

Exploring the experiences and perspectives of clinically extremely vulnerable people during COVID-19 shielding

Final report

December 2020

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1. INTRODUCTION

1.1 Background

In March 2020, people in the UK who were deemed to be '[clinically extremely vulnerable](#)' were advised to 'shield' as they were at higher risk of becoming seriously ill with COVID-19. Initially, the government-issued advice for those shielding was to avoid leaving their homes and to minimise face-to-face contact with other people. This advice was relaxed in June 2020 to allow those shielding to leave home with other members of their household or with one person from another household. On 31st July 2020, the advice was 'paused', allowing those who had been shielding the same freedoms as the rest of the population. However, a strong emphasis remains on the need for extremely vulnerable people to adhere strictly to population-level guidance around social distancing, hand hygiene, etc.

An estimated 80,000 people in Northern Ireland have been impacted by the advice to shield. In May 2020, the Patient and Client Council (PCC) sought to engage with this group, in partnership with the Chief Medical Officer and the Department of Health.

1.2 Rationale

The Department of Health wished to record the views and experiences of those shielding so that this intelligence could inform decision making and messaging around extending or relaxing the restrictions that were introduced in March 2020.

The main rationale was to ensure that the voices of those impacted by shielding would be central to decisions that would impact them. Understanding their direct experiences of shielding, and getting unique insight into its impacts, were essential to make decisions that would affect their quality of life. We needed to know what mattered to them and what needed to be considered. These data could help to inform what could be done for those shielding in the immediate future and to plan for the winter and a possible second wave.

1.3 Methods

In discussion with Department of Health colleagues, the PCC decided that a survey was the preferable method of engagement and that it should be open to – and promoted to – the general public. It was felt that, with adequate promotion efforts, a large-scale survey could generate a large volume of responses relatively quickly.

Development of the survey questionnaire was led by the PCC, with input from the Department of Health and other stakeholders, representing groups particularly affected by shielding restrictions. The main priorities were to gather insights around:

- How people had been affected by shielding;
- What the most important things were for those shielding;
- What support people had accessed to help them deal with the impact of shielding;
- What actions or changes people would require if they were advised to continue to shield in some way; and
- What information people would need to support them to safely ease shielding restrictions.

Many survey items were open-ended 'free text' questions on the basis that the experiences being explored were unprecedented. Therefore, pre-empting which categories to include in multiple choice questions would risk overlooking important themes. The full set of questions asked in the survey can be found in **Appendix 2**.

The survey was primarily available to complete online. It was considered that this was the best way to access people who were shielding, and that living under shielding restrictions may increase people's ability and willingness to respond to an online survey. However, in order to increase accessibility, people were also given the option to respond to the survey over the telephone, or a 'paper' version could be requested or downloaded, completed and sent back to the PCC via post or email. The postal, email and phone survey responses were inputted into the survey platform by PCC members of staff.

The survey was available to complete online between 2nd June and 15th July. Input of postal responses was completed by early August 2020.

The survey was promoted extensively through the PCC's social media. The survey link was also shared with relevant organisations in the PCC's network – both within the HSC system and in the community and voluntary sector – with a request to share and promote the survey.

1.4 Analysis and reporting

Questionnaire data were downloaded in MS Excel for analysis by PCC Research staff. Descriptive statistics were produced on respondent demographics and categorical responses.

A sample of qualitative responses was reviewed and recurring themes were identified against each free text question. These themes were developed into a coding frame for each free text question in MS Excel, which allowed each response

to be assigned one or more codes or themes. Codes were then counted and analysed to identify common themes within responses and to compare the prevalence of certain views and experiences within different groups or at different points in time.

Updates on respondent profiles, categorical responses and free text themes were provided to the Department of Health and Chief Medical Officer at intervals during the survey period (June-July 2020). A final summary report was sent to the DoH after the survey closed, around the time shielding advice was 'paused' on the 31st of July.

This report outlines the views of the 3,517 people who took part in the survey into shielding during the COVID-19 pandemic in Northern Ireland. Participants included individuals who were shielding as well as carers and people whose loved ones were living in care homes / supported living environments. Full details on the profile of responses and respondents can be found in **Appendix 1**.

2. LIMITATIONS

Although it is difficult to assess without a detailed profile of Northern Ireland's shielding population, responses received appear to under-represent the following groups:

- Males who are shielding and those supporting them;
- People aged 80+ and those supporting them;
- People from non-white ethnic groups and those supporting them;
- People living with disabilities and those supporting them;
- People living in care homes / supported living environments and those supporting them; and
- People without internet access.

