planning and understanding that activities can change daily
- Shopping done for us
- I have my own staff through Direct payments. However, not related to Covid 19 I was struggling to have support due to absence of staff and recruiting problems. However 1 member of staff was furloughed with her other job so she covered 5 days out of 7. For my own safety I chose to only have agency support 1 hour a week. But if I hadn't had my own staff the agency would not have been able to support my needs to the level I require
- N/a
- I don't receive any
- I do not receive any
- Receive help from husband
- None
- No one has been able to come and visit me. I have support from Shared Lives and Embrace
- Due to shielding, and big concerns around PPE which would need to be high level because of my tracheotomy, we decided to shield as a family, and my parents are delivering my care
- I have been ok because my wife is my carer
- Not applicable
- No support

Q9: How much of an impact has the coronavirus outbreak had on your mental health and wellbeing?



Q9: Comments

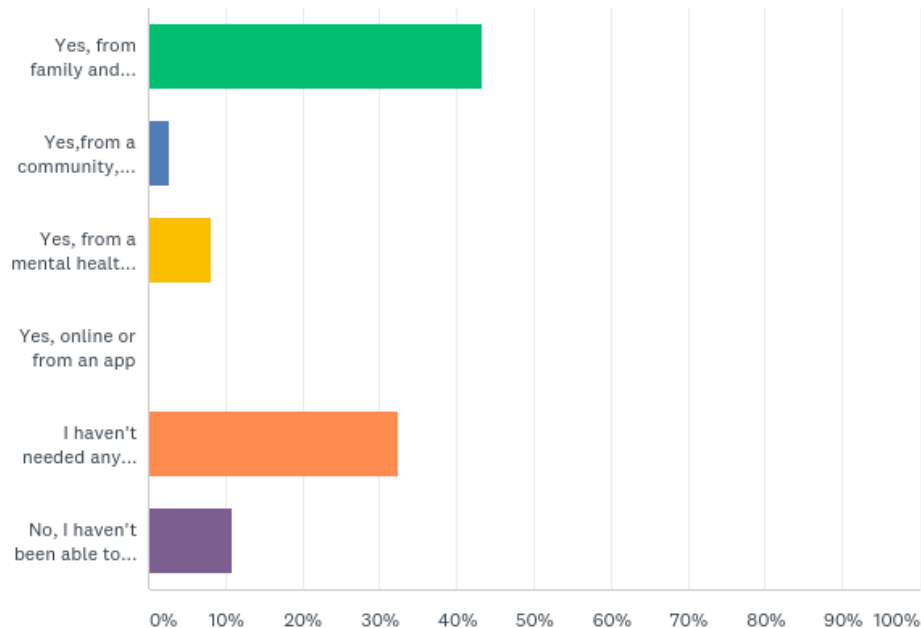
- It has put a big impact on my mental health because I have got anxiety issues and I also struggle to sleep
- I have been at rock bottom with depression and anxiety, I have a good insight into my mental wellness, so I was able to control it myself
- Worried about my health not able to get out
- Quite significant - I'm working from home so I'm experiencing isolation in that regard. My husband is continuing to go into work so that causes us more concerns and worries. I have good and bad days, but I do feel this is to be expected in this situation
- None to date
- Greatly. I was isolated before the outbreak. This has increased. It has brought back suicidal thoughts, broke my routine, caused my anxiety to increase, I am not sleeping or eating. I have taken a huge step back
- A lot! I have been anxious and scared but also, it's made me realise how grateful and blessed we are to live and have what we have in this country compared to other countries
- Very much
- Minor
- Just feel abandoned and had to beg for support getting food to top up government food which stopped abruptly. VE celebration week won't be begging for more
- Very much
- I'm sleeping and eating less due to worry and stress
- A great deal. Mental health has been difficult to control with medication. I have been very anxious and worried about not having any support
- None
- Greatly affected my mental health. Very anxious. OCD hand washing
- High anxiety levels in myself and my two Carers. I am not eating very well which is a worry. The health of my Cares is a worry also. We only receive family support and the odd telephone call from the GP's, Day Centre and Age UK. A food parcel, incontinence support, a DVD would be appreciated. We feel very alone even though family contact us daily
- A lot. Don't understand why everything is closed (why I can't go to day service and church). Dementia worsening
- I have a positive outlook on life and although I am in the shielding group, I recognise the importance of keeping myself safe over the next few weeks
- None

Q9: Comments continued.....

