

Coronavirus (COVID-19): Highest Risk – interviews report – August 2021

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Background

Interviews were conducted with people on the Scottish Government's highest risk list who receive advice and support about being at highest risk from COVID-19.

The 'highest risk list' was previously known as the 'shielding list' and contains around 180,000 people, the majority of whom were previously asked to shield by the Chief Medical Officer (CMO). People on the 'highest risk list' are still identified as highest risk from Covid-19, and receive communications, support and advice from the Scottish Government. However, since 9 August 2021 they have been asked to follow the same guidance as the general population.

These phone interviews provide qualitative insight into how people have been feeling since interviews were last carried out in January 2021. Since the last round of interviews:

- COVID-19 restrictions have decreased to baseline measures as Scotland moved 'beyond level zero'
- Case numbers have fluctuated, but remained relatively high at the time that interviews were being conducted
- The vaccination program has been widely rolled out with 94% of those who are on the 'highest risk list' having received both doses of a COVID-19 vaccination at the time

What we wanted to find out

By doing interviews at this stage of the pandemic, we wanted to understand:

- how people felt about the 'state of the pandemic' in Scotland
- how comfortable people felt as restrictions were eased
- experiences of the vaccination campaign in Scotland
- where participants looked for trusted information
- what expectations people had when returning to the workplace
- how people felt about the long term restrictions which are in place 'beyond level 0'
- if people thought that the highest risk list had any value in the future

Our research approach

We carried out 12 in-depth interviews over the phone or video call using Microsoft Teams. A user researcher facilitated each session which lasted no longer than 60 minutes. Note takers and observers also took part in the sessions.

We recruited participants by selecting contacts who had previously signed up to take part in research and who fit the recruitment criteria.

Participant recruitment criteria

Following discussions with policy team leads, we identified two groups of participants to recruit. The primary recruitment criteria were as follows:

1. People who are immunosuppressed and who are returning, or have already returned, to the workplace as restrictions are eased
2. People who are immunosuppressed and who are not in work. These participants were either unemployed, in education, looking after the home or family, retired or not working because of a long term condition

In addition, secondary recruitment criteria were also chosen to address recruitment gaps identified in previous research to assess if these users had any particular needs or faced particular problems. These participants were:

- people under 24
- people who are African, Caribbean or black, Asian, Mixed, or another ethnic group
- people who may have additional accessibility needs (e.g. who need help with reading)
- people who use English as a second language

Key Findings:

1. Vaccinations have changed the way that some participants behave but some are still unsure about how to best manage risk

- Some participants do feel more confident in managing risk after vaccination and have started to 'get back to normal'
- Participants who are immunocompromised need more individualised, condition-specific information on vaccine efficacy in order to feel safe enough to manage their risk.
- Many participants would like to receive this information from their GP or specialist as they are a trusted source of information.

2. 'Getting back to normal' is dependent on being able to control and manage the risk of getting COVID-19

- Some participants acknowledged that having confidence to do things again was a slow and incremental process that would take time
- Many of these participants suggested there was little support Scottish Government could offer and instead, it was their responsibility to gain confidence to do things again
- The behaviour of others is still a barrier as participants are trying to manage their own risk – especially in bars and restaurants.
- Being asked to go back to the office is causing concern for some as people are not able to make the choice about what is safe for them

3. Not 'returning to normal' is not always a result of being at higher risk from COVID-19

- The risk of COVID-19 is not the only thing preventing people from meeting others outside their household. Some participants are not able to 'get back to normal' because of disability or mobility issues.
- Rather than feeling forced to limit social contacts, some participants suggest that they are now more content with meeting less people.