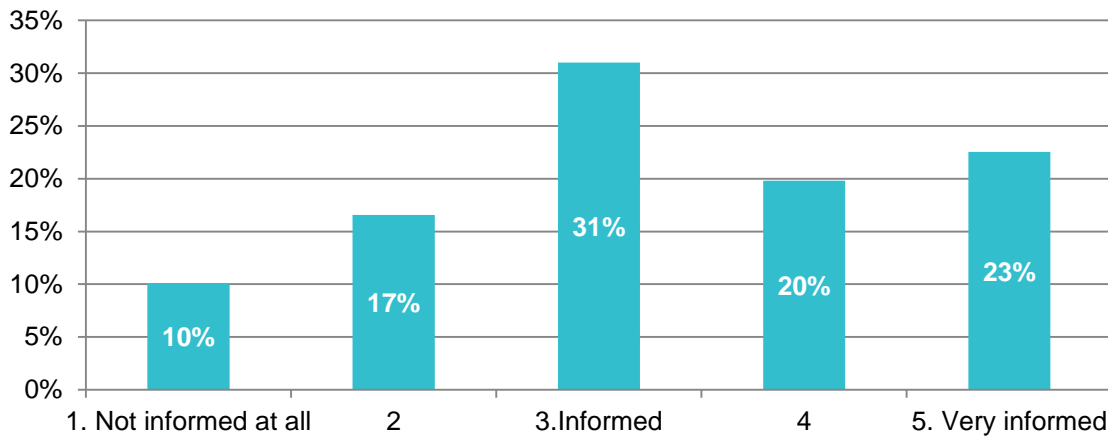
Work was undertaken to increase response rates from these groups – and the PCC has carried out a separate engagement exercise with group living residents' families and people working in group living settings – but the time sensitive nature of the survey limited our ability to draw a fully representative sample of the shielding population in Northern Ireland (e.g. through quota sampling).

3. SUMMARY OF CATEGORICAL RESPONSES

3.1 Feeling informed

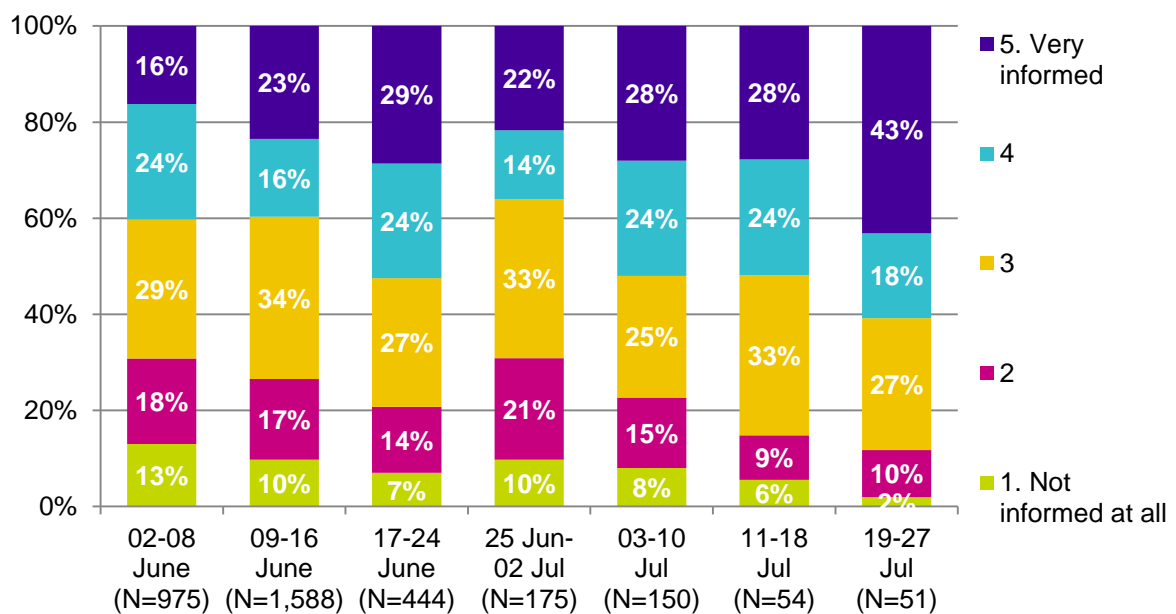
Q8a. Do you feel you have the INFORMATION you need to help you make decisions about shielding? Please indicate on the scale below how informed you feel.

Figure 1: Perceptions of feeling informed 2nd June-31st July (N=3,437)



Overall, around one quarter (27%) of all respondents answered in the negative when asked whether they felt they had the required information to inform their decisions about shielding; about one quarter felt ‘very informed’. There was a marked increase in the proportion of respondents answering in the positive over time, from 40% in early June to 61% in late July (Figure 2).

