Public Health Scotland

COVID-19 shielding programme (Scotland) impact and experience survey – part two

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At a glance

Shielding was introduced in March 2020 to protect people at the highest risk of negative COVID-19 outcomes. The term shielding has now been replaced by the term highest risk.

Between 25 October and 7 November 2021, Public Health Scotland organised an online survey of the highest risk group.

13,581 individuals participated in the survey.

This was around **7.5%** of individuals included in the highest risk group.

Survey respondents report ongoing negative impacts on…

82% – their confidence when leaving their home

77% – the amount of physical activity they do

76% – their quality of life

Respondents report ongoing worry and caution:

81% – still make decisions that are mainly influenced by fear of COVID-19 infection

36% – still try to minimise all physical contact with other households.

A large proportion of respondents (77%) agree that having been included on the highest risk list has made them feel supported.

However, there is also evidence that some needs were not met. Some groups were less likely to have felt supported, including those who are…

- socioeconomically more vulnerable
- younger than 65 years
- living with children in their household
- providing unpaid care
- living with an impairment
- severely immunosuppressed or severely immunocompromised

Going forward, more targeted guidance and additional support are likely to be helpful. When making decisions about the next steps, it will be important…

to involve individuals with lived experience of being in the highest risk group.

to consider socioeconomic vulnerability as well as clinical vulnerability.

Key findings

About the survey

- Between 25 October and 7 November 2021, Public Health Scotland (PHS) ran an online survey of individuals who, at some point since March 2020, had received a letter from the Scottish Chief Medical Officer (CMO) advising them that they were in the COVID-19 highest risk group. Individuals caring for someone in the highest risk group were also able to participate.

- This was the second survey of the highest risk group organised by PHS, following an earlier survey in June 2020. This second survey was organised to help understand: (i) the longer-term impacts of the initial (March–July 2020) shielding period; (ii) how individuals in the highest risk group are managing risk; and (iii) whether the support available to individuals in the highest risk group has met their needs.

- A total of 13,581 individuals participated in the survey. This represents 7.5% of the 180,072 individuals included on the highest risk list at the time of the survey. The profile of the respondents varies from the profile of the wider highest risk group. To address this discrepancy, data and percentages have been weighted for age and gender. The data have not been weighted for socioeconomic vulnerability, but subgroup analysis by socioeconomic vulnerability has been undertaken.

- Some groups of highest risk individuals may have been less likely to engage with an online survey. This includes those less digitally able or those without internet access. Paper copies of the survey were available, but PHS received only online responses.

Survey findings

- There is evidence of ongoing negative impacts on the lives of people in the highest risk group. A total of 76% of respondents who had already been advised that they were in the highest risk group at the time of the initial (March –July 2020) shielding period, report an ongoing negative impact on their quality of life. Ongoing negative impacts are more pronounced among respondents who are socioeconomically more vulnerable, who have an impairment or who provide unpaid care. Respondents who are severely immunosuppressed or severely immunocompromised are also more likely to report ongoing negative impacts. Socioeconomic vulnerability has the strongest association with ongoing negative impacts.

- There is evidence of ongoing worry and caution among the highest risk group. In total, 81% of respondents still make decisions that are mainly influenced by fear of COVID-19 infection, and 36% of respondents still try to minimise all physical contact with other households. Evidence of ongoing caution is more pronounced among respondents who are socioeconomically more vulnerable, who have an impairment or who provide unpaid care. Respondents who are severely immunosuppressed or severely immunocompromised are also more likely to continue to be cautious. Socioeconomic vulnerability has the strongest association with ongoing caution.

- There is evidence to suggest that the advice and support offered to the highest risk group has made a difference. For example, 85% of respondents report that the letters of the CMO have influenced some of their actions. The 'Clear your head' leaflet to support individuals' mental health is less often reported to have made a difference.

- A large proportion of respondents (77%) agree that having been included on the highest risk list has made them feel supported. Socioeconomically vulnerable respondents are less likely to have felt supported. Respondents who are younger than 65 years, who have an impairment, who provide unpaid care or who have children in their household are also less likely to have felt supported. Respondents who have been advised that they are severely

immunosuppressed or severely immunocompromised similarly are less likely to have felt supported. Socioeconomic vulnerability has the strongest association with not having felt supported. Unmet needs are diverse and include issues relating to COVID-19 advice, COVID-19 vaccination, health and social care support, and financial and employment support.

- There is evidence of ongoing advice and support needs. A total of 88% of respondents think that it is very or quite important that there continues to be a separate highest risk group. Practical examples of requests for ongoing support include access to antibody testing, additional employment protection and public awareness-raising around the continued vulnerability of the highest risk group.

Introduction

The Scottish Government COVID-19 shielding programme

The Scottish Government introduced the shielding programme in March 2020 to protect those individuals at the highest risk of severe illness or death from COVID-19 infection. The programme aimed to provide individuals with guidance to help minimise interaction between them and others – and ultimately to reduce the risk of infection, severe illness and death. The shielding programme also aimed to provide individuals with the necessary support to enable them to follow the shielding guidance, including, for example, priority access to online supermarket delivery slots.

Shielding was paused on 31 July 2020. Since then, the Scottish Government has continued to provide guidance and support to individuals at the highest risk of severe illness or death from COVID-19 infection. Some examples are below.

- In December 2020, the Scottish Government released the booklet 'Balancing the risk of daily activities during coronavirus' for those at highest risk of COVID-19. This was part of a wider approach aimed at supporting individuals at the highest risk to make their own decisions, based on their own circumstances.
- During the second lockdown, between January and April 2021, the CMO advised individuals at the highest risk of COVID-19 not to go into the workplace or use public transport.
- In the summer of 2021, after Scotland had moved to (and beyond) level 0 on the Scottish Government's five-point scale of COVID-19 protection levels,[i] the CMO advised the highest risk group to follow the same advice as the rest of the population, unless advised otherwise by their GP or clinician.

[i] As outlined in the Scottish Government's **COVID-19 Strategic Framework**.

In July 2021, the CMO indicated that he was unlikely to advise individuals in the highest risk group to shield again, pointing to the negative impacts of shielding and to the availability of vaccination as an additional protection measure. At that point, the term shielding was replaced by the term highest risk.

Evaluating the Scottish Government shielding programme

In March 2020, PHS was asked by the Scottish Government to evaluate the shielding programme. The **findings from the initial June 2020** survey of the shielding group were published in September 2020. The **full findings from the evaluation**, which covered the period between March and August 2020, were published in January 2021. Following the publication of the January 2021 report, PHS was asked by the Scottish Government to also evaluate the guidance and support offered to the highest risk group following the pause in shielding. To this end, PHS ran a second survey of the highest risk group. The current report presents the findings from this second survey.

The objectives of the second survey were to:

1. understand the longer-term impacts of shielding
2. explore how individuals in the highest risk group are managing risk in the context of COVID-19, including any changes in their approach to managing risk since the pause in shielding
3. explore how individuals in the highest risk group have experienced the guidance and support offer since the pause in shielding
4. identify ongoing support needs of individuals in the highest risk group.

Regarding the third objective, the focus of the evaluation is on the guidance and support provided by the Scottish Government. Other stakeholders, including local authorities, local Health Boards and third sector organisations, have provided guidance and support to individuals in the highest risk group.

Exploring the longer-term negative impacts of the initial shielding period presented a particular challenge. The survey questionnaire briefly reminded respondents what the initial shielding guidance advised them to do (to minimise all physical contact with others) and reminded them about the timeline of the initial shielding period (March–July 2020). The questionnaire then explicitly asked respondents to report on the longer-term negative impacts of this initial shielding period. However, respondents may have found it difficult to disentangle the negative impacts of the initial shielding period from the negative impacts of the COVID-19 pandemic, population-wide COVID-19 restrictions or being at higher risk of negative COVID-19 outcomes. As a result, the survey findings relating to the ongoing negative impacts of the initial shielding period must be interpreted with care.

How the survey was done

The survey ran for two weeks, between Monday 25 October 2021 and Sunday 7 November 2021. At the time of the survey, Scotland had moved beyond level 0 on the Scottish Government's scale of COVID-19 protection levels and most of the remaining legally imposed population-wide restrictions had been lifted. The survey took place before the first case of the omicron variant of the virus was detected in Scotland (29 November 2021) and before the omicron variant was first reported to the World Health Organization (24 November 2021).

A total of 13,581 individuals participated in the survey. This represents 7.5% of the 180,072 individuals included in the highest risk group at the time of the survey. The survey was developed as an online survey, but paper copies of the questionnaire were available on request.

The survey consisted mainly of closed questions. The survey included one fully open question: respondents who disagreed with the statement that they had received the advice and support they needed following the pause in shielding were able to provide a free-text response around what advice or support had been missing. A total of 1799 free-text responses were received. The survey also included two multiple-choice questions where respondents could add a free-text comment if they selected ‘other’ as their response option. This was the case for the multiple-choice question whether

being included in the highest risk group had any positive impacts (777 free-text responses). This was also the case for the multiple-choice question on what would be useful to help individuals feel comfortable doing most (or all) of the things they did before COVID-19 hit (548 free-text responses). Key themes and quotes from these free-text responses are presented throughout the report. Quotes were adjusted to correct spelling mistakes or add missing punctuation to improve readability. Lengthy quotes were occasionally shortened; three-dot punctuation in square brackets is used throughout this report to indicate that text has been left out.

Limitations

The survey has a number of limitations which need to be considered.

- The survey responses reflect the views of individuals who self-report that they (or the person they care for) have received a letter from Scotland's CMO advising them that they were in the shielding or highest risk group.
- A number of different channels were used to advertise the survey, but the only direct recruitment channel was a text message to individuals registered with the shielding text messaging service. This means that survey respondents may be more likely than the wider highest risk group to have engaged with the support on offer in the first place. This needs to be carefully considered, in particular when interpreting survey responses relating to the support offer.
- Individuals who would otherwise be unable to participate in the survey were able to request a paper copy of the questionnaire. However, PHS received only one such request (for an Easy Read paper copy of the questionnaire) and did not receive any completed paper copies.
- Overall, the survey response is therefore not based on a representative sample of the highest risk group. The next section (Profile of respondents) describes how this limitation was addressed.

- This report does not present any subgroup analysis which combines variables relating to respondents' personal characteristics (for example, subgroup analysis by age and by clinical category). This means that some of the differences in reporting by one variable may be confounded by differences in another variable.

Profile of respondents

The profile of respondents varies from the profile of the wider highest risk group in a number of ways (see Table 1). Survey respondents are more likely to be female and less likely to be aged 65+ years. They may also be less likely to face socioeconomic vulnerability. In the remainder of the report, all data and percentages are weighted for age and gender (except for any subgroup analyses by age or gender and excluding Table 1 which presents the unweighted data).

The data have not been weighted by socioeconomic vulnerability, but subgroup analysis has been undertaken based on the question whether finding £100 for an unexpected expense would be impossible, a big problem, a bit of a problem or no problem. This indicator is used as a proxy indicator for socioeconomic vulnerability throughout the report. As the report does not contain subgroup analysis combining variables, some of the differences in reporting by socioeconomic vulnerability may be confounded by differences in age, clinical category and so on.

Table 1: Profile survey respondents vs. wider highest risk group

Profile	Survey respondents	Wider highest risk group
Gender	• 61% female • 39% male	• 56% female • 44% male
Age (years)	• 47% 65+ • 53% < 65	• 51% 65+ • 49% < 65
Clinical category	• 47% respiratory disease • 5% clinician identified* • 30% immunosuppression • 12% cancer • 6% rare disease • 4% organ transplant	• 40% respiratory disease • 29% clinician identified • 20% immunosuppression • 14% cancer • 6% rare disease • 4% organ transplant
Ethnic group	• 98% white	• Unknown
Socioeconomic vulnerability	• Distribution by Scottish Index of Multiple Deprivation (SIMD) quintile unknown**	• 26% 1st SIMD quintile • 23% 2nd SIMD quintile • 20% 3rd SIMD quintile • 17% 4th SIMD quintile • 14% 5th SIMD quintile

Source: The wider highest risk group data are taken from the biweekly PHS update on the demographics of the highest risk group (on 25 October 2021, which is the date when the survey went live).

* The wording of this question in the survey 'none of the above – I was advised to shield by my GP or consultant' may explain the low percentage (5%) among survey respondents compared to the 29% reported across the wider highest risk group. Across the wider highest risk group, individuals can be categorised as clinician identified **and** as having one or more other clinical highest risk condition. Survey respondents could only tick the clinician-identified response option if they had no other clinical highest risk condition ('none of the above').

** There is no information about the SIMD profile of survey respondents, but several survey questions offer some insight into the socioeconomic profile of respondents:

- half (51%) of respondents report that finding £100 for an unexpected expense would be no problem
- 9 in 10 (90%) have access to a private or shared garden
- the vast majority (98%) have access to the internet at home.[ii]

Report structure

The report is structured as follows:

- Part one explores the impacts of being included in the highest risk group.
- Part two focuses on risk management approaches in the highest risk group.
- Parts three to five discuss the support offer to the highest risk group. Part three explores the impact of the support offer on people's behaviour. Part four focuses on how individuals in the highest risk group experienced the support offer. Part five discusses future support needs.
- The final sections in the report include the conclusions and recommendations section, as well as three appendices which summarise key findings from the survey relating to employment, mental health and carers.