- Not being able to go out and carry out social activities is hard for me
- Just accepted and adapted
- I've been worried about NOT seeing my GP re being able to discuss my worries about medication
- Not much as I have an unusual way of looking at things. With everyone being in the same position I felt less stressed because all of society was doing the same thing. As the weeks went on, I did need to venture out a little with observing social distancing rules, but I was extremely careful when being out and about, wearing gloves and sometimes a mask
- A great deal as my son has autism and ADHD
- None
- None
- Very restrictive, frustrating and depressing at times. Keeping well mentally by gardening
- I feel much better mentally remaining at home
- Made me a lot more anxious and panicky
- I've been anxious and missed my Personal Assistants, but I have been keeping in touch by zoom
- I have been a bit down once or twice but that's all
- None
- My health limits activities and I have previously adjusted to this. Online groceries were a problem initially as I have needed this service for the last 10 years but did not have priority. Luckily Ocado have given some long term customers priority and I am included
- Affected sleep worrying a lot about children and family members
- Feelings of anxiety fluctuate on a daily basis make coping with my existing conditions more difficult. Feelings of depression are compounded by the length of days and no access to the gym
- Not too much change as I am predominantly housebound anyway
- Quite a bit. At the beginning I was very anxious as I had received the shielding letter. I spoke with my GP who gave me advice on managing whilst living with my family and he has checked up on me since
- A bit sad during lockdown but I'm coping

Q10: Have you been able to access support for your mental health and wellbeing if you have needed it during this time?

Answered: 37 Skipped: 1



ANSWER CHOICES	RESPONSES
Yes, from family and friends	43.24% 16
Yes, from a community, voluntary or charity group/organisation	2.70% 1
Yes, from a mental health care provider	8.11% 3
Yes, online or from an app	0.00% 0
I haven't needed any support	32.43% 12
No, I haven't been able to access any support	10.81% 4
TOTAL	37

Q10: Comments

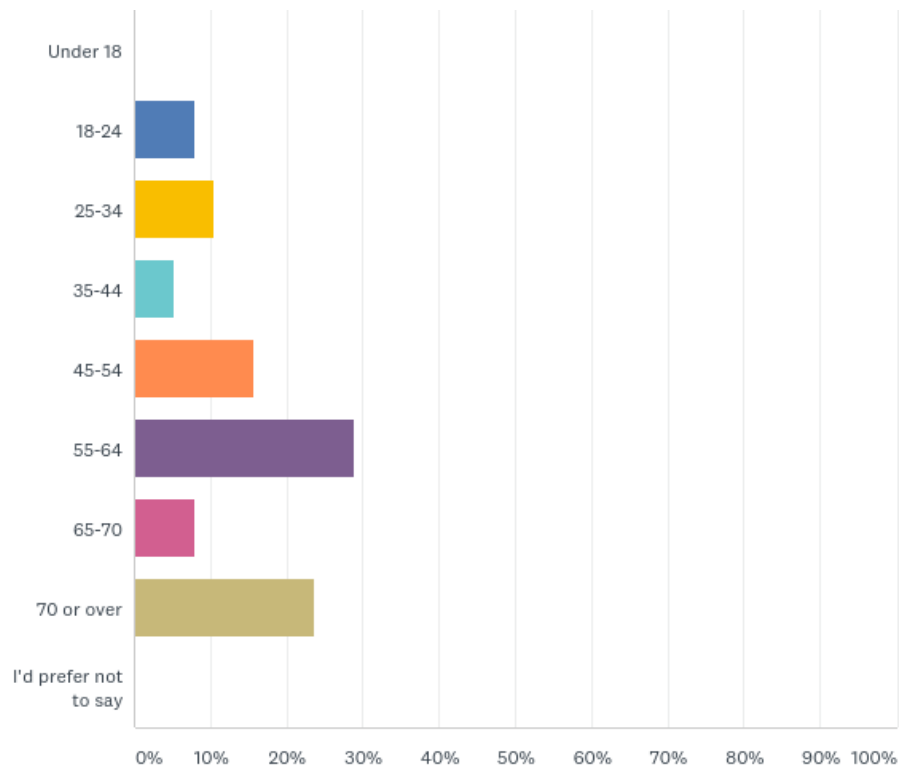
- I have recently tried Shared Lives
- Only from 2 church members by phone
- It is only because of my family and friends that have helped me
- I am under the mental health team and they swapped to weekly phone calls instead of face to face sessions. This has helped to an extent
- I feel that I will need support after things have settled as I have anxiety
- Am on medication
- I don't beg all my stress upset and worries have been about food supplies
- I have had phone support from my GP which has been very helpful as well as my social care package
- There was no response as I needed more than a phone call. My GP won't increase medication without mental health team diagnosis
- Facebook has been a lifeline with keeping in touch with friends and 'having a laugh' kept my spirits up
- It has taken a number of weeks to finally get video calls from a psychologist
- Embrace Wigan and Leigh, I have been accessing their Skype sessions
- Previous experience of limited activity levels means this is my normal
- A clearer timeline for coming out of lockdown, more access to my family. Access to a listening service perhaps through my GP A routine question as to how I was coping when I rang for my repeat prescription Routine calls to registered carers to check how individuals were coping and appropriate signposting
- I spoke with my GP who gave me some advice and told me he could refer me to the mental health team if I felt it was necessary

Q11: Is there anything else you would like to tell us about using health and/or care services during the coronavirus outbreak?

