



Coronavirus and You - VOX Members Survey

July 2020

1. Background

VOX decided it was important to quickly find out how our members were experiencing life during the pandemic whilst the lockdown was taking place. We ran a members survey from the middle of April until the middle of June. We received responses from 154 individuals with lived experience of mental health issues.

The main aim of the survey was to understand the key concerns related to the pandemic for our members, what people were finding was helping them, and what we could do as an organisation to support them.

The impact of the pandemic on the mental health of the population has been profound, a great deal of research and surveys have been carried out to understand how people are being affected. Bentall, Gibson-Miller et al.ⁱ saw an immediate spike in the number of people reporting significant increases in levels of depression and anxiety following the Prime Minister's initial 23 March announcement of a lockdown. They noted that on Tuesday 24 March, 38 per cent of study participants reported significant depression and 36 per cent reported significant anxiety. On the day before the announcement, 16 per cent had reported significant depression and 17 per cent reported significant anxiety.

In May 2020, a survey carried out by the mental health charity Mindⁱⁱ received more than 16,000 responses. More than one in five of all adults (22 per cent) with no previous experience of poor mental health stated that their mental health was poor or very poor.

Whilst a great deal of research has focussed on population health and how those with no previous mental health problems are being affected, we want to highlight the impact on those with lived experience of mental health issues.

2. Key findings – Summary

70% of respondents were most worried about their **mental health deteriorating**. This is not unexpected, however, it is important to note that this was seen as **more of a concern than catching the virus for our members**.

63% of the individuals we surveyed felt their mental health had deteriorated (either a little or significantly) . A small percentage of people - 9% felt their mental health had improved (we are unsure why some felt better, however a few comments mentioned they felt less pressure).

This finding is in line with the Mental health charity Mindⁱⁱⁱ who reported that 65% of adults and 75% of young people aged 13 to 24 with an existing mental health condition had reported worsened mental health during the lockdown.

Key concerns highlighted by VOX members were as follows (mental health underpins each of these concerns);

- Family dynamics/competing demands
- Current support being affected negatively/difficulty in accessing services
- Missing contact with others
- Worry about contracting the virus
- How to get back to normal after lockdown

The main concerns highlighted by VOX members are very much in line with those highlighted by Cowan^{iv}, for the Academy of Medical Sciences and research charity MQ.

Our survey also captured a broad range of activities our members engaged in to help to manage their situation, this included creative activities, the arts, exercise, being outdoors and self-help/alternative approaches to help minimise negative effects of the pandemic. It was frequently mentioned that avoiding the media was hugely important.

We are extremely concerned about the mental health of our members and the deepening of inequalities which is likely to occur for people who currently have lived experience of mental health issues.

We also recognise that whilst this unprecedented situation has led to sudden changes in service provision and society more generally, some of these societal changes, such as a better sense of community may help us to identify how to develop compassionate and supportive communities.

3. Main Concerns raised by VOX members

Family dynamics: The pandemic has accentuated complexities within families. It was clear from the responses we received that already difficult situations that people faced within their families were now becoming more unmanageable for many.

This included the following;

- Issues relating directly to individuals own mental health deteriorating meaning they have less capacity/resource.
- Dynamics within families now being under greater pressures than ever before (due to being together without many outlets)
- Juggling increasing demands e.g. home-schooling, work, caring for parents.
- Support and other networks no longer/less available, cancelled appointments, less support from friends.
- Background of increased financial, health and work related worries.

The interaction between some of these complex dynamics is highlighted in the quotes below;

“my son has stopped taking medication for psychosis, I have mental health problems too and now I’m trying to deal with this”

“being cooped up at home with 3 other adults, one being my dad who I have a difficult relationship with”

“my son is beginning to struggle with the impositions of lockdown and I have to find ways of keeping him busy”

“how to manage the kids, my son has ASD, work and maintain mental health enough to stay out of hospital”

“I’ve simply got too much to do, home-schooling is out the window”

“I worry about coping with all the different priorities I now have”

“it feels like a pressure cooker my husband who has no mental health problems has started taking anti-depressants”

It is clear that families have been under more pressure and that these difficulties have deepened throughout lockdown. Each family is different, and given the size of the survey it would not make sense to make too many assumptions on the range of situations which we received feedback on, however, it was clear that having a mental health problem, receiving less formal and informal support whilst having more responsibilities and family pressures is leading to unmanageable levels of stress and inability to cope.