4. Accessing health care is still difficult for many

- Many participants are having issues in accessing regular health care, especially GP appointments and are worried that this will have long-term impacts on their health.
- Some participants are concerned that COVID-19 safety protocols in health care settings would not keep them safe

5. There is a lack of consensus about future communication and support needs

- Communications from Scottish Government and NHS remain two highly trusted sources of information
- Some participants suggest communications to those on the highest risk list should be reduced and only include essential information whereas some suggest there is now limited need
- Others suggest that the highest risk list should exist throughout the winter as a precaution in the case of new variants of COVID-19 and heightened case numbers.

How people's lives have changed in the last two months

On 9 August 2021, Scotland moved 'beyond level zero', meaning that the majority of COVID-19 restrictions were eased and limits on the numbers of people gathering indoors and outdoors were removed. A number of baseline measures were left in place, including enhanced hand hygiene, wearing a face covering where required, self-isolation and taking a PCR test with symptoms and working from home if possible. Physical distancing in certain settings were advised but not mandatory. Those at highest risk of COVID-19 were advised to follow the same advice as the general population.

From June - August 2021, [case numbers in Scotland have remained relatively high](#) and the vaccination program in Scotland has continued as more young people have now been vaccinated.

People are still cautious about meeting those outwith their household

Despite most participants having had two doses of the vaccine, many acknowledged that this did not give them full protection against COVID-19. Most were still taking steps to reduce the number of social contacts from outside their household:

[I'm still tending to decline social invites where there's a lot of people because I'm not keen to put myself in that kind of environment. Other than my parents and some immediate family, no one has been in my house and I haven't been in anyone else's house.](#) (Participant 4)

Some participants reiterated that while they went through a period of feeling more comfortable to start doing things again, the more recent high case numbers and lifting of restrictions have meant that they are starting to be more cautious. Some participants felt that the baseline measures are not enough to protect them and so they must take extra precautions:

[Recently, I've been feeling more anxious again. I'm starting to feel more isolated now than previously because of lack of restrictions and compliance, with people not wearing masks. I'm going out less than I was previously.](#) (Participant 10)

Participants are taking additional distancing and hygiene measures to make them feel safer

Some participants said they would continue to go beyond the advice given to the general population by taking additional measures to keep themselves safe. Some examples of these include wearing a face covering in places where they are not

required to do so, physical distancing, using hand sanitiser regularly, wearing gloves, wiping down groceries, not meeting people indoors and only shopping at quieter times:

I keep myself as safe as possible and follow rigorous hygiene and distancing. I use hand gel every time I touch something in the shop. I always wear a face mask and disinfect my hands and the trolley when going in and out of shops and whenever I touch money or a card. I also distance myself from people. (Participant 12)

Those at highest risk have been advised to follow some of these precautions earlier in the pandemic and it is clear that these are still playing a role in the way that people manage their risk.

Some participants are taking advantage of loosening of COVID-19 restrictions

Despite high levels of overall caution, some participants have started going out and meeting people again. Participants talked about their experiences of meeting people indoors, going out for coffee, going shopping and going to bars and restaurants.

I've started going out for dinner again. We [the family] have always gone out for a Sunday meal to the same place. They [the restaurant staff] know me and I ask for a table away from everyone else so I feel safe. I just tell myself, 'you are doing all you can to stay safe and need to live your life.' (Participant 9)

Impact of the vaccine

Around 94% of those on the high risk list were fully vaccinated and vaccination rates in the general population were also very high. For some participants, this has affected how they understand their risk, although many acknowledged that vaccination is not considered a fail-safe way of being protected from COVID-19.

Reasons why people are not fully vaccinated

Two participants explained why they have decided not to be fully vaccinated. We spoke to the parent of a higher risk young adult whose daughter had a bad reaction to the first dose of the vaccine. While the participant acknowledged that they could not be certain that their daughter's ill-health was linked to her vaccine, they felt it was too risky for their daughter to have the second dose until they received further information from the consultants about whether it was safe to go ahead.