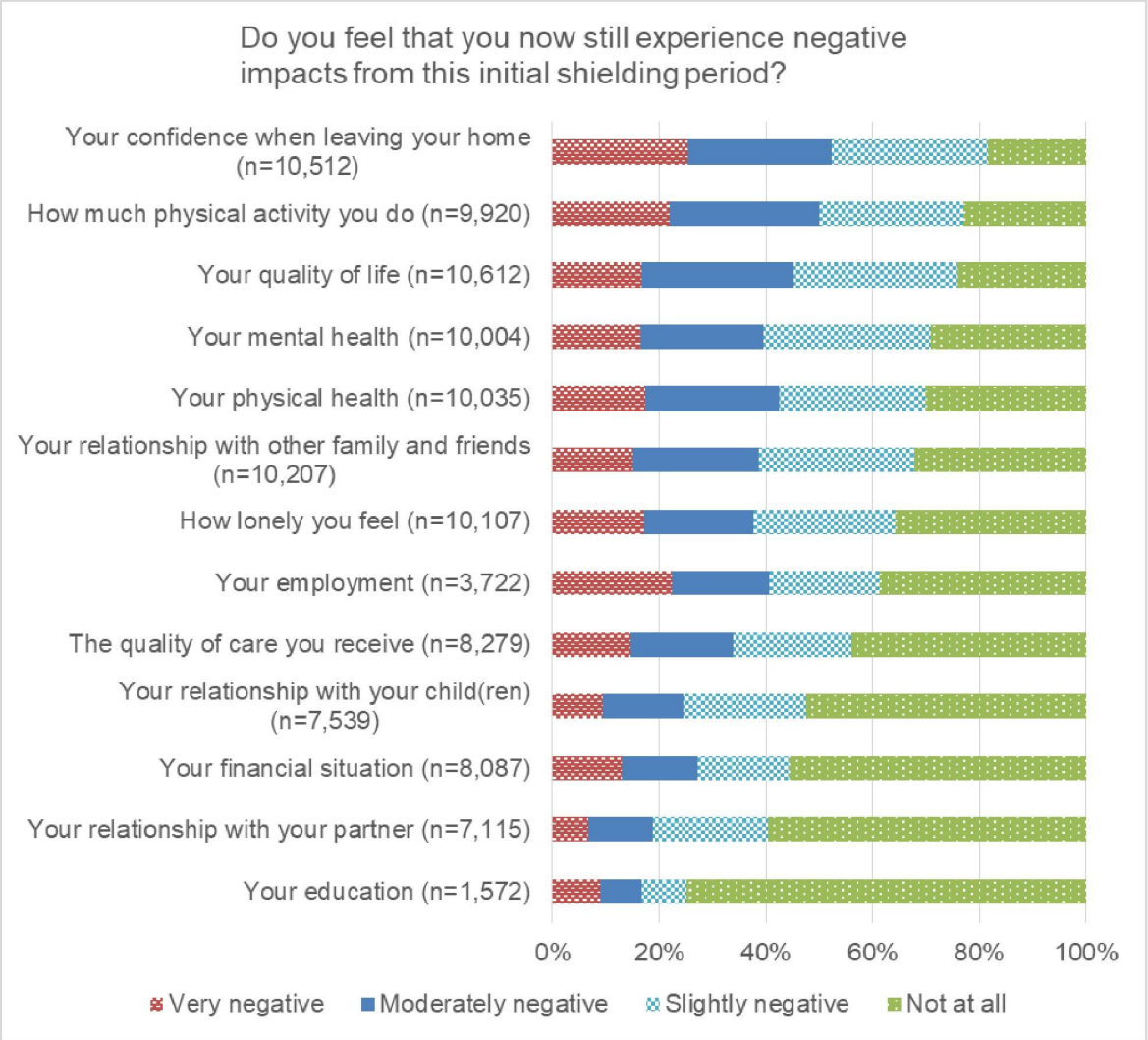
[ii] These data are not available for the wider COVID-19 highest risk group. Some Scotland-wide data are available, but no direct comparison with the findings from the PHS survey is possible because of differences in the wording of the question or in the timing of the surveys. In the 2019/2020 **Scottish Crime and Justice Survey**, 77% of respondents reported that finding £100 for an unexpected expense would be no problem. A **2020 Office for National Statistics survey** suggests that 13% of households in Scotland did not have access to a private or shared garden during the first lockdown. In the **2020 Scottish Household Survey**, 93% of respondents had access to the internet.

Part one: Impacts of being in the highest risk group

Ongoing negative impacts

There is evidence of ongoing negative impacts on the lives of people in the highest risk group. Respondents who had already been advised that they were in the highest risk group at the time of the initial shielding period (March until July 2020) were asked whether they still experienced negative impacts from this initial shielding period (see Figure 1).

Figure 1: Ongoing negative impacts



Note: The analysis in Figure 1 excludes the 639 respondents who had been advised that they were in the highest risk group **after** 31 July 2020.

When interpreting the results in Figure 1, it is important to remember that respondents may have found it difficult to disentangle the negative impacts of the initial shielding period from the negative impacts of the COVID-19 pandemic, population-wide COVID-19 restrictions, or their experience of being at higher risk in the period since the initial shielding period.[iii]

Respondents are most likely to report an ongoing negative impact on their confidence when leaving their home (82% of respondents report an ongoing negative impact), the amount of physical activity they do (77%), their quality of life (76%) and their mental health (71%). However, very negative ongoing impacts are reported less frequently. For example, one in six respondents report very negative ongoing impacts on their quality of life (17%) or their mental health (16%). Respondents are most likely to report a very negative ongoing impact when commenting on their confidence when leaving their home: one in four (25%) report a very negative impact. One in four (25%) respondents report an ongoing negative impact on their education. However, among the small group of respondents who were in education at the time of the survey (n = 156), this is higher: almost eight in 10 (78%) respondents in education report an ongoing negative impact on their education.

[iii] The 2020 **Scottish Health Survey** (SHeS), which ran between August and September 2020, found lower wellbeing scores among adults who had been advised to shield than among adults who had not been advised to do so, suggesting that factors **specific** to the highest risk group – and not just the impact of the COVID-19 pandemic or population-wide restrictions – may have played a role. However, the SHeS data still do not allow to differentiate between the impact of being at higher risk more generally and the impact of the advice to shield. Moreover, similar SHeS comparisons between the highest risk group and the rest of the population are not available for 2021.

Ongoing negative impacts are more common among respondents for whom finding £100 for an unexpected expense would be impossible or a big problem. For example, 86% of individuals in this group report an ongoing negative impact on their mental health, compared to 71% of all respondents. Socioeconomic vulnerability[iv] has the strongest association with negative impacts but ongoing negative impacts are also more common among respondents who have an impairment, who provide unpaid care or who are severely immunosuppressed or severely immunocompromised. For example, 78% of respondents who provide unpaid care report an ongoing negative impact on their mental health, as do 75% of respondents who have an impairment or who are severely immunosuppressed or severely immunocompromised.

In the free-text responses, several respondents mention negative impacts on their life. Negative mental health impacts feature most often, with respondents reporting loneliness and isolation, anxiety, fear, loss of confidence and depression. Respondents also report negative impacts on their physical health, on their employment situation, on their finances and on their relationships with others. These impacts are not always the result of the initial shielding period – respondents also explicitly refer to negative impacts of the COVID-19 pandemic, population-wide restrictions or their higher vulnerability and risk. The **pause** in shielding is mentioned as having impacted negatively on the employment status of several respondents.

> […] The experience has left me frightened, anxious and a shadow of my former self in terms of confidence. (Female, 45–64 years old)

> […] I have lost everyone because I was shielding. I'm incredibly lonely. (Sex and age unknown)

[iv] As measured by the question whether finding £100 for an unexpected expense would be a problem.

> […] My body doesn't work to move as good as before, my legs won't walk any more than a few steps without me being in agony […] (Female, 65–69 years old)

> […] Some jobs have no option to work from home. So when shielding ended, I had to go on long-term sick. It affected my finances badly. I'm in debt now and eventually my work pressuring me to return was too much and I had to leave my job […] (Female, 25–44 years old)

Comparison with June 2020 survey responses

It is possible to compare the results from the October 2021 survey with the results of the earlier June 2020 PHS survey of the highest risk group. However, it is important to differentiate between the two surveys: the October 2021 survey asks respondents about **ongoing** negative impacts (from the initial shielding period); the June 2020 survey took place during the initial shielding period and asked about the negative impacts of shielding **at that time**. It is also important to remember the likely ambiguity in the negative impact responses across both surveys. Reported negative impacts are likely to be the result of a complex mix of experiences, including the experience of: living through the pandemic, being at highest risk, being asked to shield and living through population-wide restrictions, such as lockdowns. The two surveys asked about negative impacts on (some of) the same aspects of life.

For some aspects of life, the October 2021 survey presents a slightly more positive picture than the June 2020 survey. For example, in the June 2020 survey, nine in 10 (87%) respondents report a negative impact of shielding on their quality of life. In the October 2021 survey, eight in 10 (76%) respondents report that they still experience an ongoing negative impact on their quality of life. Similarly, in June 2020, more than one in three (35%) respondents reported a very negative impact on the amount of physical activity they did. In October 2021, fewer than one in four (22%) report that they still experience a very negative ongoing impact on the amount of physical activity they do.

For other aspects, the October 2021 survey results are just as, or even slightly more, negative than the June 2020 results. For example, in the June 2020 survey, 15% of respondents reported a very negative impact of shielding on their mental health. In the October 2021 survey, 16% of respondents report that they still experience a very negative ongoing impact on their mental health. In June 2020, one in three (32%) respondents reported a negative impact of shielding on the quality of care they received. In October 2021, almost six in 10 (56%) report that they still experience an ongoing negative impact on the quality of care they receive. Responses are also more negative in the October 2021 survey with regard to respondents' relationship with their partner, their relationship with other family and friends and their financial situation.

The free-text responses provide some insight as to why the October 2021 (mental health) picture in the highest risk group may be no better than the situation in June 2020. Several free-text respondents explicitly mention that they are feeling worse than during the initial shielding period. They report feeling less safe because population-wide restrictions have now been eased or because the remaining restrictions are being ignored. They also contrast the ongoing limitations those in the highest risk group face with the fact that others have largely been able to go back to their own lives: a sense of being left behind features prominently in the free-text responses.

> […] I feel more isolated and a social outcast than ever before. Everyone is getting on with life and mixing, socialising. I can't as I'm too scared to mix with people as all precautions have completely gone out of the window. (Female, 45–64 years old)

> […] This was far harder and much more stressful than the initial shielding period, when we were all at home together […] (Female, 25–44 years old)

Inclusion in the highest risk group after 31 July 2020

A relatively small group of respondents (n = 639) were first advised that they were in the highest risk group after 31 July 2020. They were not advised to follow the initial

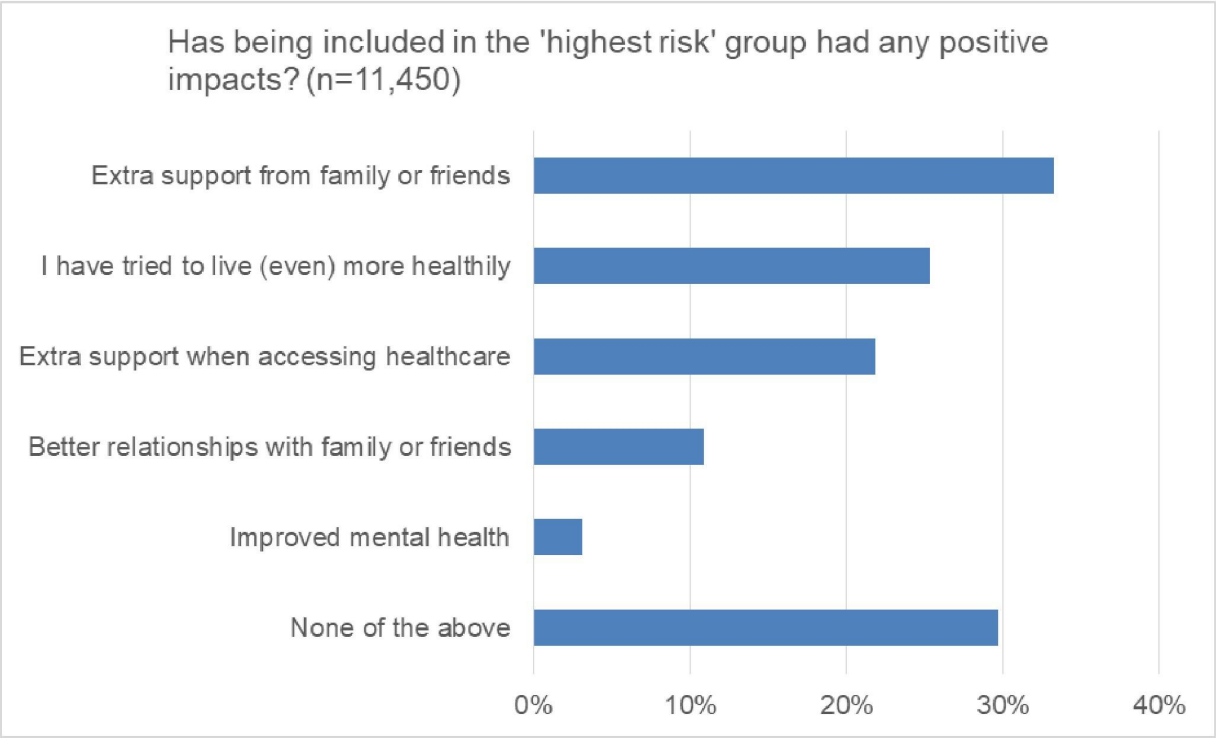
(March–July 2020) shielding guidance, so it would not have made sense to ask them the survey question about the longer-term negative impacts of the initial shielding period. This group of respondents was asked a more general question about the negative impacts of being included in the highest risk group.

Those advised after 31 July 2020 that they were in the highest risk group are as likely to report negative impacts as those advised before the end of July 2020. Any differences tend to be small. For example, 76% of respondents who were advised before the end of July 2020 that they were in the highest risk group report an ongoing negative impact on their quality of life from the initial shielding period. Among respondents who were advised after 31 July 2020 that they were in the highest risk group, 78% report a negative impact on their quality of life as a result of being included in the highest risk group. The similarity in responses between the two groups may reflect the fact that it is difficult for respondents to differentiate whether a negative impact is the result of the initial shielding period, the COVID-19 pandemic, population-wide restrictions or being at higher risk.

