

Covid-19: Impact on disabled and RIDC older people survey #3

1st June and 5th June 2020

The following quotes are taken from the open-ended questions that RiDC panel members responded to in our third Covid-19 survey. In this summary we have grouped the comments by various themes that emerged from the data.

Lifting of restrictions

Lack of trust and faith in government

"The government advice has been giving mixed messages so I do not trust them when they say I can leave my house."

"The Govt has not done enough to support those in shielding and still not doing so, do not trust their scientific experts/govt at all, especially when they have messed up so much on handling this pandemic."

"Felt we weren't specifically considered/mentioned for weeks then sudden change out of the blue! In view of the Government's handling of various issues during the development of this pandemic, it's hard to have complete confidence in the rationale of their decision making!"

"Disgusted at the lack of scientific evidence for changes in shielding and the ad hoc manner in which it was announced."

Confusion about guidelines

"It has been very unclear to a lot of people that shielding was advice and not a legal requirement. This led to some people not even going in their own gardens and some wanted to follow social distancing so they could still go out to exercise but thought they would get into trouble with the police if they did."

Nervousness about easing of restrictions

"It's not over yet. The restrictions are being eased too soon. I'm scared

"I will not feel safe until I am vaccinated. I will not be going out until then."

"With so many disregarding the social distancing I think I'm going to be very careful who I agree to see. I think a second deadly spike is almost a certainty. Lifting our lockdown should be 2 weeks after the rest to give time for further assessment."

Government's vulnerable list

Not meeting the list's criteria

"I don't meet the criteria. However, I have mobility issues and receive the high rate of PIP for care and mobility. I've been disabled for over 40 years!"

"Asthma, COPD, and diabetes - does this combination not make me vulnerable?"

Consequences of exclusion from the list on supermarket shopping

"It seems that unless we are EXTREMELY vulnerable, we are forgotten. We are unable to get delivery slots from supermarkets although I am only able to carry two items at a time. It does not matter disabled/vulnerable people can shop at a certain time per day. How am I supposed to get it home? I waited 10 weeks for a delivery slot from Sainsburys. Other supermarkets were as bad. I have severe sight loss/mobility problems."

"I'm registered blind. Shopping is difficult anyway but not being able to see where people are, follow markers on floors, read sighs etc is impossible. I also touch door frames, tables, shelves etc to help me understand where I am in relation to what I can see - all frowned upon now. If I go out I'm putting myself & there's a risk but I'm not vulnerable or disabled enough to get additional support."

Consequences of exclusion from the list on risk of Covid-19 exposure

"I enquired before the lockdown if I should be on the vulnerable list as I frequently catch infections. My GP replied I was not in the government's criteria. Of course I fought Covid and was quite ill. I now have a post viral syndrome and have lost ten weeks of my life."

Care visits

Wish to no longer receive care visits

"Too dangerous, don't want the risk of being exposed."

"No protective clothing or equipment."

End of supply of care visits

"I was being supported by Headway Cardiff and South East Wales, a charity, but due to Covid-19 the Staff were furloughed and are working from home... Volunteers who provide support for Social Groups, the Independence and Well-being Centre and Administration are all social distancing. As a charity there are no opportunities for fundraising and, like many Charities, it is a worry that support and services may not be available in future due to lack of funds. These Charities plug gaps in Social and Healthcare which are important for the disabled and their families."

"The RNIB have currently stopped all volunteer contact."

Concerns about care visits still taking place (reduced staff, PPE and associated costs)

"I have carers twice a day but the agency like many others is experiencing staff not wanting to work because they will be in contact with patients discharged from the hospital who still have the virus. This worries me also as the PPE they have been provided with is laughable. I have tried to get my own PPE for extra help but the costs are prohibitive."

"I have had no information or guidance from East Sussex County council who pay my Direct Payments for PA. Nor from People Plus. I have had to order PPE myself. Hopefully it will arrive soon so I can have the other PA's back to work. I only have one PA working at moment because other two have other high risk jobs. I have got more help from a Direct Payments Peer Support group on Facebook."

Medical consultations, treatments or services

Barriers to using health-related services by phone or online

"Unable to get face to face treatment or speak to anyone. I am profoundly deaf."

"I can no longer make an appointment but have to email or ring then wait for a GP to ring me back and tell me if I qualify to see them. I am 60 years old and know when I need to see a GP. I feel alienated from the medical system as due to my hearing I struggle with telephone calls"

"The GP wanted to check my symptoms by video call but I don't have and can't use a smartphone."

"Difficult. The latest is G.P contact suggesting we now video conference. What happens with those of us who do not have smartphones? Many do not have computers or are users of I.T."

"I have been offered mental well-being and OT appointments via internet. Because I'm deaf and a lip reader I haven't been able to access these. I have been taken off both waiting lists and have to re-apply, which in itself is difficult as I don't use a phone. Deaf people have been forgotten in this time."

Cancellations of consultations or treatments

"Was due an x-ray following lung cancer operation but has been left for two months."

"A 3-day diagnostic session for amyloidosis (life threatening) was cancelled. A heart transplant assessment was cancelled and the rescheduled with no certainty it will go ahead. A cardiology appointment next week has been cancelled. It gets a little wearing."

"I've had most of my hospital appointments cancelled completely (with no prospect of knowing when they may happen) and some consultants have even completely discharged me from their service, despite me still needing to see them."

Access to prescriptions or medication

Delays and difficulties in obtaining medication or prescriptions

"Large queues, long delays, several visits to get medication."