She's frightened to go for her second jag. After the first time, her kidney function dropped. If that happens again [with the second dose], you're talking about her kidney dropping to about 20% - is that a risk we're going to take? We're waiting on

the hospital to give us an update on whether it's safe to take a second jab
(Participant 2)

Another participant had chosen not to receive either dose of the vaccine because they were concerned about reacting badly because they are immunocompromised. They also disclosed that they live rurally and believed that the risk of contracting the virus was relatively low and because they did not believe that the vaccine has been adequately tested with people with compromised immune systems. The participant said they would prefer to wait until there were more 'peer-reviewed medical journals' which evidenced how the vaccine may react with their condition before deciding to get the vaccine.

My immune system is not functioning properly. There is not enough evidence of the benefit compared to the risk for me. I don't want to put something in my body when I don't know how it will react. I read that it's been tested on humans and people died.
(Participant 12)

Vaccination made some participants feel more confident

Some participants felt that their risk of catching or becoming seriously ill from COVID-19 had reduced since having their second dose of the vaccine and that this had allowed them to feel more confident to do things again. While there were questions about the efficacy of the vaccine for those with compromised immune systems, some felt that vaccines had offered a degree of protection:

I felt the risk had decreased [after vaccination] - not eliminated but decreased. I know the risk of severe disease goes down once vaccinated. (Participant 5)

More information about the efficacy of the vaccine is needed

Many participants said that they were looking for more information about how well the vaccine has worked and about the difference between different vaccines but they found it difficult to find conclusive answers:

We don't know what effect the vaccine will have on people who are immunosuppressed. You read data one day that says it works, other days, that it doesn't – I've still got no idea. If I can get the data, then I can assess if I feel happy going out as other people seem to be doing at the moment. (Participant 10)

Some participants felt that having condition-specific information on the efficacy of the vaccine would give them more confidence to manage their own risk and allow them to start meeting more people from outside their household again. Along with this, some participants questioned what role booster vaccines may play in the future,

depending on the effectiveness of the vaccine for those who are immunocompromised:

When I went for my second vaccination, the nurse said they didn't know if the vaccinations would be as effective from my group but I heard there might be a booster? (Participant 9)

Information about vaccine efficacy should come from a healthcare professional

Vaccines had changed the way that many participants thought about their risk and the impact that COVID-19 may have if they caught it. However, there were many questions from participants about how the vaccine may interact with a medical condition or medication. Participants told us that having condition-specific information from a trusted source would allow them to better manage their own risk and may give them more confidence to make decisions:

...this made me feel a lot better. Since speaking to the consultant, I feel a lot more chill about my risk. (Participant 3).

For those who were still looking for more information or reassurance, many suggested that they would feel more confident if this information came from a medical professional:

I feel slightly more protected after double dose but I know it's not possible to tell exactly how much protection I have, given that I'm immuno-compromised. I'd have trust in my doctor to give me that information, rather than just looking on Google. (Participant 4).

'Getting back to normal' is dependent on being able to control risk

Participants felt more comfortable to do things again when they were in control of the risk. Some balanced the benefits of seeing people against the risks of transmission in certain places and at certain times, before making a decision. However, not being able to control the risk increased anxiety.

Gaining confidence takes time

Many participants were taking steps to start doing things again after long periods of being very cautious and limiting social interactions. Given the impact that shielding had on peoples' perceptions of safety and risk, readjusting to do things and seeing people again was taking time, with many understanding this as an incremental process:

I've started to move towards better integration – but slowly ... at my own pace. I'm in no hurry. I'll go back to normality in my own time. I'll keep wearing a mask and keep being careful when I need to. (Participant 6)

Although participants were largely still being cautious and not doing all the things that they felt comfortable doing before the pandemic, many participants acknowledged that there was little guidance Scottish Government could offer to make them feel safer, and that instead, it was their responsibility to start doing things again when they felt ready:

I don't think there is anything more the government can do. I need time to take wee steps and be confident to get there. I am still nervous. I can only take responsibility for myself. I am fed up being in the house and need to stop existing and start living. (Participant 9)