Positive impacts of being in the highest risk group

Alongside the negative impacts, respondents also report positive impacts of having been included in the highest risk group (see Figure 2). One in three (33%) respondents report extra support from family or friends and one in four (25%) report that they have tried to live (even) more healthily. Three in 10 (30%) respondents have not felt any (of the suggested) positive impacts.

Figure 2: Positive impacts



Among those in employment (n = 2,839), one in two (50%) respondents report flexibility from their employer as a positive impact. Among those in education (n = 211), one in three (33%) respondents report flexibility from their school, college or university. (These percentages are not shown in Figure 2.)

Respondents could add a free-text comment if they selected ‘other’ as their response option to the question about positive impacts. A total of 777 free-text responses were received. Several respondents mention protection against COVID-19 infection and feeling reassured and informed as positive impacts of being included in the highest risk group. They also cite priority access to COVID-19 vaccination as a positive impact. There are also multiple references to the practical support provided to the highest risk group early on in the pandemic, including priority access to online supermarket shopping and delivery of free food parcels.

> Avoiding COVID. Faster access to vaccination. Ability to get shopping deliveries. (Male, 25–44 years old).

Free-text respondents also refer to improved mental health or wellbeing, for example because they feel less pressure to participate in social activities or have time to take up new hobbies or learn new skills. This includes several references to online activities and learning IT skills. Respondents also mention better relationships with family, friends and neighbours.

> Support from my community, reduced stress due to having a quieter, calmer life and more time to do things I love. (Female, 45–64 years old)
>
> Made me become more resourceful in using the internet. (Male, 80+ years old)

There are also multiple examples of improved physical health. Respondents report fewer chest infections, fewer flare-ups of chronic conditions or better recovery following illness or injury. Respondents mention that they are trying to live more healthily and have, for example, taken up walking, running or cycling.

> Since I have been shielding, I have had no hospital admissions, which is significant because the three years previous I spent about 52 weeks hospitalised. (Male, 45–64 years old)

Working from home is mentioned for its positive impacts on mental and physical health and on people's financial situation, as they no longer face the cost of commuting. Being included in the highest risk group is described as having helped make the case for support on employment issues.

> More disposable income as I'm saving money on commuting. Better work–life balance. (Male, 25–44 years old).
>
> Being included in group added weight to requests to minimise risk at work. (Female, 45–64 years old)

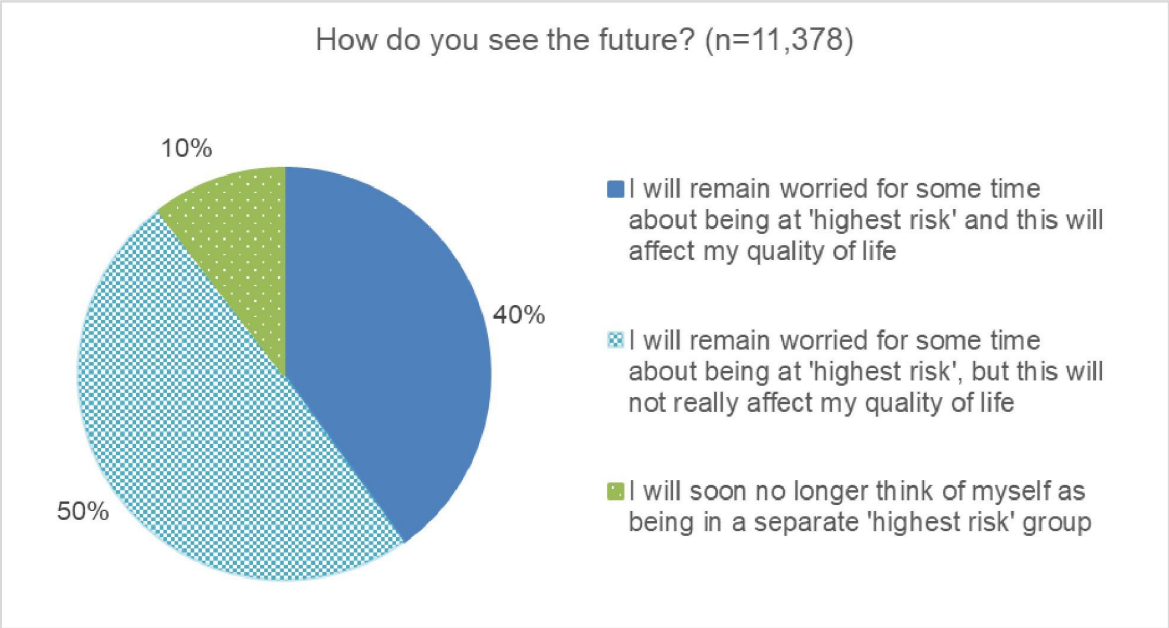
Part two: Approach to risk management

Levels of fear and worry in the highest risk group

There is evidence to suggest high levels of ongoing worry and fear among the highest risk group.

Eight in 10 (81%) respondents agree with the statement that they still make decisions that are mainly driven by fear of COVID-19 infection. This is despite seven in 10 (71%) respondents reporting that they are less afraid of COVID-19 infection since they have been fully vaccinated. Nine in 10 (90%) report that they will remain worried about being at highest risk for some time (see Figure 3).

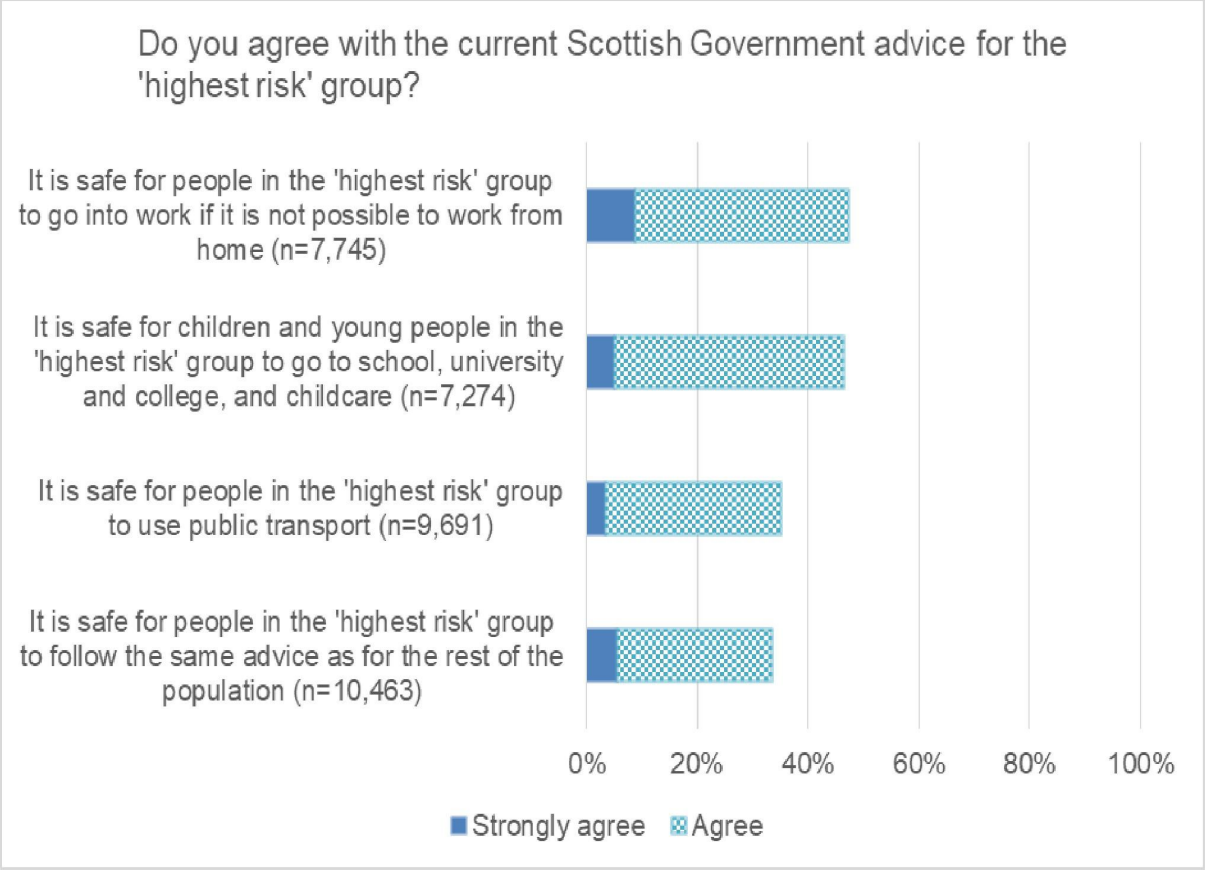
Figure 3: Anticipated future worry



More than two thirds (68%) of respondents agree with the statement that they find it hard to trust guidance which tells them that it is now safe to do things. Fewer than half of respondents agree with four key elements of Scottish Government guidance that it is safe to do things (see Figure 4). Among respondents who are economically active (employed, self-employed or unemployed, n = 3081) just over half (52%) agree that it is safe for people in the highest risk group to go into work if it is not possible to

work from home. This is slightly higher than the percentage in Figure 4, which presents the results for **all** respondents (47%), irrespective of their employment status.

Figure 4: Agreement with Scottish Government guidance



Does this worry affect respondents' quality of life?

As reported earlier, nine in 10 (90%) report that they will remain worried about being in the highest risk group for some time (see Figure 3). A smaller group, but still four in 10 (40%) of all respondents, report that this continued worry will affect their quality of life.

Respondents who are more vulnerable socioeconomically, who are aged younger than 65 years, who provide unpaid care or who have an impairment are more likely to report that this ongoing worry will affect their quality of life. Socioeconomic

vulnerability has the strongest association with expected quality of life impacts. Among respondents for whom finding £100 for an unexpected expense would be impossible (n = 1085), seven in 10 (69%) report that they will remain worried for some time about being at highest risk and that this will affect their quality of life.

Respondents who have been advised that they are severely immunosuppressed or severely immunocompromised are also more likely to expect an ongoing impact on their quality of life. Half (49%) of respondents in this group expect continued worry about being in the highest risk group to affect their quality of life. This compares to three in 10 (31%) respondents who are not severely immunosuppressed or severely immunocompromised.

Respondents who have received an organ transplant are most likely to expect that ongoing worry about being in the highest risk group will affect their quality of life (50% of them report this). Respondents who were advised by their GP or consultant to shield are least likely to expect ongoing quality of life impacts (34%).

Levels of worry in the population at large

YouGov polling suggests that, at the time of the PHS survey of the highest risk group, 52% of the Scottish population agreed or tended to agree with the statement 'I feel worried about the Coronavirus situation'.[v] Questions about levels of worry in the PHS October 2021 survey of the highest risk group result in higher percentages.

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[v] YouGov polling has helped the Scottish Government understand public attitudes to COVID-19 since the start of the pandemic. The most recent published YouGov polling data can be found in the latest **'Public attitudes to coronavirus' update** on the Scottish Government website. The percentage referenced above (52%) refers to data collected between 2 and 4 November 2021. The YouGov polling sample is demographically and geographically representative of adults 18+ years across Scotland.

For example, 90% of respondents report that they will remain worried about being in the highest risk group for some time. However, no direct comparison is possible as the wording of the question is different.

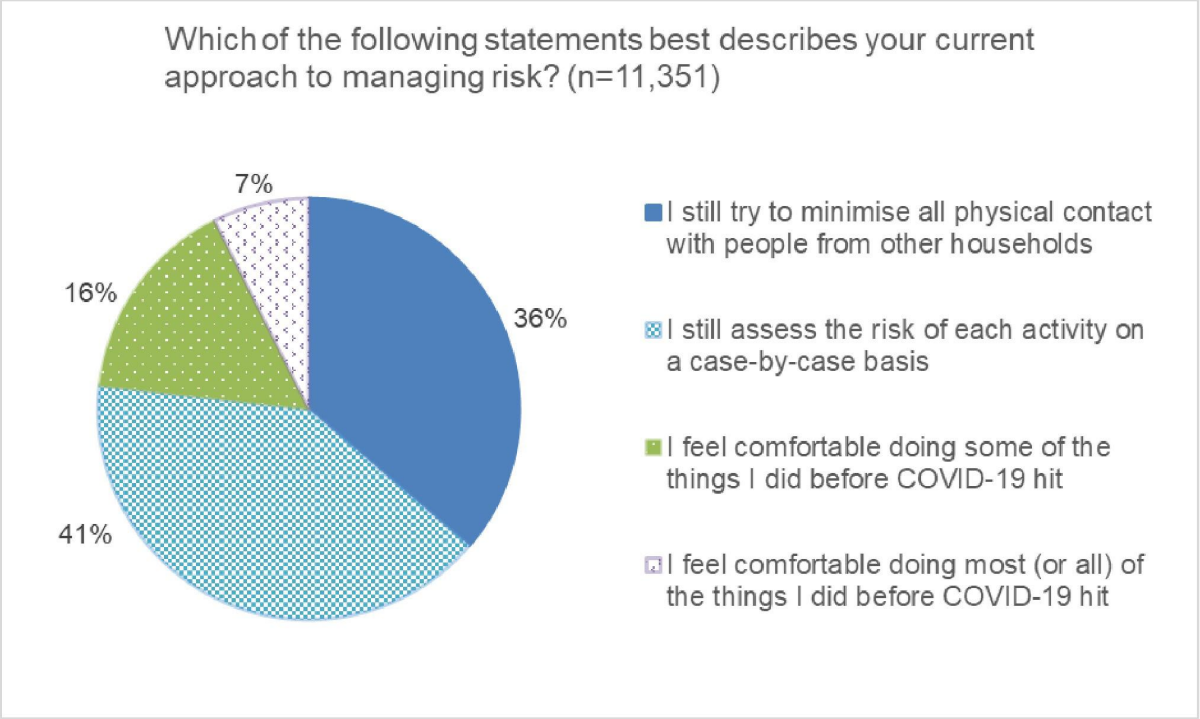
Levels of caution in the highest risk group

There is evidence to suggest that individuals in the highest risk group continue to exercise caution in their approach to managing the risk of COVID-19 infection.