Services (clinical and general) : In terms of clinical services there was a mixed response throughout from services in terms of supporting people. This ranged from all clinical appointments (in some areas) being stopped e.g. psychology and psychiatry. In other areas people were told they could get in touch if they needed help, and in other places people accessed appointments either by phone-call or through a video call system called *‘near me’ (a Scottish Government approved secure video system used for consultations).

There were a number of difficulties which arose from these changes, and in hindsight having more personal choice would have been helpful. With no appointments, people understandably felt abandoned, and in some cases this will have worsened peoples mental health markedly.

“I have suicidal thinking, and now no support”

Schonegevel¹⁹, in a Rethink briefing (looking at accessing NHS mental health support for people with severe mental illness) stated that 42% had said their own mental health had deteriorated because of reduced support, with 58% believing that support available had worsened overall.

In terms of asking people to reach out if they need help, this can be useful for some, but for others (even without the pandemic) they feel they are wasting time and resources, or for other reasons which can be complex will not ask for help.

In relation to other ways of holding appointments some found “near me” useful and much better than nothing, and others find it unnerving, again, the importance of personal preference cannot be underestimated as it can make or break someone seeking and participating in appointments. Phone appointments were found to be better than nothing, but there was a general worry that this may become normal, and that if this was the case this would be concerning for a number of people.

In terms of third sector support many found it more flexible and better at reaching out, however there were mixed response to video calls (which was the main way people who responded were receiving support from the third sector). Some who were very depressed and did not want to come out the house found video calls helpful.

“I can still take part, even just to listen, this helps me hugely”

as mentioned previously others find this format unnerving and exhausting.

“I find it drains me rather than energising me”

It would be good to look into this in more detail in the future, people felt there were some advantages to new ways of connecting but they also worried that funding cuts may lead to poorer quality/less person centred practice because it was seen as being successfully used during lockdown.

“I hope this doesn’t become the “new norm”!”

There was also a worry from some about appearing to “manage through lockdown”, and that this may lead to them being dropped from the service.

As well as the formal support there was a great deal of recognition of the informal support people get from community activities.

“not being as free to engage with activities that would usually help me de-stress and manage anxiety”

Finally in relation to support/services there was a great deal of concern about NHS appointments for health conditions being cancelled or delayed, or not wanting to take the risk of seeking appointments for health related issues.

“I have no wish to seek medical attention (despite a number of serious health concerns)”

“it’s just going to end up a bigger problem... now they’ve cancelled my next appointment (to check my heart)”

Isolation/Loneliness – human interactions: The importance of human interaction and what that brings to us was clearly evident in the responses we received. The importance of this has been highlighted by the major charity, Rethink^{vi}, who found that 69% of its survey respondents stated that their mental health was poorer because they could not see family or friends.

The members we surveyed stated that they felt lost, trapped and sad not seeing their friends, family and others in the community. They also talked about the fact that this was having a negative effect on preventing their mental health problems from deteriorating.

"I miss my family and need to hug them" "I feel closed in and trapped"

"Support from those who usually support me is now reduced/not available"

"the lack of contact with people who are usually there to help me keep on top of both mental and physical health problems"

There was also a sense from people shielding that they feel particularly isolated.

"People shielding feel very left behind, claustrophobic and frightened.....losing hope"

Others felt a sense of relief in having less pressure to socialise.

I actually like the isolation, I feel some of the pressures of day to day life have been taken away"

Worry about contracting the virus: The feedback we received highlights the high levels of anxiety many of our members feel in terms of contracting the virus. Many people talked about the fact that they had a range of other health conditions which would make it harder for them to fight the virus. There was also a sense of not having the mental strength/resources to get through it they did catch it.

"my immunity is low so I will catch it"

"I don't think I'll make it through"

Coming out of lockdown: Although all the survey responses were received whilst in full lockdown, we were already starting to have members saying they are concerned about coming out of lockdown.

"the possibility of too much too soon"

"will it ever end, and what will the future be like for me, government cuts in benefits"

"I worry that my services will be cut or lost"

"what comes next: I lost my job a few weeks ago"

There was also a great deal of fear around coming out of lock-down for those with long term health conditions and their vulnerability regarding catching coronavirus. Particularly from those who have been shielding.