The behaviour of others is still causing concern

Many participants were still concerned about the behaviour of others and this was often cited as something which prevented those at higher risk from being able to start doing things again. Not having control over the behaviour of others introduces risk for those at highest risk and so many were choosing to avoid places where they believed that risk to be highest:

I tend to get really anxious about the actions of other people - who are they seeing? Are they being safe? I'm particularly not keen on going to pubs because people get too close. A room full of drunk, rowdy people not physical distancing is not my idea of fun. (Participant 1)

Additionally, some participants mentioned that recently, their levels of anxiety had increased as Scotland moved 'beyond level 0' because physical distancing had been removed.

I just feel anxious now that restrictions have been eased. I feel a bit sad that I feel that I can't do things again [because of the lack of restrictions]. I think that it'll get worse again in the winter and people meeting more indoors because it's cold and rainy. (Participant 10)

Returning to the workplace removes 'choice' when trying to manage risk

Being asked to return to the workplace in the near future was a stressful time for many participants. While participants said that they had a choice about whether they did things like going to a bar or meeting friends inside, having to return to work removed this choice and forced those at highest risk into situations which they were not comfortable with:

If they made me go back I have actually thought about leaving - I know that sounds extreme. Having to go back removes that element of choice. What's going to happen with the work situation when the cases rise in the future, if I did have to go back?

Having to go back would put myself in a really difficult position of work or long term sick or giving up employment completely. This is my most urgent need. It's the reason I am doing this interview." (Participant 10)

People's feelings of anxiousness about returning to work depended on how understanding their employer is of their high risk status, the measures that have been put in place to make offices more Covid-19 secure and whether hybrid working is an available option.

There are questions about the practicalities of a 'high risk identifier'

[In a recent survey](#), we asked those at highest risk, 'If you were offered something small to wear (such as a wristband) to indicate that you'd prefer people to keep their distance, would you use it?' This would likely be a small item, such as a wristband, lanyard or badge, which would signal to others to keep their distance and take more precautions to protect those at higher risk. In this follow-up qualitative research, questions were asked about the practicalities of such a scheme and about whether it would alter people's behaviour:

I don't know if that would be helpful or if people would even notice it if it's small. Would it make much difference? I hope a few decent people would take notice but the majority of people wouldn't make much difference. But I would wear just to make me feel I was doing everything I could to make myself safe (Participant 4)

There was a breadth of opinion on the usefulness of a high risk identifier with some saying it could be used to '[reduce stigma and embarrassment](#)' (Participant 1) while others said they would avoid using it because '[I don't want it \[my condition\] tattooed on my forehead](#)' (Participant 12).

Not 'returning to normal' is not always a result of COVID-19

While research has previously told us what participants felt comfortable with as restrictions were eased in Scotland, some participants told us that not taking part in social activities, such as meeting people outwith their household, was not necessarily because they were at highest risk of COVID-19.

Pre-existing disability/mobility issues mean that people cannot do more as restrictions are eased

Some people who are at highest risk have pre-existing medical conditions which may impact mobility. As a result, some participants were limiting social contacts not only because they are at highest risk from COVID-19 but also because of existing or deteriorating mobility or other disability issues. This means that they are not able to 'get back to normal' in the same way as others:

It's kind of tricky because I had been going out and now I feel less like going out because I can't drive anymore because of my MS. In a way, I had to stop doing these things, rather than choosing to. For me, that means not getting out of my house much but not because of the pandemic. (Participant 8)

Some are content with fewer social interactions

Some participants also discussed feeling more comfortable with fewer social interactions than they had before the pandemic because they are now more comfortable with socialising less than they did before. It appears that the threat of catching COVID-19 is not the only factor which has changed the way people choose to socialise and that the way of living through the pandemic more generally, has changed the way that they socialise:

I just don't really feel like big nights out and not just because of the virus. I'm kind of happy and comfortable being more antisocial than I was before. I don't feel like I'm missing out on anything really (Participant 4)

Accessing health care is still difficult for many

Many participants disclosed that they have had difficulties when trying to access primary and secondary health care and that this was something which continued to affect their physical health. Attending medical appointments was seen as part of 'getting back to normal', however this was something which was still causing stress for many participants.