Nine in 10 (91%) respondents agree with the statement that the initial (March 2020) shielding advice[vi] continues to influence their approach to risk. When asked about their current approach to managing risk (see Figure 5), almost eight in 10 (77%) respondents choose the two more 'cautious' response options available: 36% of respondents are still trying to minimise all physical contact with people from other households; 41% are still assessing the risk of each activity on a case-by-case basis.

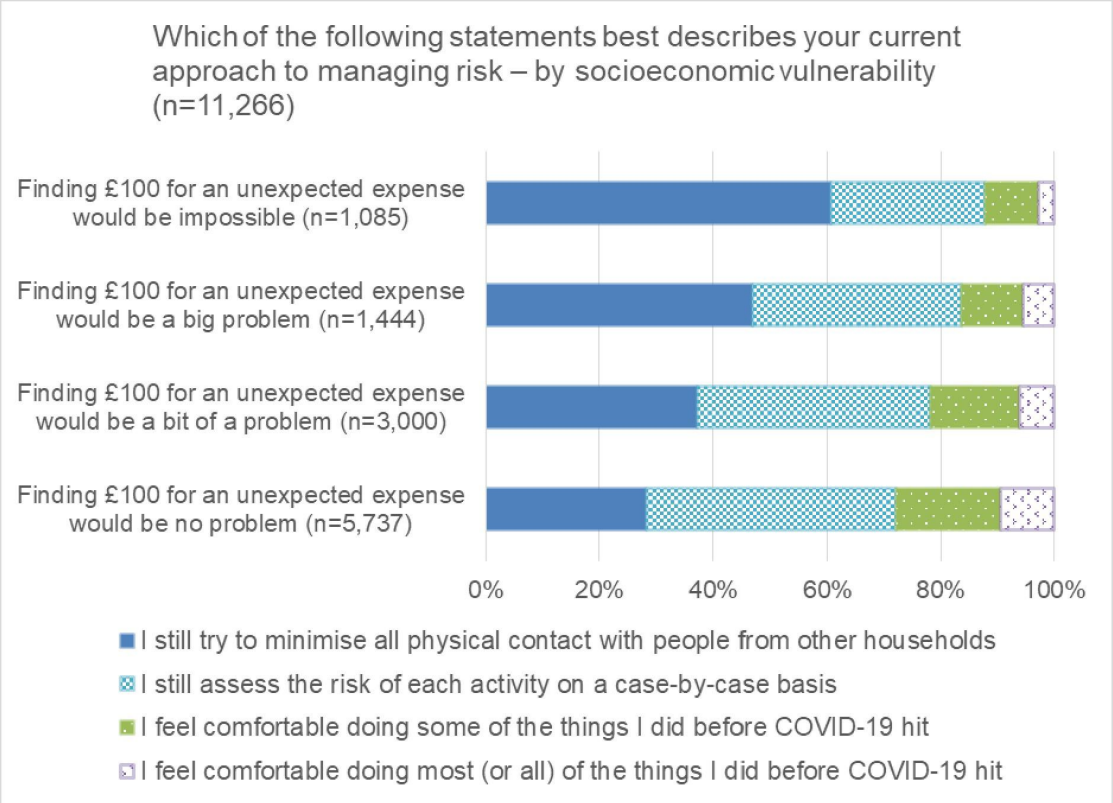
[vi] The initial shielding advice recommended individuals to stay at home at all times and avoid all face-to-face contact, except from carers and healthcare workers. Individuals were also advised to socially distance from others in their household.

Figure 5: Approach to managing risk



Respondents for whom finding £100 for an unexpected expense would be impossible are more likely to report a more cautious approach (see Figure 6). Six in 10 (61%) respondents in this group still try to minimise all physical contact with people from other households. This compares to fewer than three in 10 (28%) among those for whom finding £100 for an unexpected expense would be no problem. Respondents who provide unpaid care or who have an impairment are also more likely to still try to minimise all physical contact with other households, but socioeconomic vulnerability (as measured by the question whether finding £100 for an unexpected expense would be a problem) has the strongest association with ongoing caution.

Figure 6: Approach to risk – by socioeconomic vulnerability



Do levels of caution vary by clinical profile?

It is not possible to directly explore how levels of caution among survey respondents correspond with their level of risk. The relative risk of individuals within the highest risk group is still not fully understood. Moreover, the risk of severe illness or death from COVID-19 infection is complex and multifaceted. The clinical condition which acts as a trigger for inclusion in the highest risk group (e.g., severe respiratory disease) may vary in severity between individuals. Other factors, for example comorbidities, age and external factors, such as occupational or housing circumstances, may interact to determine risk.

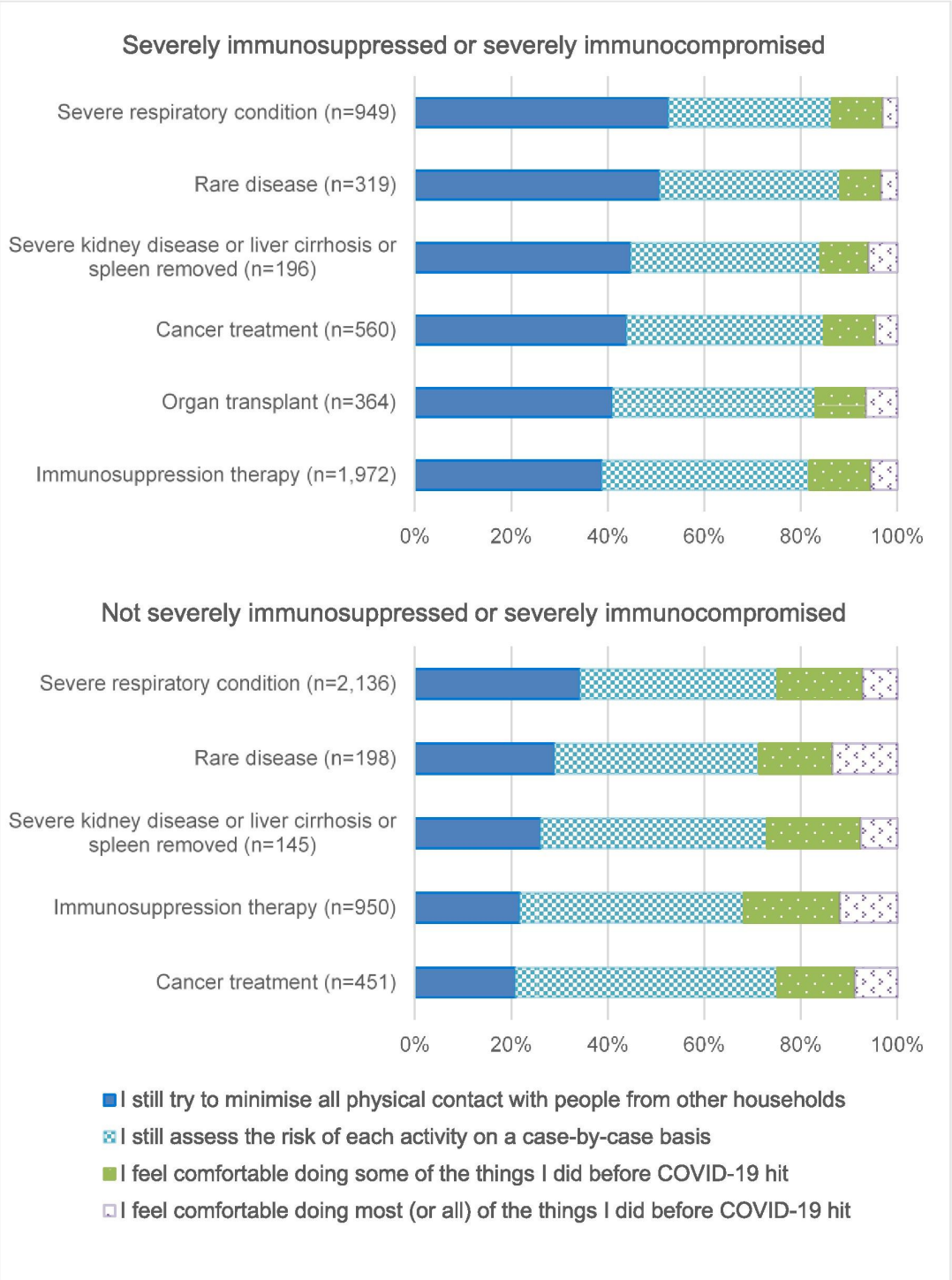
However, a partial analysis is possible. We can compare levels of caution between respondents with different clinical conditions. We can also compare levels of caution between respondents who are severely immunosuppressed or severely immunocompromised and those who are not.

In terms of clinical condition, respondents with severe respiratory disease are most likely to report more cautious behaviour. However, severe immunocompromised or severe immunosuppressed status has a stronger association with caution than (any) clinical condition (see Figure 7). Overall, more than four in 10 (42%) respondents who have been advised by their GP or consultant that they are severely immunosuppressed or severely immunocompromised still try to minimise all physical contact with other households. This compares to fewer than three in 10 (28%) among respondents who are not severely immunosuppressed or immunocompromised.

The survey is not representative and cannot provide a robust estimate of the total number of severely immunosuppressed or severely immunocompromised individuals in the highest risk group in Scotland. It is interesting to note, however, that almost half (46%) of survey respondents have been advised by their GP or consultant that they are severely immunosuppressed or severely immunocompromised.[vii] This suggests that these individuals may constitute a substantial proportion of the highest risk group. Respondents who are more vulnerable socioeconomically, who have an impairment, who are female or who are aged younger than 65 years are more likely to have been advised by their GP or consultant that they are severely immunosuppressed or severely immunocompromised.

[vii] This analysis excludes a large group of respondents who are not sure whether they are severely immunosuppressed or severely immunocompromised. When including these respondents in the analysis, the results are as follows: 32% of respondents are severely immunosuppressed or severely immunocompromised, 38% are not and 30% are not sure.

Figure 7: Approach to risk – by clinical condition



Note: Only 59 survey respondents had an organ transplant and had not been advised by their GP or consultant that they were severely immunosuppressed or severely immunocompromised. This small group was excluded from the analysis in Figure 7.

Lack of clarity about immunosuppression or immunocompromise status also appears to be correlated with higher levels of caution. Respondents who are not sure whether they are severely immunosuppressed or severely immunocompromised are almost as likely as those who are severely immunosuppressed or severely immunocompromised to still try to minimise all physical contact with other households (40% compared to 42%).

Which other factors determine levels of caution?

The previous sections have demonstrated that respondents who are socioeconomically more vulnerable, who provide unpaid care, who have an impairment or who are severely immunosuppressed or severely immunocompromised are more likely to be cautious.

The free-text responses provide some additional insight as to why some survey respondents continue to remain cautious. There appears to be two key drivers behind more cautious behaviour. At times, these two drivers interact.

First, echoing the findings reported earlier (Figure 7), one group of respondents points to their severely immunosuppressed or severely immunocompromised status and report that vaccination has not removed the risk for them. Some go further and report that the removal of COVID-19 restrictions, or people's non-compliance with the remaining restrictions, has put them at higher risk than was the case previously. To this first group, continued caution appears to be an entirely logical response to continued risk. Respondents who have been advised against taking the COVID-19 vaccine or who feel that their clinical condition continues to put them at risk despite vaccination similarly see continued caution as an entirely logical response to continued risk.

> […] The government guidance abruptly stopped shielding when in actual fact nothing had changed for immunocompromised people. With no evidence of an individual's protection from the vaccine, the danger remained as high as ever […] (Male, 45–64 years old)

> Being immunosuppressed has still left me and others like me very fearful of contracting COVID-19 with little immunity protection […] (Male, 45–64 years old)

A second group of respondents argues that they have internalised the advice to be cautious to such an extent that it is difficult to stop being cautious. Respondents experienced the pause in shielding as too abrupt. Several respondents feel that they were expected to simply 'go back to normal' and that this was impossible after having lived through such a long period of worry and caution.