"Time taken to deliver medication has increased from 1-2 days prelockdown to 5-7 days now."

"Some medication not available and no one from the pharmacy able to deliver."

Online supermarket shopping

Difficulties securing online delivery slots

"Because I was not on the vulnerable list they could not do anything for me. I emailed and spoke to them on the telephone, and they said unless I got that letter from the government they can't help. Now I get emails from Tesco telling of what a wonderful job they are doing and how great they are." (Tesco)

"Not prioritising delivery slots for people who are disabled but not on the government list. Prioritising able bodied NHS workers over disabled and vulnerable people. Pretending to have a priority shopping hour for elderly and vulnerable people, but in reality letting anyone and everyone in. Hiking prices to cash in" (Tesco)

"It took 8 weeks or more to accept that I was shielding." (Ocado)

"I could not get a delivery during the first six weeks. They also suspended their phone line." (Ocado)

"Although I have been a Waitrose customer for over a decade, and always stated that I was disabled on the form, I was unable to get slots because the Gov had missed me off the list, until I applied to join the extremely vulnerable." (Waitrose)

"I am not able to have a priority booking for a delivery slot. No slots available for me and I'm 60, widowed, living alone, too disabled/immune deficient to safely shop for myself." (Asda)

"I was a regular weekly customer for food delivery for 13 years due to disability and illness. However, I don't meet the limited government guidelines and so delivery slots are found only by lucky timing." (Sainsbury's)

Physical supermarket visits

Difficulties accessing supermarkets at special hours

"Because I have a hidden disability and need someone with me at all times. I have had to explain I am disabled as people can't see this. I feel this is a serious violation of my rights as a person I should not have to explain to anyone." (Morrisons)

"The hours set aside by Sainsbury Leatherhead are inconvenient (requiring the elderly or vulnerably to rise early in order to avail themselves of this service). The queue to enter the store was over 30 minutes, a difficulty for me (standing is uncomfortable due to neuropathy) and the store was poorly stocked at that hour (Staff were only just beginning to stack the shelves). Shopping during the middle of the day has actually been much less troublesome." (Sainsbury's)

Social distancing – proximity issues for visually impaired

Impact of adaptations made to streets

"I have not yet seen the changes myself, but I know of their existence and I have had them described to me. I am very concerned that all of the essential physical, tactile, and auditory clues and landmarks that blind people need, will have been moved, removed, or interfered with"

"More cycling on pavements which can be hazardous for somebody with a sight disability."

"I cannot get out of the way as I have hearing difficulties as well as being blind so people come very close if they choose."

Difficulties with social distancing

"I've been shouted at for not keeping my distance. I am more anxious about going out with my white cane than before in case people blame me (& other disabled people) for the lockdown."

"I am a blind person that uses a long cane. I am often finding myself in situations where people have become very close to me without letting me know. I am also uncomfortable about the fact that other people do not hesitate to pat my dog without consent, possibly passing on virus without thinking."

"I am very concerned as I feel that since Dominic Cummings broke the rules & now that the restrictions have been eased, that people are definitely forgetting social distancing."

Online communication technologies

Difficulties accessing and using online communication platforms

"Not secure enough" (Zoom)

"Audio quality appalling." (Zoom)

"I'm blind and find it difficult to use at all. People don't tend to narrate whatever they're showing on the screen so I miss out on a lot of information." (Zoom)

"Microsoft Teams seemed to not have keyboard shortcuts etc. Web interface didn't play nice with larger fonts etc. Accessibility seemed better in stand-alone app BUT a lot of the things possible to enlarge items were reliant on Scroll Wheel and no documentation etc. So felt like another "feature that Microsoft might break/remove" like many large font features in Windows 10 for the first 2-3 years of that product. Leaves me feeling like I could be redacted from Work/society because of poor policy and action at Microsoft." (Microsoft Teams)

Additional themes

Impact on mental health

'My mental health has been seriously impacted'

"Mentally it's getting harder to cope with the depression that comes over me in the evenings, this then affects me physically meaning my mobility and general well-being. I am tending to go to bed earlier and earlier as the weeks go by."

Inadequate government communication with the Deaf community

"I am deeply concerned about the government's lack of support for disabled during this crisis. The difficulty in getting a BLS interpreter for the Downing Street daily briefings. The excuse being that the room was too small to have an interpreter present. However they used the garden for Dominic Cummings press interview. The interpreter now is supplied by BBC not the government"

"Lack of an interpreter during government briefings, unlike Scotland and Wales! They gave a lame excuse that it wasn't feasible due to CV, however both Scottish and Walsh parliaments made every effort to provide both accessibility and safety. Therefore our PM is an utter disgrace!"

Notes

- Survey administered to RiDC's Consumer Panel between 1st June and 5th June 2020.
- The survey was sent to a total of 1,655 disabled and older people. A total of 759 people responded.

Covid-19 resources

We have compiled a list of resources and guidance aimed at supporting disabled and older people through the current Covid-19 crisis. As new resources are developed, we will update this page https://www.ridc.org.uk/news/coronavirus-useful-links

About RiDC

We are a user-led research charity, run by – and for – people with a personal experience of disability.

We believe that products and services should be inclusive and accessible for all, from the word go, not as an afterthought. We want a society that works for everyone, regardless of their abilities or age. Please visit our website www.ridc.org.uk to find out more.

For more information about this research, please contact Gordon McCullough (gordonmccullough@ridc.org.uk).