- My husband was anxious about his cancer appointment, he had to phone and check himself
- My doctors have changed to online even more I have to download an app and I didn't understand. And my staff can't come in and help me and every time I ring the doctors they keep saying go online, but I can't do it and it's really stressing me out, I have a chest infection and other health needs at the moment and I do not need added stress!
- Went to hospital by ambulance & had checks. Was sent home with advice to isolate & go back if chest worse. Next day phoned 111 as I was worse - they advised me to go to A&E. A&E nurse guarding the entrance said to go home. No examining. Told her 111 advised me to go. She said 111 would have phoned A&E. I phoned 111, who asked to speak to her. She said 111 would have to phone A&E. I had to wait outside. I don't know what was said, but I was sent home & told isolate. Most hospital staff are excellent, but this one was rude & abrupt. I did not complain about her
- Nobody checked if we were ok feel totally abandoned by local services and government and no ongoing services for shielded
- No, because services had to be redirected and had to remain safe also. I felt more isolated and frustrated
- All social care has stopped for us. We began getting this support as my condition is a challenge to manage. It is a huge challenge now and we are not getting any support
- Phone call from nurse at GP surgery to check all was OK was good and to inform if needed medical advice to contact surgery. That was reassuring
- I have registered with the NHS service for support with food shopping but have had no contact
- I do worry about elderly who live alone, feeling isolated
- If my member of staff (i.e. my daughter) hadn't have been able to work for me like she has done, my time during this pandemic would have been very serious. My food allergies would have meant I would not have eaten so well. My hygiene needs would have been severely impeded I would have been put at more risk of catching the virus if the agency had have come to me more often (PPE was totally inadequate even when it was available!) Thank goodness for my daughter being furloughed. Due to this I have been well, fed properly and less stressed because she could do things the way I needed them to be done. PLUS my wonderful neighbour always on hand to help out as much as he could. If there were services out there for disabled people, I was not aware of them - lack of promotion, and they would probably not been flexible enough for my requirements
- I think it has taken time to get certain areas of care set up
- Only the fact that I must go to Boston House instead of Aspull clinic for my B12 injection
- Was still able to get B12 injection at Doctor's surgery
- We are still really worried about providing the right level of PPE due to my overnight ventilation and tracheotomy
- Repeat prescription from GP without difficulty
- Remember that people with chronic health problems may always need this support
- I have tried not to contact the NHS due to respecting the level of acute and serious illness they are dealing with. I would be very concerned if I had to enter a practice in case the clinician, I was to see had had contact, possibly in another role, with Covid patients e.g. working at the local hospital also

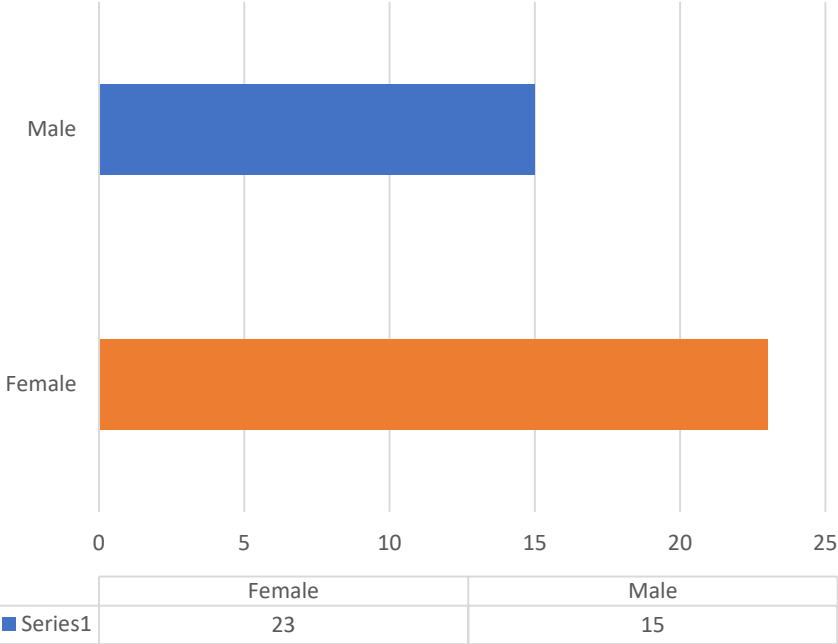
Q12: Please tell us which age category you fall in to