> […] It is physically impossible to be scared to leave your home for months then expected to get back to 'normal' […] (Female, 25–44 years old)

> One minute you're high risk, stay at home, don't go out – next minute, hey everything's fine, you're fine, go out, it's a beautiful day, so you're not high risk!!! […] (Female, 65–69 years old)

> Only received letters saying I could go out again, but after being advised you are in the highest risk, do you realise how hard that is as you feel so vulnerable? (Sex and age unknown)

Ability to manage risk independently

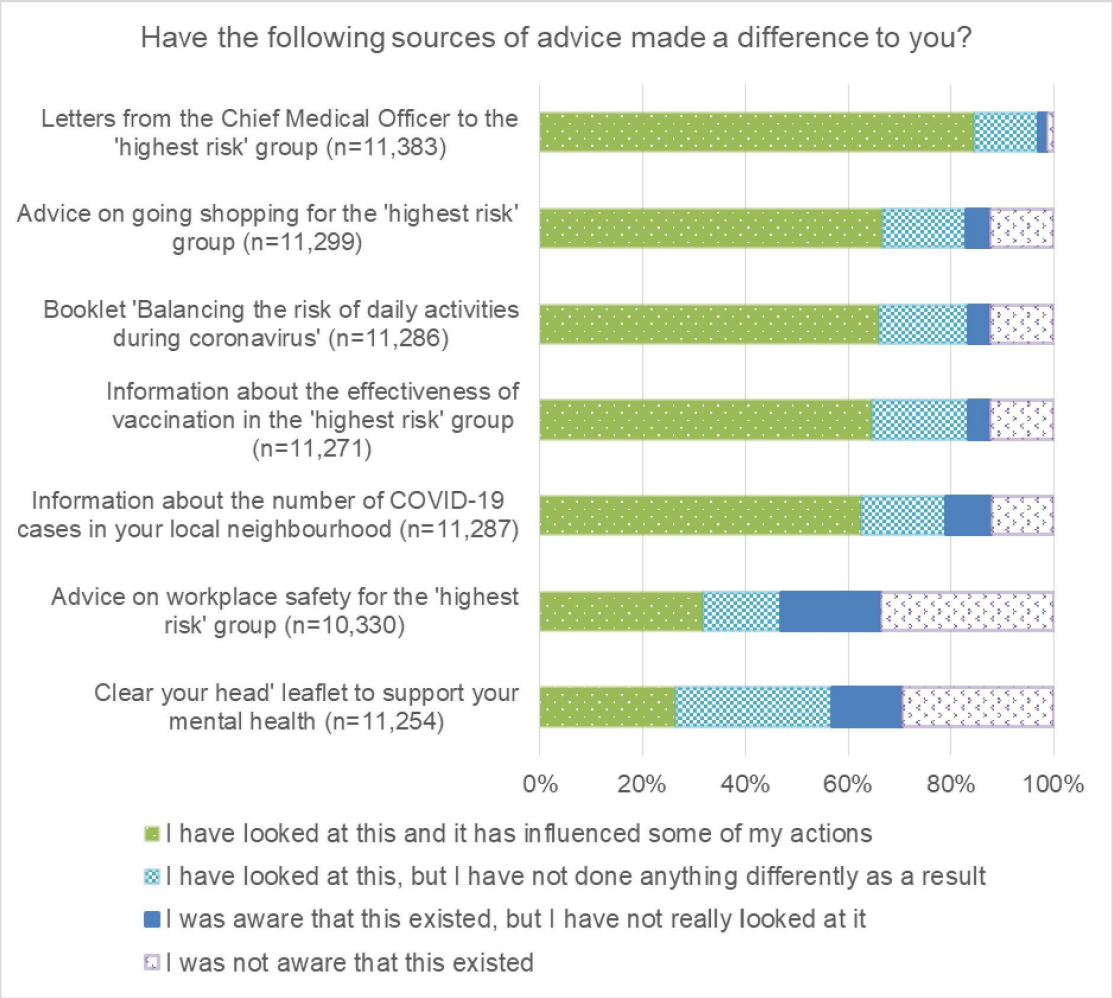
Almost six in 10 (58%) respondents agree that they no longer depend on Scottish Government advice to manage their risk and that they can make their own decisions. Respondents who are younger than 65 years, who are socioeconomically more vulnerable, who have an impairment or who provide unpaid care are more likely to still depend on Scottish Government advice. Respondents who are severely immunosuppressed or severely immunocompromised are similarly more likely to still depend on Scottish Government advice. Socioeconomic vulnerability has the strongest association with ongoing need for Scottish Government advice.

Part three: Impact of advice and support offer

Has the advice changed behaviour?

There is evidence to suggest that the advice offered to the highest risk group has influenced behaviour and has made a difference (see Figure 8).

Figure 8: Impact of the advice



More than eight in 10 (85%) respondents report that the letters of the CMO have influenced some of their actions. More than six in 10 respondents report that some of their actions have been influenced by the advice on going shopping (67%), by the 'Balancing the risk of daily activities during coronavirus' leaflet (66%), by information about the effectiveness of vaccination in the highest risk group (65%) and by information about the number of COVID-19 cases in their local neighbourhood (63%). Among respondents who are economically active (n = 3385), six in 10 (60%) report that some of their actions have been influenced by the advice on workplace safety for the highest risk group. This is higher than the percentage in Figure 8, which presents the results for **all** respondents (32%), irrespective of their employment status.

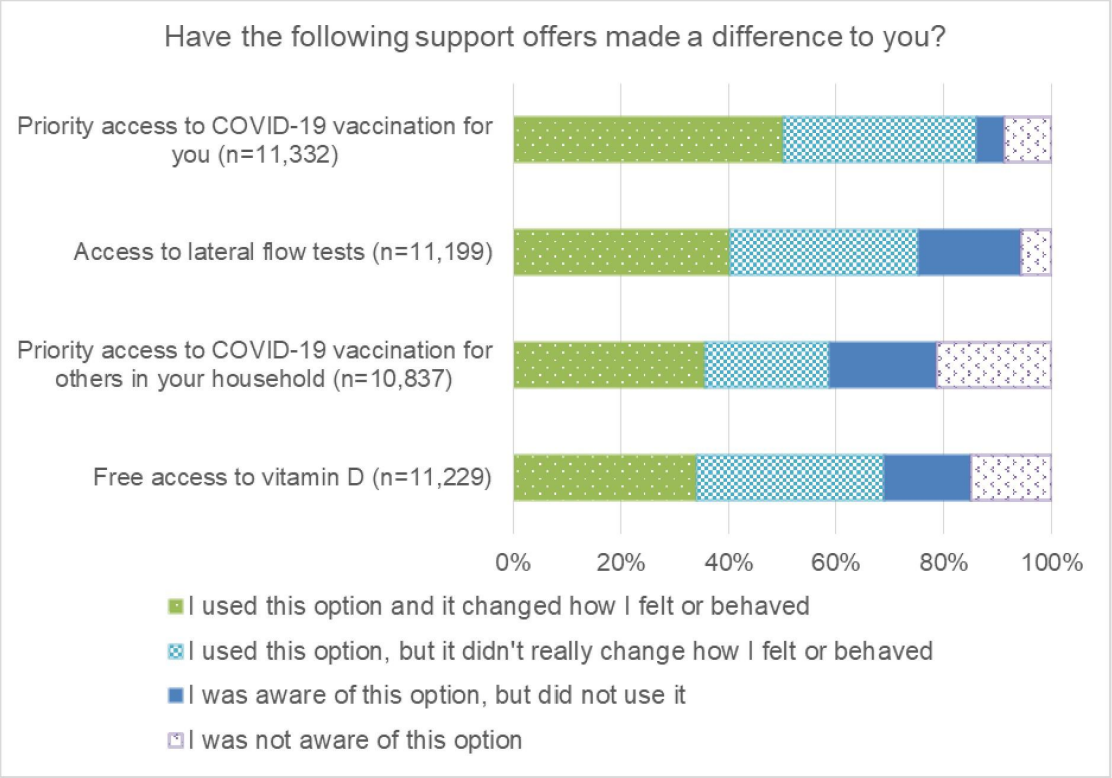
The 'Clear your head' leaflet to support individuals' mental health is less often reported to have made a difference. Fewer than three in 10 (26%) respondents report that this leaflet has influenced some of their actions. This is despite seven in 10 (71%) respondents reporting ongoing negative impacts from the initial shielding period on their mental health (see Figure 1).

Awareness of the different sources of advice is very high. More than eight in 10 respondents are aware of the different sources of advice included in the survey questionnaire. This is also true for the workplace safety advice (83%) when only including economically active respondents. Almost all respondents (99%) are aware of the letters from the CMO. The 'Clear your head' leaflet again scores slightly lower: 70% of respondents are aware of this leaflet.

Has the support changed behaviour or attitudes?

There is evidence to suggest that the support offered to the highest risk group has changed the behaviour or attitudes of some individuals (see Figure 9). For example, half (50%) of respondents report that priority access to COVID-19 vaccination changed how they felt or behaved.

Figure 9: Impact of the support



Awareness of the different support offers is high among survey respondents. More than nine in 10 (94%) respondents are aware that they can access lateral flow tests. Nine in 10 (91%) respondents are aware that they have priority access to COVID-19 vaccination for themselves. Slightly fewer, but still eight in 10 (79%), respondents are aware that others in their households also have priority access to COVID-19 vaccinations.

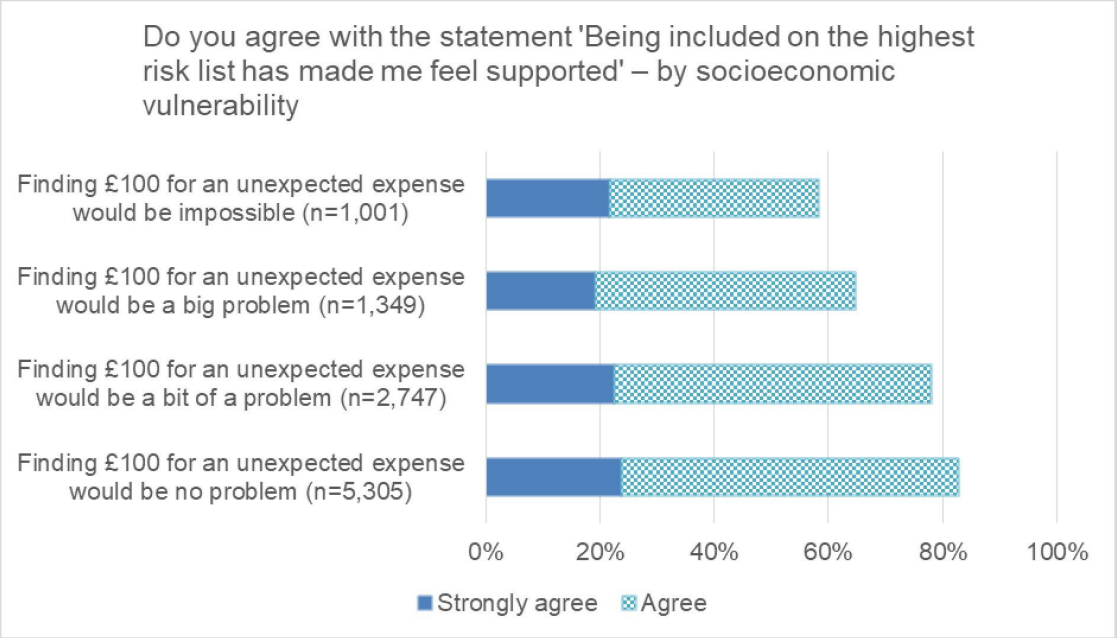
Part four: Experience of the support offer

Feeling supported

More than three in four respondents agree with the statements that being included on the highest risk list has made them feel supported (77%) or that they have received the advice and support they need since shielding was paused at the end of July 2020 (78%). Respondents are less likely to **strongly** agree. Only about two in 10 respondents strongly agree that being included on the highest risk list has made them feel supported (23%) or that they have received the advice and support they need since shielding was paused (18%). Just fewer than three in four (72%) respondents agree that being included on the highest risk list has made them feel vulnerable.

Respondents for whom finding £100 for an unexpected expense would be impossible, are less likely to agree that being included on the highest risk list has made them feel supported (see Figure 10). Fewer than six in 10 (58%) agree. This compares to more than eight in 10 (83%) among those for whom finding £100 for an unexpected expense would be no problem.

Figure 10: Feeling supported – by socioeconomic vulnerability



Respondents who are aged younger than 65 years, who have an impairment, who provide unpaid care or who have children in their household are also less likely to have felt supported. Respondents who have been advised that they are severely immunosuppressed or severely immunocompromised similarly are less likely to have felt supported. Socioeconomic vulnerability (as measured by the question whether finding £100 for an unexpected expense would be a problem) has the strongest association with not having felt supported.

Feeling unsupported

The free-text responses to the question 'what advice or support has been missing' can provide some insight in the experience of those who have felt unsupported. It is important to remember that this question could only be answered by those respondents who disagreed with the statement that they had received the guidance and support they needed. The free-text responses to this question do not provide a picture of people's overall experience of the support offer but tend to be about what has not worked.

Many free-text respondents feel that they were expected to simply return to normal and were not sufficiently supported to do so. Many felt 'unsupported', 'abandoned' or 'forgotten' after the pause in shielding.

> It was like dropping off a cliff […] (Female, 45–64 years old)

> Told to just 'get on with it'. Not confident that I would be safe going about a normal life, but no support or information other than: 'it's okay to carry on as normal!' (Male, 16–24 years old)

Several free-text respondents think that they would have benefitted from support with 're-entry' – although precisely what this support would consist of often remains vague.

> Shielding was paused as of 1 August 2020 with no support for reintegration. It was very daunting to know that I was expected to go out and about as normal. I would have preferred a phased return to normal life under guidance. (Female, 65–69 years old)

> I would have benefited from support in going back to 'normal'. Session with a counsellor or even GP. (Male, 25–44 years old)

Free-text respondents feel that the needs of the society at large have taken precedence over the needs of the highest risk group. Some feel that they are being 'sacrificed' to allow the population at large to go back to normal.

> The moves towards easing restrictions focused too much on what was possible for low at-risk people, leaving those at risk even more isolated, since there was and is no allowance for vulnerable people's needs. (Male, 45–64 years old)

> Since then, we have been left without support and put more at risk by the easing of restrictions to an extent that it feels as if our lives are no longer of importance/value, but are a hindrance to the government. (Female, 45–64 years old)

The sense of abandonment is strong among some free-text respondents who report that COVID-19 vaccination is less likely to offer them protection – or who do not know how much protection vaccination offers them. Several respondents feel 'in limbo' as there appears to be no way out of the situation for them.

> […] 'Do what you are already doing' was the advice. For how long? Till COVID is gone? In 2 years? 5 years? Just keep dodging that bullet? (Male, 45–64 years old)

Feeling poorly advised

The free-text responses to the question 'what advice or support has been missing' also provide some insight in the experience of those who feel poorly advised. The free-text responses to this question do not provide a picture of people's overall experience of the advice offer but tend to be about what has not worked.

The most common complaint about the advice to the highest risk group is that the advice has been ambiguous and unclear. Many free-text respondents comment that there have been 'mixed messages'.