"Im worried about whether I will be safe going back to work after shielding"

"having to go back to work with the public is a huge concern....I'm so afraid of bringing this illness home"

4. What is helping our members?

We were keen to find out what people find helpful during the current situation. A range of activities and ways of living are helping our members minimise the impact of the pandemic.

Arts, crafts, photography and music were frequently mentioned by our members as activities which help people to have a sense of freedom, expression and distraction.

“Crafting is helping me greatly, it takes my mind off the feeling of being trapped in”

Being outside is also helping people to manage their situation. People talk about their garden being their sanctuary, or the walk that they do each day as being a life saver.

“Being outside in the fresh air and nature....helps me try to keep things in perspective”

Some people have started taking part in new forms of exercise for example starting *“couch to 5k” exercise programme, and participating in online fitness classes.

Yoga and a range of other approaches were also found by many to be helpful, people mentioned breathing techniques, yoga based exercises, repetitive prayer, positive psychology/gratitude and various forms of self-help.

“I’ve started a gratitude journal”

“I find repetitive prayer helpful (if I wake in the night)”

Routines/daily plans and organising things was helping some people find a sense of control, and helping them to focus.

“A routine daily plan helps me, I’m not looking too far in the future”

In terms of connecting with others, video calls to friends and family were found to be helpful to some people. Online learning, activities, podcasts and ted talks seemed to be useful in keeping people busy and preventing boredom.

Avoiding the news was also highlighted a number of times as being hugely important. Some people talked about the “social media hysteria” which they felt was unhelpful and had fuelled a lot of anxiety. They would have preferred facts and basic/clear information.

“I’m avoiding the news as it compounds anxiety”

5. What could VOX do throughout this period to support/help?

Three main themes emerged from the responses we received. The key response was to continue to ensure that policy makers and others don’t forget about the impact this is having on people with mental health problems, and that we should keep engaging through surveys and other means to find out how members are managing, and to use this to influence change.

Members also stated that we should keep them up to date with any changes which affect them, both in relation to coronavirus and more generally.

Finally, members suggested we find ways to open up creative opportunities and interesting online activities to provide distraction etc.

6. What is causing most concern?

The responses to this question (tick box) backed up the open question about key concerns.

As mentioned 70% of the respondents were most worried about their **mental health deteriorating** (more of a concern than catching the virus for our members). This figure is also higher than The Health Foundation's Covid-19 survey^{vii}, carried out with Ipsos Mori, which showed that almost half of respondents (49%) had concerns that the pandemic would negatively affect their mental health.

The next two issues were family/caring responsibilities at 55% which has been noted earlier and Isolation and loneliness at 54% again noted earlier.

Other issues which are worth mentioning are 51% of people were worried about catching the virus and 38% were concerned about their physical health.

7. Is there anything else you would like to mention in relation to coronavirus?

The main point people made in relation to this question was that they were concerned about deepening inequalities, and what the future would be like for them.

"increased need for food banks whilst others are getting appropriate support"

"people are really struggling and falling between the cracks, the situation is worse for asylum seekers and refugees"

There was a lot of anger expressed towards the UK and Scottish Government. This was in relation to the following; a lack of clarity in what the public should be doing, trust towards the government caused by what was seen as intentionally presenting facts in ways which suited the political agenda. There was also felt to be a lack of good decision making (especially in terms of speed of going into lockdown) and frustration with the public not always sticking to the rules.

"its difficult dealing with peoples misinformation and misinterpretation of the rules"

"I was angry at the government for not taking decisive action quickly enough"

"some applying the rules and others not bothering"

There were a few people who said they were used to isolation, and had a lot of coping skills/ways to keep themselves busy they had already developed due to their mental health issues. Some different viewpoints emerged on this issue ranging from resentment to hope.

"I'm resentful for all this help being available now when my situation isn't really any different in practice"

There was some hope expressed around the fact that the pandemic had led to a sense community spirit and potential opportunities for positive change.

"I think it is a wake up call to make the world a better, healthier and more compassionate place"

"some people have actually taken time to talk to me now, I hope we can still keep looking out for each other"

"for the first time in ages I was asked if I needed anything"

8. Next steps

We all have mental health, and many people have been negatively affected by the pandemic, however, it is important to highlight what is happening to people with lived experience of mental health issues, and the deepening of inequalities potentially taking place.