Answered: 38 Skipped: 0

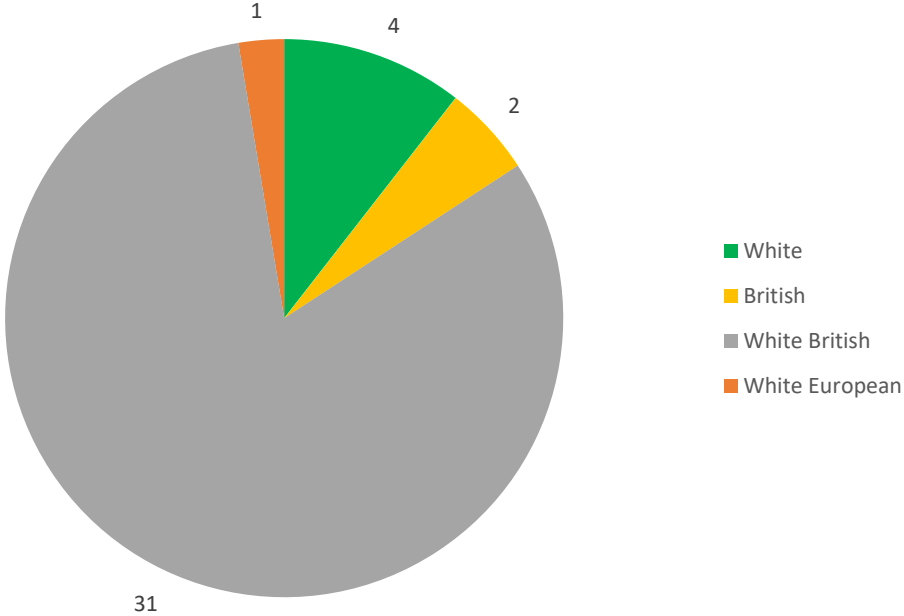


ANSWER CHOICES	RESPONSES	
Under 18	0.00%	0
18-24	7.89%	3
25-34	10.53%	4
35-44	5.26%	2
45-54	15.79%	6
55-64	28.95%	11
65-70	7.89%	3
70 or over	23.68%	9
I'd prefer not to say	0.00%	0
TOTAL		38

Q13: Please tell us which gender you identify with

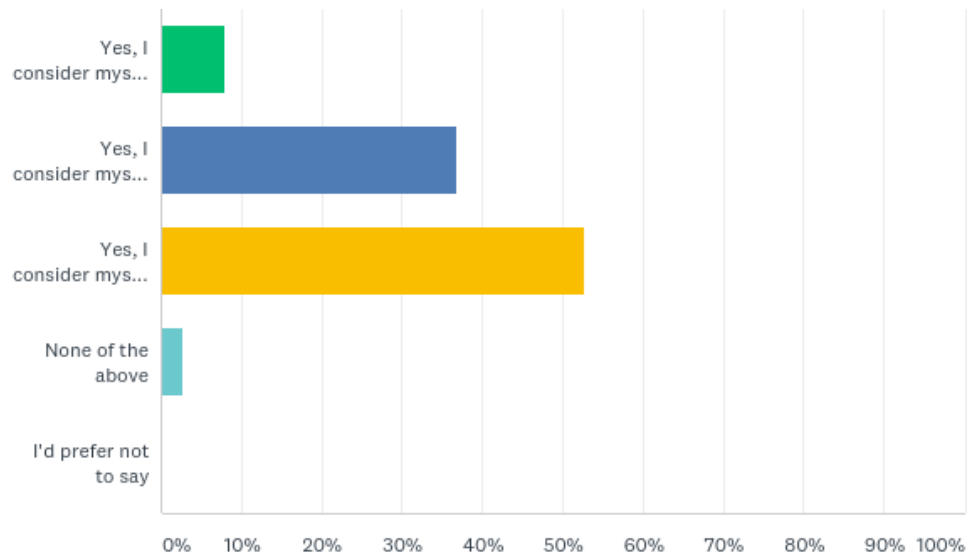


Q14: Please tell us your ethnic background



Q15: Do you consider yourself to be a carer, have a disability or a long term health condition (Please tick all that apply)

Answered: 38 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes, I consider myself to be a carer	7.89%	3
Yes, I consider myself to have a disability	36.84%	14
Yes, I consider myself to have a long term health condition	52.63%	20
None of the above	2.63%	1
I'd prefer not to say	0.00%	0
TOTAL		38