> […] Your advice contradicts itself all the time. (Male, 25–44 years old)

> […] I found a lot of advice I received was not straightforward enough and because of this I felt like I was in situations that made me much more vulnerable to catching COVID-19 […] (Female, 16–24)

There are several specific examples of advice seen as conflicting, including advice relating to specific clinical conditions or advice relating to going to work. More

generally, the advice that it is safe to follow the population-wide guidance is seen as conflicting with messages to still remain careful or messages that vaccination may offer less protection to some groups. This causes unease for some respondents.

> I have a blood cancer. There has been confusion. CMO for Scotland says 'take no different precautions from rest of population', but now told and have had fourth primary vaccine […] (Female, 65–69 years old)

> Being given conflicting advice about staying safe and continuing to limit contact or be in busy places, yet being told it's safe to still work in a public-facing role in a busy public setting. (Female, 25–44 years old)

> I feel like whilst restrictions have eased for the general population, the advice to 'be extra careful' for shielding people is difficult to navigate [...] (Male, 25–44 years old)

Some respondents feel that the advice has been 'condescending' or 'insulting' by telling people that it is now safe to do things when this may not be the case.

> […] The guidance has been inadequate, contradictory and – by implying that fear of catching the virus is a mental problem you should talk yourself out of, an irrational fear – insulting […] (Female, 45–64 years old)

> […] Advice to do as everyone else is 'but be more careful' was quite frankly insulting. (Male, 45–64 years old)

In a number of cases, free-text respondents call the advice 'misleading' or 'wrong'. In particular, some respondents who report that vaccination is less likely to offer them protection or who do not know how much protection vaccination offers them, feel that the advice they have been given is wrong.

> My last CMO letter told me to follow the same guidance as everyone else, but I've seen in recent research that I'm still very vulnerable after two doses because of my treatment. If I'd known that, I would have been more careful. Why did you give me the wrong advice? (Female, 25–44 years old)

The free-text responses appear to suggest that the advice may be too generic to provide sufficient guidance for some individuals. The most common request for additional guidance from free-text respondents is for clearer advice on what the risk is to them personally or what is safe for them to do. One specific example mentioned by several respondents is a request for access to antibody testing, to enable them to assess to what extent COVID-19 vaccination offers them protection. This is discussed further in part five (Future support needs).

Access to health care, vaccinations and social care

Overall, more than five in 10 (56%) survey respondents report an ongoing negative impact from the initial shielding period on the quality of care they receive (see Figure 1). This increases to more than six in 10 respondents who have an impairment (63%) or who provide unpaid care (66%). In the free-text responses to the question 'what advice or support has been missing', several respondents comment on the challenges of accessing health or social care support.

Access to health care

Free-text respondents report difficulties accessing a range of healthcare services, including their GP practice; NHS consultants; dentists, opticians and audiologists; podiatry, physiotherapy or rehabilitation support; cancer support; and mental health support. Respondents also report difficulties getting hold of medications. Difficulties accessing a GP is mentioned most often.

> […] Trying to see a GP is impossible […] (Female, 45–64 years old)

> I still sit in my room every day; my mental health is bad and the lack of help is shocking. I see a psychiatrist once a year because of shortages. Suicide is something I consider a lot, because I'm lonely and afraid to leave the house […] (Male, 54–64 years old)

Many respondents report how challenging it has become to have face-to-face contact with their healthcare providers – again most often referring to contact with their GP. There are also many examples of cancellations or long waits for appointments and surgery, as well as examples of regular check-ups having become less regular. Respondents also report examples of poor quality of care – although more free-text responses relate to access to care than to quality of care.

> It has been almost impossible to access physical health care. Not everyone is okay and fully understands zoom calls. You can't get a physical examination through zoom and not everyone has access to the internet. (Female, 45–64 years old)

> […] My routine hospital appointment which was my opportunity to ask questions about my condition and vulnerability to COVID was delayed by four months. (Female, 70–74)

> […] While being told I needed to get seen within 24 hours I was also told they had no idea how I would get access. They wished me luck and left me to it […] (Female, 45–64 years old)

The difficulties in accessing health care contrast with high levels of demand and expectations. Several free-text respondents point out that they would have expected their GP or consultant to proactively reach out to them.

> I would have benefitted from a phone call from my GP, but nothing in the past two years. (Female, 75–79 years old)
>
> My GP practice didn't at any point contact me to give additional support or advice. I felt unsupported and lacked guidance. (Male, 45–64 years old)
>
> I've not had any input from my GP. No one from the practice has asked 'are you ok?' (Female, 45–64 years old)

The free-text responses relating to health care identify a possible tension in the guidance to the highest risk group: the guidance encourages individuals to liaise with their GP of consultant for more personalised advice. This assumes that individuals can easily access their GP or consultant and that there is enough capacity in the healthcare system to enable GPs and consultants to provide this personalised advice. The free-text responses suggest that this may not necessarily be the case.

> I asked to speak to my doctor about my concerns about returning to work, but they refused and said just follow government guidelines. (Female, 45–64 years old)
>
> […] GP, when asked, stated shielding was nothing to do with them so they would not help […] (Male, 45–64 years old)

Access to COVID-19 vaccinations

Challenges around accessing COVID-19 (and flu) vaccinations similarly feature in the free-text responses. The two main issues raised are delays in getting the vaccine – and the impact of these delays on wellbeing – and a widespread lack of information. Comments about lack of information relate to advice about whether and when individuals should get vaccinated, as well as information about the effectiveness of COVID-19 vaccines in the highest risk group. Other issues were mentioned, including the challenge of travelling to mass vaccination centres, getting family members or carers vaccinated, cancellations of appointments or issues with patient records.

> […] It is well over 6 months since my second vaccine, and I have had no word about booster. This makes me very scared. (Female, 65–69 years old)
>
> Research has suggested that 40% of people in the immunosuppressed group may have very low, if any, protection after having the vaccines. This fact has not been properly communicated and it means that some immunosuppressed people will be taking major risks without realising they may not be protected at all by the vaccines […] (Male, 45–64 years old)

Access to social care

Survey respondents who disagreed with the statement that they had received the support they needed since the pause in shielding were asked how difficult it had been to access the social care support they needed. Among those who had required social care support (n = 747),[viii] more than half (52%) of respondents reported that this had been very difficult. A further one in three (32%) reported that this had been quite difficult. Challenges in accessing social care also feature in the free-text responses to the question 'what advice or support has been missing'.

[viii] This analysis (n = 747) excludes respondents who responded 'I am not sure/I have not needed social care support'. When including these respondents in the analysis (n = 2232), the results are as follows: 67% are not sure or have not needed social care support, 17% report that it has been very difficult to access the social care support they need, 11% report that it has been quite difficult, 4% report that it has not been very difficult and 1% that it has not been difficult at all.

No home care support for personal care due to staff shortages. Still waiting for this to be reinstated. (Male, 16–24 years old)

I am housebound and social care was inadequate. I am now full time in a care home at my own expense in spite of wishing to stay at home. (Male, 80+ years old)

My daughter's day care services didn't reopen until November. I couldn't work. I wasn't furloughed. I didn't qualify for ICA [Invalid Care Allowance]. Our care package disappeared. (Female, 25–44 years old)

[…] As a registered carer, with own health issues, asked to shield. No help to cover my caring duties offered. Help if I was employed by saying 'stay at home' and you have a fit for work note to cover this, but didn't help when you are an unpaid carer. (Female, 45–64 years old)

Access to employment and financial support

Access to employment support

Among survey respondents who are economically active (n = 2926), just fewer than two thirds (63%) report an ongoing negative impact on their employment from the initial shielding period (see Figure 1). As reported previously, among survey respondents in employment, one in two report flexibility from their employer. The free-text responses to the question 'what advice or support has been missing' provide some insight in the experience of those who have felt unsupported on employment issues.

There are several examples where employers are described as unsupportive or inflexible. Several free-text respondents report high levels of stress because of being made to go to work despite feeling unsafe. A number indicate that they have had to take sick leave or decided to leave their job. Several respondents working in health and social care or in teaching report feeling unsupported around employment issues.

Suffering bad anxiety going back to work. Didn't get support from my workplace […] (Female, 45–64 years old)

[…] I had to return to an office of young people, who were socialising in pubs, putting me at huge risk and I would get no benefits if I chose to leave my employment through fear. (Female, 45–64 years old)

There has been no additional support for me working in a hospital within acute medicine. I have gone from shielding to being told to 'wear PPE and get on with it' […] (Female, 25–44 years old)

[…] You simply seem to be hoping that teachers and school staff get on with it regardless of their risk […] (Female, 45–64 years old)

Free-text respondents comment that the employment guidance is not sufficiently clear. They contrast the clear messaging to employers at the time of the initial shielding period to more ambiguous messaging at the time of the survey. There is a request for clearer guidance around working in public-facing jobs or jobs that cannot be done from home. However, some respondents also report that they are in a job that could be done from home, but that their employers do not allow them to do so.

[…] Current advice is deliberately unclear in my opinion and open to interpretation by employer. This is additional stress. When seeking advice, seems to be a merry-go-round until employer finds advice that 'fits' them… (Male, 45–64 years old)

[…] Trying to force high-risk employees into an area that is coming into close contact with people has to be looked at. (Female, 45–64 years old)

Scottish Government advice is to work from home if you can – employers should not be able to insist that people in the high-risk group return to office working. (Female, 45–64 years old)

Access to financial support

More than four in 10 (44%) survey respondents report ongoing negative impacts from the initial shielding period on their financial situation (see Figure 1). This increases to eight in 10 (83%) among respondents for whom finding £100 for an unexpected expense would be impossible or a big problem. The free-text responses to the question 'what advice or support has been missing' provide some insight in the experience of those who feel there was insufficient financial support.

> […] It has also been costly getting to appointments as I was advised not to take buses, only use taxis and no financial support was provided for this. (Female, 25–44 years old)

> Financial support as I am on PIP [Personal Independence Payment] and ESA [Employment and Support Allowance] and have had no additional funds for heating or paying taxis to pick up medication. (Female, 45–64 years old)

> I was sent text messages, but as for support? Why have people on Universal Credit received an extra £20 per week and disabled people on ESA have received nothing?? I would really appreciate a response to this. (Female, 45–64 years old)

Access to other support

Free-text responses to the question 'what advice or support has been missing' suggest challenges in accessing a wide range of other support services, including housing support, support from social workers, childcare and support around education. The examples below demonstrate that unmet support needs across these other support services can be highly problematic at times. Overall, only 35[ix]

[ix] This number is not weighted.

individuals younger than 16 years or individuals caring for someone younger than 16 years completed the survey. This makes it difficult to provide a separate or in-depth analysis of the experience of the support offer relating to children in the highest risk group or their education.

I am in a HA [housing association] property needing major adaptations which have been delayed for 2 years. I cannot use my kitchen at all as a wheelchair user. (Female, 45–64 years old)

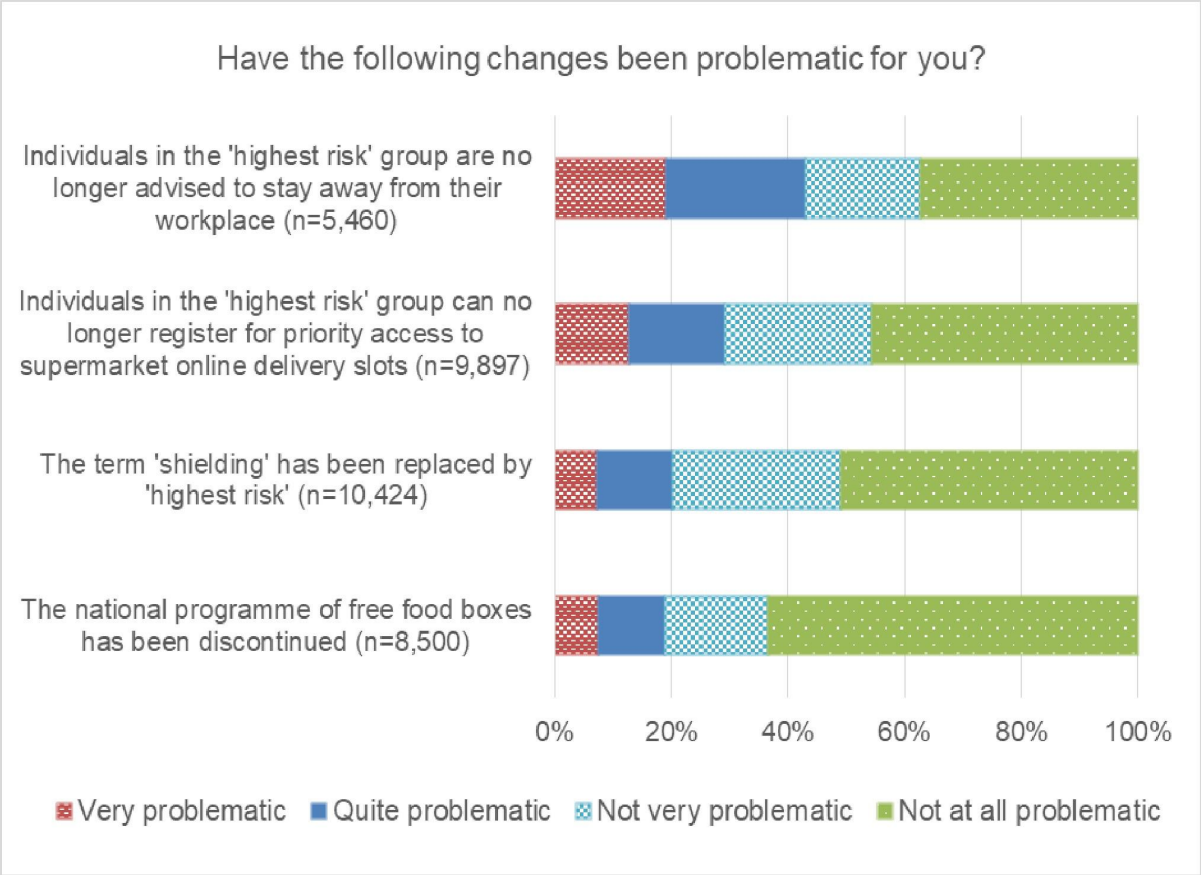
I tried to end my life just a few months ago. Police were called and I was assured social work would be in touch. I've never even heard from them despite my daughter calling them and the police twice. I was just left to cope. (Female, 45–64 years old)

Became overwhelmed in education and am choosing to leave school to avoid the stress of it. (Male, younger than 16)

Changes in the support offer over time

There is evidence to suggest that some changes in the shielding programme have been problematic for some highest risk individuals (see Figure 11). More than four in 10 (43%) respondents consider the fact that individuals in the highest group are no longer advised to stay away from their workplace as very or quite problematic. This percentage is slightly higher (46%) among respondents who are economically active. Three in 10 (29%) respondents see the fact that individuals in the highest risk group no longer can register for priority access to supermarket online delivery slots as very or quite problematic.