Difficulties accessing health care

Many participants were still having difficulties accessing GPs and specialist appointments. In particular, a lack of face-to-face GP appointments as a result of the pandemic was causing increased anxiety as participants feared their underlying health condition may worsen or that this may have longer term impacts on their health:

Having less access to health care has been difficult during the pandemic. Being able to be seen by a GP has been a lottery. I hope in the future, medical care gets more normal. (Participant 6)

In addition to the stresses of being at highest risk of COVID-19, some participants said that the difficulty in accessing medical care was contributing to the feeling of isolation:

I've felt completely alone with my illness. I've not had enough support to manage my kidney condition and I've had to try to do that alone. (Participant 9)

Some don't feel safe attending health care settings

Additionally, in some primary care settings, some participants were concerned about catching COVID-19 while they were in healthcare settings. In some cases, this had caused anxiety when people have needed emergency health care:

I had to go to A&E and there was no social distancing. There was no room and people were sitting on the floor. I think people at high risk should be more protected in these situations, such as a separate area for those at high risk. It was very upsetting. (Participant 9)

For participant 9, the level of mitigations in healthcare settings did not make them feel safe. They wanted to see more diligence with physical distancing, the use of PPE and limiting the number of healthcare professions an individual has to interact with.

Understanding if there is a future need for communications

Assessing what needs and expectations users have for the future of the highest risk list (formally the shielding list) will be important when looking forward in the pandemic.

Scottish Government and NHS advice are trusted sources of information

The majority of participants suggested that they used Scottish Government and NHS information when looking for information about COVID-19 restrictions or about the pandemic. This information was particularly useful when information was thought to be changing quickly and was seen as a trusted source:

I tend to look on the Scottish Government website for information. That is information I trust because it's from the government and I've no doubt that it's correct. (Participant 11)

When looking for information about COVID-19, how to keep themselves safe and information about the vaccine, participants often referred to the NHS website for support as again, this was seen as a trusted source:

I would go to NHS Inform for information. It's their job to protect you and they would never put you in danger. It means I don't need to worry about what other sources might say (Participant 4).

Referring to trusted sources of information has been particularly important for those at highest risk as there is a general awareness of the amount of information on social media and on news websites which was seen as “unhelpful and untrustworthy” (Participant 5).

There is no consensus on the future need for the highest risk list

Participants were split on the future need for a highest risk list, particularly about whether they should continue to receive direct information through letters.

The uncertainty around the future trajectory of the virus was the main reason given for maintaining the list. Participants wanted to continue to be informed of changes in risk or guidance.

You see so much info on the news but receiving a letter with a summary of the main important points gives a level of reassurance. (Participant 5)

Some found the regular communications reassuring and ‘would like to see that support continue into that period (flu season) to give peace of mind’ (Participant 10), while others said that the list could be used to get information for other public health information, for example “if there is a really bad flu strain” (Participant 1)

However, some felt the opposite, and felt that there was limited future value in further communications:

I've been getting lots of letters with lots of words and little change. It's too much. (Participant 12)

I don't think we can get anything out of it anymore. At some point the world needs to move on and live with COVID (Participant 9)

Several people suggested that rather than receiving information about the pandemic more generally, instead, they would need more condition-specific information as they felt the guidance and information wasn't bespoke enough to their individual level of risk following vaccination.

The communications were incredibly valuable at the time, in protecting me and people in much worse situations. Going forward, there might be people who still

need to be protected but I imagine it will be a much smaller list because people will have had a vaccine. It might be a waste of resources for some people now.

Participant 4)



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