As mentioned 63% of those who responded are feeling negatively impacted by the pandemic, and 70% felt they were more worried about their mental health than catching the virus. Whilst the statistics might not be hugely different for the general population, what is different is the fact that our membership already have higher levels of poverty, are less likely to be in employment, often have complex family dynamics (including caring responsibilities), long term health conditions and other factors which make them more likely to be negatively impacted. In addition to these sociological factors their lived experience of mental health issues give rise to an uphill battle of coping during the pandemic.

In order to reduce the negative impact of the pandemic support should be provided to families to lessen the impact of competing demands, person-centred approaches in clinical care should be further developed, and the role of the arts, self-help/mindfulness, exercise and the outdoors should be promoted.

Extra support for people with lived experience of mental health issues will be needed to help them “come out” of lockdown due to the impact this has had on their mental health. A survey by Anxiety UK^{viii} showed that the prospect of lifting or easing of lockdown restrictions had led to an increase in anxiety for almost 67% of 745 members.

It is of utmost importance that we continue to capture the experiences of those most likely to be severely impacted by this situation. We will focus our next survey on “coming out of lockdown” with an aim to influence the Scottish Government and Health Boards policy and practice . We also aim to explore the impact of the pandemic on our members from Black, Asian and Minority Ethnic (BAME) communities, focusing not only on the health impact but also the economic and social impacts.

Annexe A

1. How do you currently feel?

The same as I usually do

My mental health has deteriorated a little

I feel better than usual

My mental health is now very poor

Other (please specify)

- 2. Due to Coronavirus my main concern just now is? Please explain in the box below.**
- 3. What helps you just now? Activities, ways of thinking, things to avoid (we may use some of your ideas as the basis for an arts project)**
- 4. What could VOX do throughout this period to support/help?**
- 5. Please tick the issues which are causing you most concern (tick up to six boxes)**

Physical health issues

Mental health issues

Isolation/Loneliness

Getting enough food in

Getting medicines you need to stay well

Getting exercise

Worries about work

Financial concerns

Boredom

Catching coronavirus

Family/Caring related worries

Other (please specify)

- 6. Is there anything else you would like to mention in relation to coronavirus?**

References

- ⁱ Bentall, R., Gibson-Miller L et al. (2020) Covid-19 Psychological Research Consortium (C19PRC) Initial Research Findings on Covid-19 and Mental Health In The UK, University of Sheffield. [Online] Available from: <https://www.sheffield.ac.uk/news/nr/depression-anxiety-spiked-after-lockdown-announcement-coronavirus-mental-health-psychology-study-1.885549> [Accessed 1 July 2020]
- ⁱⁱ Mind (2020) The Mental Health Emergency [Online] Available from https://www.mind.org.uk/media-a/5929/the-mental-health-emergency_a4_final.pdf [Accessed 30 June 2020]
- ⁱⁱⁱ Mind (2020) The Mental Health Emergency [Online] Available from https://www.mind.org.uk/media-a/5929/the-mental-health-emergency_a4_final.pdf [Accessed 30 June 2020]
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- ^v Schonegevel, L. (2020) Rethink Mental Illness Covid-19 Briefing. [Online] Available from: <https://www.rethink.org/media/3793/access-to-mh-services-final-040220.pdf> [Accessed 1 July 2020]
- ^{vi} Rethink Mental Illness (2020) 80% of people living with mental illness say current crisis has made their mental health worse. [Online] Available from: <https://www.rethink.org/news-and-stories/news/2020/04/80-of-people-living-with-mental-illness-say-current-crisis-has-made-their-mental-health-worse/> [accessed 30 June 2020].
- ^{vii} The Health Foundation (2020). The Health Foundation Covid-19 Survey [Online] Available from: <https://www.health.org.uk/sites/default/files/upload/publications/2020/Health-Foundation-2020-COVID-19-Polling-Full.pdf> [Accessed 1 July 2020]
- ^{viii} Anxiety UK (2020) A further rise in anxiety levels can be expected with easing of lockdown restrictions [Online] Available from <https://www.anxietyuk.org.uk/blog/anxiety-uk-survey-indicates-a-further-rise-in-anxiety-levels-can-be-expected-with-easing-of-lockdown-restrictions/> [Accessed 1 July 2020]

*'Near me' Near Me is a secure form of video consulting approved for use by the Scottish Government and NHS Scotland <https://www.nearme.scot/>

*'Couch to 5k' Couch to 5k is a running plan, approved by the NHS <https://www.nhs.uk/live-well/exercise/couch-to-5k-week-by-week/>