Figure 11: Changes in the support offer



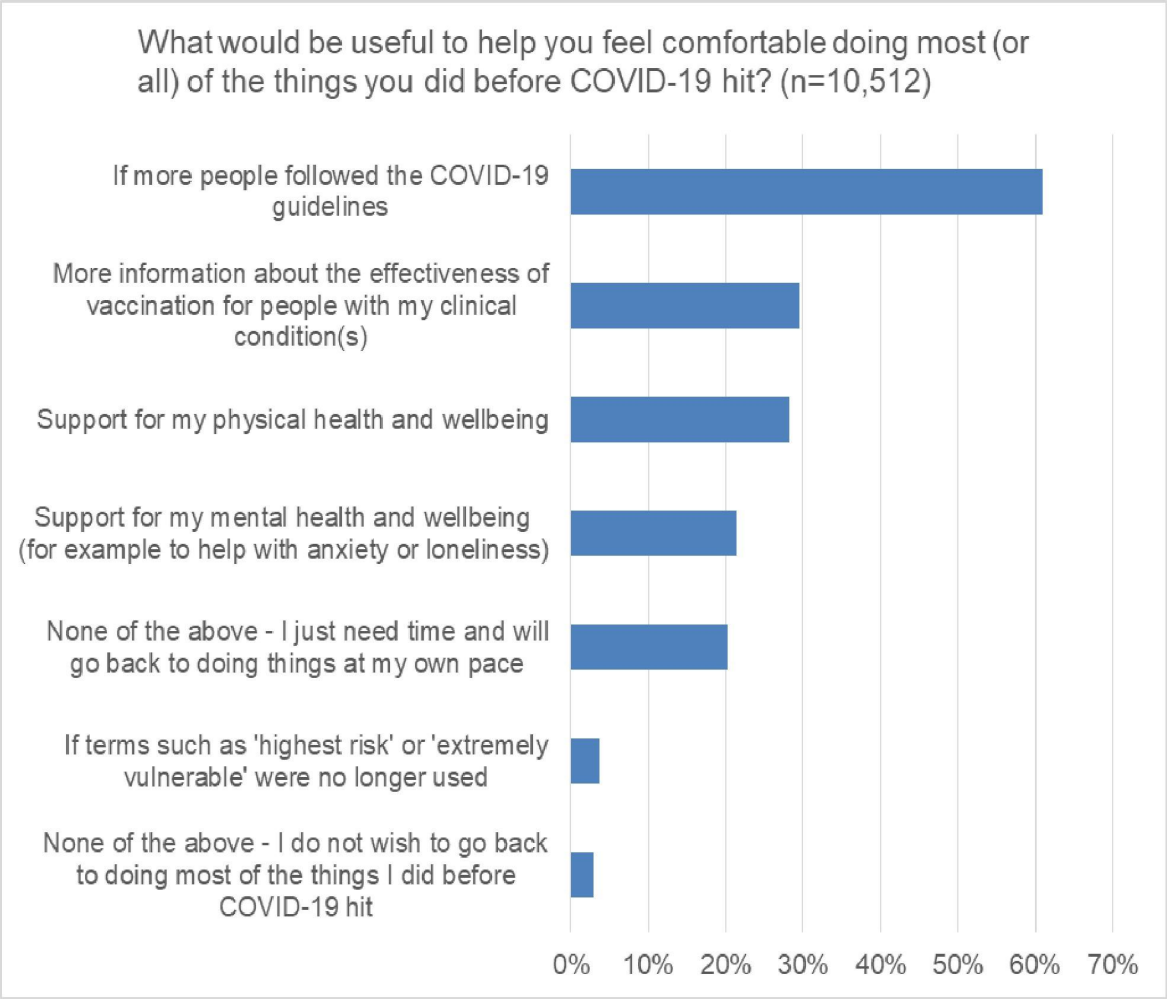
Respondents for whom finding £100 for an unexpected expense would be impossible or a big problem are more likely to report a change as problematic. For example, more than four in 10 (45%) report the discontinuation of the national programme of free food boxes as very or quite problematic. This compares to one in 10 (10%) among respondents for whom finding £100 for an unexpected expense would be a bit of a problem or no problem.

Part five: Future support needs

Support to feel comfortable going back to doing things

Those who are not comfortable doing most (or all) of the things they did before COVID-19 hit, were asked what would be useful to help them feel comfortable doing so (see Figure 12).

Figure 12: Support to go back to doing things



Six in 10 (61%) respondents report that it would be useful if more people followed the COVID-19 guidelines. Three in 10 (30%) report that more information about the effectiveness of vaccination for people with their clinical condition(s) would be useful. Just fewer than three in 10 (28%) ask for support for their physical health and wellbeing. Only two in 10 (21%) think that support for their mental health and wellbeing would be helpful. This is despite seven in 10 (71%) respondents reporting ongoing negative impacts of the initial shielding period on their mental health (see Figure 1). Only 4% of respondents think that support to help them return to work or find a new job would be useful. However, among the small group of respondents who were unemployed at the time of the survey (n = 252), this increases to one in five (20%). Only 1% of respondents think support to help them return to education would be useful, but among the small group of respondents who were in education at the time of the survey (n = 173), this increases to 14%.

Those for whom finding £100 for an unexpected expense would be impossible or a big problem are more likely to ask for support. Almost four in 10 (36%) respondents in this group report that support for their physical health and wellbeing would be useful (compared to 28% for all respondents). Almost four in 10 (38%) report that support for their mental health and wellbeing would be useful (compared to 21% for all respondents).

Respondents who have been advised that they are severely immunosuppressed or severely immunocompromised are more likely to ask for information about the effectiveness of vaccination. Almost four in 10 (37%) respondents in this group report that this information would be useful (compared to 30% for all respondents). In terms of clinical condition, respondents who have received an organ transplant are most likely to ask for information about the effectiveness of vaccination (45% report that this information would be useful), followed by those who have a rare disease (43%) and those who are on immunosuppression therapy (39%).

Respondents could add a free-text comment if they selected ‘other’ as their response option to the question ‘what would help you feel comfortable doing the things you did before COVID-19 hit’. A total of 548 free-text responses were received. These free-text comments echo some of the results already presented in Figure 12, the fact that six in 10 (61%) respondents would find it useful if more people followed the COVID-

19 guidelines. Many free-text respondents comment that continued or stricter restrictions and better compliance with existing restrictions would help them feel more comfortable. Higher rates of vaccination and vaccination being offered to (more) children would similarly be reassuring to some respondents – the latter in particular to free-text respondents who work as teachers. Parents of school-age children would feel reassured with additional measures to reduce the risk of infection in schools. Several respondents want to see a lower prevalence of COVID-19 or wide availability of effective antiviral treatments before they will feel comfortable going back to what they did before COVID-19 hit. Some respondents who report that the current COVID-19 vaccines are less likely to offer them protection would feel reassured once an alternative, effective COVID-19 vaccine was available for individuals in their situation.

Free-text respondents also raise a number of more practical elements that might help them. Many of these more practical requests are similar to the themes in the responses to the question 'what advice and support has been missing'. These themes have already been reported in part four. Practical elements that might help people feel more comfortable going back to doing the things they did before COVID-19 hit include the following:

- Additional public awareness-raising around the continued vulnerability to COVID-19 of some individuals. A small number of respondents ask for a specific mechanism, such as a lanyard or wristband, to identify themselves as being at highest risk, but most ask for increased awareness-raising more generally. This ask for additional public awareness-raising is despite relatively high levels of awareness of the continued vulnerability of the highest risk group among the Scottish population at large.[x] Free-text respondents also

[x] In a YouGov poll (between 2 and 4 November 2021) of Scottish adults, 87% of respondents agreed or tended to agree with the statement 'I am aware that we all still need to be careful when out and about to protect the people who are at the highest risk from coronavirus due to their health'. In this same poll, 79% of respondents agreed or tended to agree with the statement 'I take extra care when

wonder whether organisations might make some (small) adaptations that might enable them to participate in activities more easily, including for example improved ventilation. There is also a suggestion to include clinical vulnerability (to COVID-19) under disability legislation.

- Access to antibody testing to help individuals access the effectiveness of vaccination to them personally. This is raised by several respondents.

- More detailed advice about the risk to them personally in case of infection. Free-text respondents ask for more detailed examples of risk in different situations, including 'a scale of risk with examples'. They ask for an opportunity to talk to someone about their risk – again citing examples when a clinician was unable or unwilling to answer their questions. One respondent explicitly suggests a 'helpline for clarification of concerns', but there are several more general requests for 'somewhere to ask questions about risk'. Free-text respondents stress their interest in information about the effectiveness of vaccination for their clinical condition, with one respondent being 'very, very keen' for this information. Respondents also ask for the different subgroups in the highest risk group to be differentiated more clearly – again to make the advice more relevant to them.

- Better access to vaccines was raised by those who had not (yet) been offered COVID-19 vaccination for themselves or people in their household. There are also examples of individuals struggling to access vaccination centres because of mobility issues or because of lack of dedicated support for those with learning disabilities at vaccination centres.

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out and about to protect people who are at highest risk from coronavirus due to their health (e.g. by keeping a safe distance from other people)'. The YouGov polling sample is demographically and geographically representative of adults 18+ years across Scotland.

- Better access to services and support. This includes better access to health care or social care, access to financial support and additional support around employment issues.

Additional public awareness-raising

Reinforcement to the general public that many people still have to shield and to wear masks and keep distance […] (Female, 70–74 years old)

Public awareness that immunosuppressed are still at risk as the vaccine doesn't work as well […] (Female, 45–64 years old)

Specific times/events for people in the shielding group who you know are going to be more cautious around masks, vaccines, etc. than the general population. Maybe special times for swimming/gym, shopping and social events. (Female, 45–64 years old)

Antibody testing

Antibody testing for immunosuppressed so we know our individual risk. (Female, 45–64 years old)

Regular spike antibody testing so I can assess my own risk. (Female, 45–64 years old)

More detailed, personalised advice about risk

Differentiate the 'severely immunosuppressed' from the 'highest risk' group […] (Female, 45–64 years old)

More understanding of different reasons for compromised immunity. You feel the groups are just bunched together for ease of reference […] (Female, 45–64 years old)

Better access to vaccines

I will feel better when I have had my booster jab. (Female, 75–79 years old)

A vaccine for my 10-year-old daughter. (Female, younger than 16 years, survey completed by carer)

Better access to services

Being able to see a GP or a consultant. My GP surgery aren't seeing patients as they did before. Consultant is by phone only […] (Female, 70–74 years old)

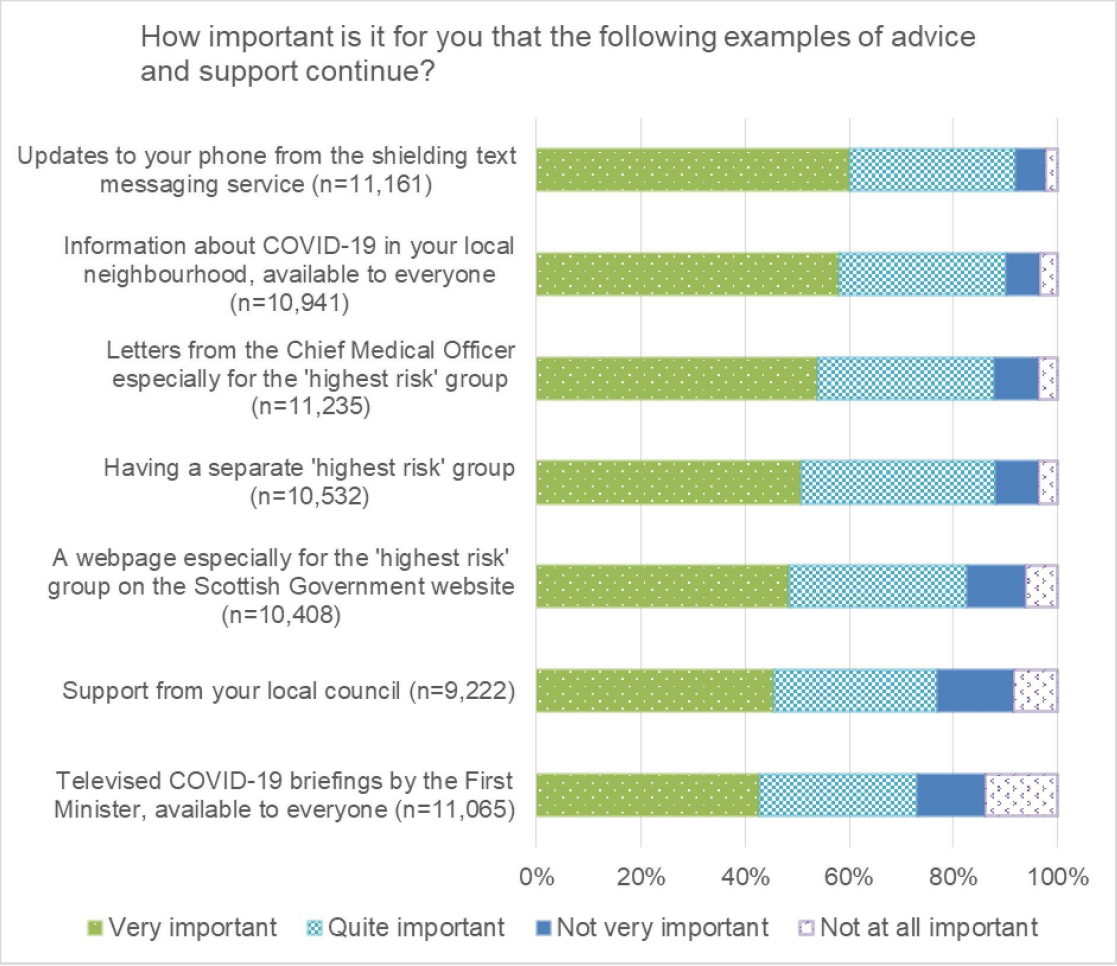
Legislation to ensure employers do not discriminate against people like us and must take additional steps to ensure our safety by ensuring the workplace is safe. (Female, 45–64 years old)

Help to find a safer job that will not put me at risk of COVID, e.g. working from home. (Male, 45–64 years old)

Importance of continuation of the support offer

There is evidence to suggest that continuing the advice and support currently on offer is important to the highest risk group (see Figure 13). Almost nine in 10 (88%) respondents think it is very or quite important that there continues to be a separate highest risk group.

Figure 13: Continuation of advice and support



Conclusions and recommendations

Conclusions

- There is evidence of ongoing negative impacts on the lives of people in the highest risk group, in particular on their confidence when leaving their home, the amount of physical activity they do, their quality of life and their mental health. It is difficult to determine to what extent these ongoing negative impacts result directly from the initial shielding period. For example, free-text responses also refer to the negative impacts of the COVID-19 pandemic, population-wide restrictions and people's higher vulnerability and risk. Although it is not possible to directly compare the October 2021 survey findings to the findings from the earlier June 2020 survey of the highest risk group, there is no evidence to suggest that (self-reported) negative impacts have consistently become less over time.

- There is evidence of ongoing worry and caution among the highest risk group. A degree of worry or caution may not, in and of itself, be problematic. However, a substantial minority of respondents (40%) confirm that ongoing worry will impact on their quality of life going forward. Moreover, among some subgroups, this anticipated impact on quality of life is pronounced. For example, among respondents who are most vulnerable socioeconomically, seven in 10 report that ongoing worry will affect their quality of life. Other subgroups, including those who are severely immunosuppressed or severely immunocompromised, are also more likely to anticipate ongoing quality of life impacts. However, socioeconomic vulnerability has the strongest association with ongoing quality of life impacts.

- Free-text responses suggest that there are two separate, at times interacting, factors that drive respondents' ongoing caution: ongoing risk and an established habit of cautious behaviour. To some respondents, continued caution appears to be an entirely logical reaction to continued risk: they point to the continued risk implied in their clinical profile or the fact that COVID-19 vaccination is less likely to offer them protection. Those who are severely

immunosuppressed or severely immunocompromised are more likely to be more cautious, which appears to confirm this relationship between ongoing caution and ongoing risk. Other respondents argue that they have internalised the early advice to be cautious and that it is difficult to simply stop being cautious.

- There is evidence to suggest that the advice and support offered to the highest risk group has made a difference. For example, 85% of respondents report that the letters from the CMO have influenced some of their actions. It is important to remember that survey respondents may be more likely than the wider highest risk group to have engaged with the advice and support offer in the first place – particularly as the survey was advertised directly to individuals who had signed up to the shielding text messaging service.

- Overall, there is evidence to suggest that individuals in the highest risk group have felt supported since the pause in shielding. Three quarters of survey respondents report that they have felt supported. However, just fewer than one in four respondents have not felt supported and some subgroups are noticeably less likely to have felt supported. Respondents who are socioeconomically more vulnerable, who are younger than 65 years, who have an impairment, who provide unpaid care, who have children in their household or who are severely immunosuppressed or severely immunocompromised are less likely to have felt supported. Socioeconomic vulnerability has the strongest association with not having felt supported. Unmet needs are diverse and include: clear, relevant COVID-19 advice; timely and easy access to COVID-19 vaccination; access to (face-to-face) health care; sufficient social care support; and financial and employment support, including for individuals employed in the healthcare and education sectors.

- Going forward, 88% of survey respondents think that it is very or quite important that there continues to be a separate highest risk group. There is also an ask to differentiate more clearly between the different highest risk subgroups, including the subgroup of those who are severely immunosuppressed or severely immunocompromised to make the advice more targeted and relevant.

Recommendations

- The fact that three quarters of survey respondents have felt supported is encouraging. Going forward, the main question is how to get the support right for the subgroup of highest risk individuals whose support needs remain unmet. There is a strong moral obligation to address not only the support needs that are the result of ongoing clinical risk among some individuals in the highest risk group, but also those support needs that are an unintended negative consequence of earlier guidance.

- Unmet support needs relate to a wide spectrum of services, going beyond support that can be provided directly by the Scottish Government. It may be worth (re)investing in awareness-raising among service providers, reminding them of the ongoing vulnerability, fear and support needs of some individuals in the highest risk group. There may be value in starting a series of dialogues with different groups of service providers, each based on those findings from the survey that are most relevant to them. It may be worth exploring whether Scottish Government messaging that it is safe for the highest risk group to follow the advice for the population at large, may have 'desensitised' service providers to an extent – reversing the earlier sense of a joint mission across Scotland to support the highest risk group.

- Some requests for additional support would require direct Scottish Government intervention. This includes, for example, the requests for, additional public awareness-raising around the continued vulnerability of some individuals in the highest risk group; additional employment protection, including legislative support in some circumstances; access to antibody testing for (some) individuals in the highest risk group and better information about and better access to COVID-19 vaccination.

- There may be value in targeting elements of any enhanced support package on specific subgroups, including, for example, those who are severely immunosuppressed or severely immunocompromised or those for whom, based on clinical guidance, vaccination is less likely to offer protection or is not appropriate. The fact that individuals may not know whether they fall in these

categories would need to be carefully considered. Irrespective of whether any enhanced support package is targeted towards specific subgroups, additional guidance to help individuals gain clarity about their immunosuppression or immunocompromised status may be important. Lack of clarity appears to be correlated with high levels of ongoing caution. It will be important, in making decisions around the targeting of support, to remember that socioeconomic vulnerability has a stronger association with unmet support needs than clinical profile.

- One request for additional support relates to advice on ongoing risks to individuals personally. Existing guidance encourages individuals to liaise with their clinician for personalised advice, but the survey suggests that this route may not be available to all. Personalised advice from a clinician who is aware of the individual's medical history and social circumstances is likely to be the optimal route to obtaining the best possible risk management advice. There are ethical challenges to suggesting alternative, potentially suboptimal approaches. However, given capacity constraints in the healthcare system, policy-makers may still wish to explore alternative routes of providing tailored and condition-specific risk management advice, such as closer collaboration with medical charities and the establishment of risk information helplines – as suggested by survey respondents. The resource implications for the charities involved would need to be considered.

- Irrespective of the scope to improve the individual risk management advice offer, the survey suggests that the guidance for the highest risk group may at times be too generic. There may be scope to provide more targeted advice to the different subgroups within the highest risk group. This may again include the subgroup of individuals for whom vaccination, based on clinical guidance, is less likely to offer protection or those who are severely immunosuppressed or severely immunocompromised. More targeted communications may help counter the impression of ambiguity in the advice offer or the sense of abandonment among some.

- Those for whom vaccination is more likely to offer protection may have different advice needs. It is not impossible that the risk perception of some

individuals in this group is out of proportion to their 'actual' risk. However, repeatedly stressing that it is now safe to do things may not be the best response for this group either. First, there may be important ethical challenges to consider. It would be problematic to encourage groups of people to adjust their risk perception, when the actual risk to any individual member of the group remains unclear: risk continues to be complex and multifaceted. Second, COVID-19 risk perception may be complex and multifaceted in its own right – and may prove resistant to change. More than 18 months after the initial guidance to shield was first shared, nine in 10 survey respondents still report that this initial guidance influences their approach to risk. Any comprehensive discussion of risk perception or cognitive bias falls outside the scope of this report. However, there may be value in engaging more actively with risk communication experts to explore some of these issues in more detail.[xi] As survey respondents explicitly point out, encouraging people to adjust their risk perception may even come across as condescending or insulting. It may be worth considering more innovative approaches to exploring risk perceptions, including use of personal stories, peer-support strategies or building on individuals' pre-pandemic lived experience of managing risks associated with their long-term conditions.

- Finally, survey respondents ask for 're-entry' support – but it remains relatively vague what this re-entry support should consist of. Despite evidence of ongoing negative mental health impacts, relatively few respondents think that mental health support would be useful in helping them go back to the things they did before COVID-19 hit. It is also worth noting in this respect that the 'Clear your head' mental health support leaflet receives a low impact and usefulness score from survey respondents. It may be worthwhile exploring other approaches, such as peer-support mechanisms or dedicated risk management support from community rehabilitation staff who have expertise

[xi] For example, the continuing influence of the March 2020 shielding guidance may reflect the anchoring-and-adjustment cognitive bias, with the initial shielding guidance acting as an anchor against which only small adjustments are possible.

in supporting people to go 'back to normal' following an injury or period of physical or mental ill-health. However, it will be important to test these or any other suggestions directly with people with lived experience of being in the highest risk group (or caring for someone in the highest risk group) and co-produce future guidance and support approaches.

In summary, key recommendations from the survey are as follows:

- Invest in more targeted risk management guidance to the different subgroups within the wider highest risk group.
- Develop additional guidance to enable individuals in the highest risk group to know whether or not they are severely immunosuppressed or severely immunocompromised.
- Explore the feasibility and potential added value of the different additional support measures suggested by survey respondents. Building on this, implement a package of additional support for those with ongoing support needs (including those requiring additional support to go back to 'normal' and those for whom vaccination is likely to offer less protection).
- Directly involve individuals with lived experience of being in the highest risk group (or caring for someone in the highest risk group) in the decision-making process about next steps.
- Carefully and consistently consider socioeconomic vulnerability (alongside clinical vulnerability) in the decision-making process about next steps.

Appendix 1: Employment

Key findings from the survey relating to employment

Three in 10 (30%) respondents are economically active. Among economically active respondents:

- Just fewer than two thirds (63%) report an ongoing negative impact on their employment from the initial shielding period.
- More than four in 10 (42%) report flexibility from their employer as a positive impact of having been included in the highest risk group.
- Almost eight in 10 (77%) report that, since shielding paused, they have received the advice and support they need. This is the same as the percentage across all respondents (78%).
- Six in 10 (60%) have looked at the advice on workplace safety for the highest risk group and it has influenced some of their actions.
- Three in 10 (31%) still try to minimise all physical contact with other households. That is slightly lower than the percentage across all respondents (36%).
- One in 10 (9%) think that support to help them return to work or find a new job would be useful in helping them return to doing most or all things they did before COVID-19 hit.
- Just fewer than half (46%) consider it very or quite problematic that individuals in the 'highest risk' group are no longer advised to stay away from their workplace.
- Just over half (52%) agree that it is safe for people in the highest risk group to go into work if it is not possible to work from home.

Appendix 2: Mental health

Key findings from the survey relating to mental health

- Seven in 10 (71%) respondents report a negative long-term impact on their mental health from the initial shielding period. More than eight in 10 (82%) report an impact on their confidence when leaving their home and more than six in 10 (64%) report an impact on how lonely they feel.

- Female respondents and respondents who are younger than 65 years, who are socioeconomically more vulnerable, who have an impairment, who provide unpaid care or who have children in their household, are more likely to report an ongoing negative impact on their mental health. Respondents who have been advised that they are severely immunosuppressed or severely immunocompromised are also more likely to report ongoing negative mental health impacts.

Among respondents reporting an ongoing negative impact on their mental health:

- Eight in 10 (80%) respondents report that being included in the highest risk group has made them feel vulnerable. That is higher than the percentage among all respondents (72%).

- Seven in 10 agree that being included in the highest risk group has made them feel supported (71%) and that they have received the advice and support they need since the pause in shielding (73%). This is slightly lower than the percentages among all respondents (77% and 78% respectively).

- Three in 10 (29%) think that support for their mental health and wellbeing may be useful to help them return to doing some or most or all the things they were doing before COVID-19 hit. This is higher than the percentage for all respondents (21%).

- Three in 10 (29%) have looked at the ‘Clear your head’ leaflet and have been influenced in some of their actions by this leaflet. This is the same as the percentage for all respondents (28%).

Appendix 3: Carers and care needs

Key findings from the survey relating to carers

Just fewer than one in five (18%) respondents provide unpaid care to a friend, neighbour or family member who would struggle on their own. Among those providing unpaid care:

- Eight in 10 (80%) report an ongoing negative impact on their quality of life from the initial shielding period. This is slightly higher than the percentage for all respondents (76%).
- Two thirds (66%) report an ongoing negative impact from the initial shielding period on the quality of care they receive. This is higher than the percentage for all respondents (56%),
- Just fewer than half (47%) will remain worried for some time about being at highest risk and this will affect their quality of life. This is higher than the percentage for all respondents (40%).
- Just more than four in 10 (42%) are still trying to minimise all physical contact with people from other households. This is higher than the percentage for all respondents (36%).
- Seven in 10 (69%) report that they have received the advice and support they need since shielding was paused. This is lower than the percentage for all respondents (78%).
- More than six in 10 (64%) report that it has been very difficult to access the social care support they need. This percentage refers to a small group of respondents (n = 281). Only those respondents who disagreed with the statement that they had received the support they need since the pause in shielding were asked about difficulties accessing social care. Moreover, not everyone in this group had required social care support. The percentage for

respondents who provide unpaid care (64%) is higher than the percentage for all respondents (52%).