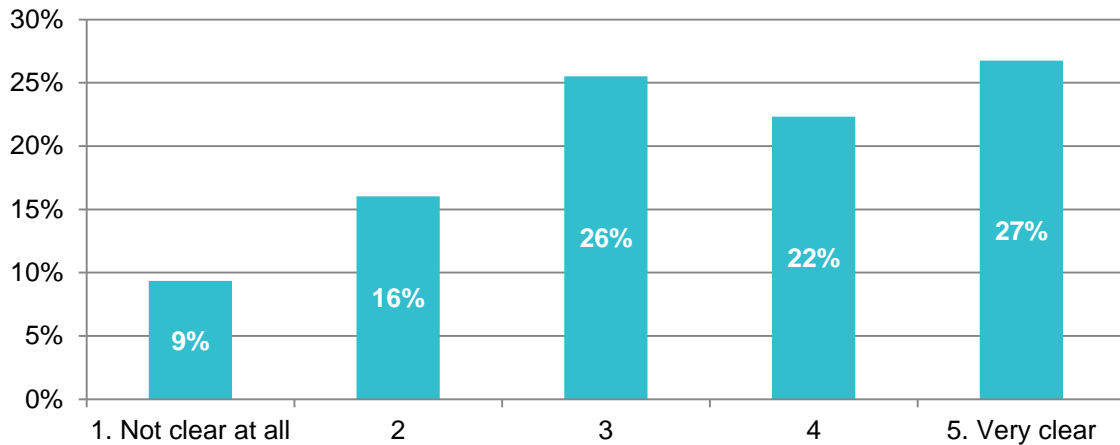
Figure 2: Perceptions of feeling informed over time (N=3,437)



3.2 Clarity of information

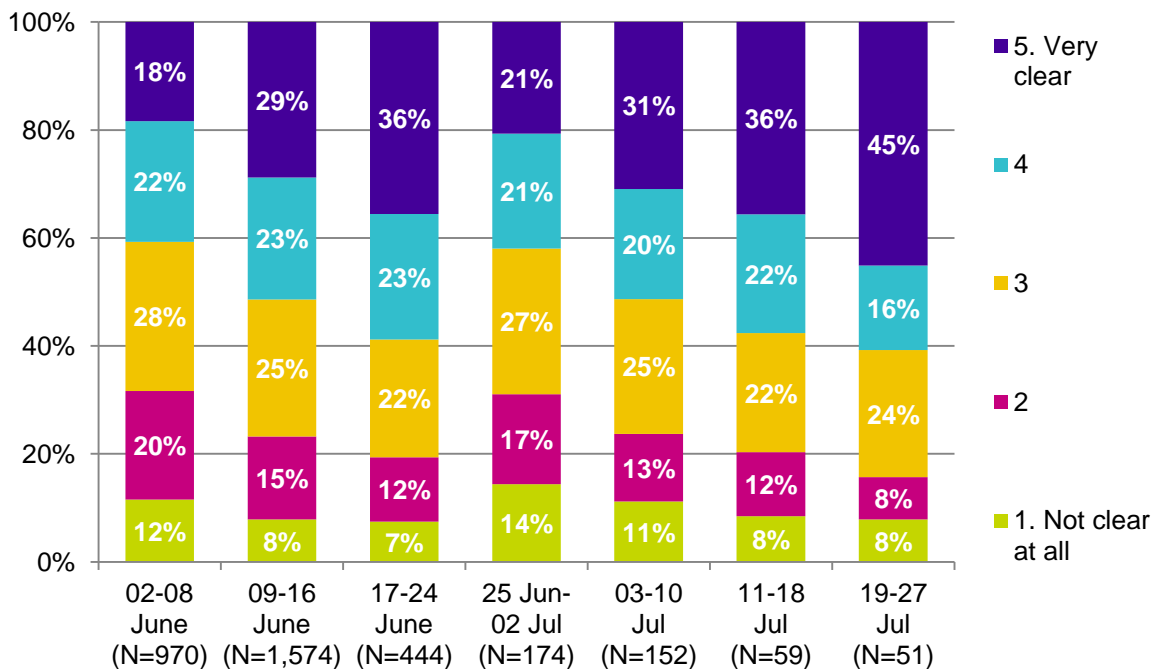
Q9a. How clear has the information and advice you have received about shielding been?

Figure 3: Perceived clarity of information 2nd June - 31st July (N=3,424)



The profile of responses around the clarity of shielding information and advice was similar to those around 'feeling informed', with 25% of respondents selecting options towards the negative end of the scale (Figure 3). The shift in responses over time was also very similar: the perceived clarity of information improved significantly between early June (18% 'very clear') and late July (45% 'very clear') (Figure 4).

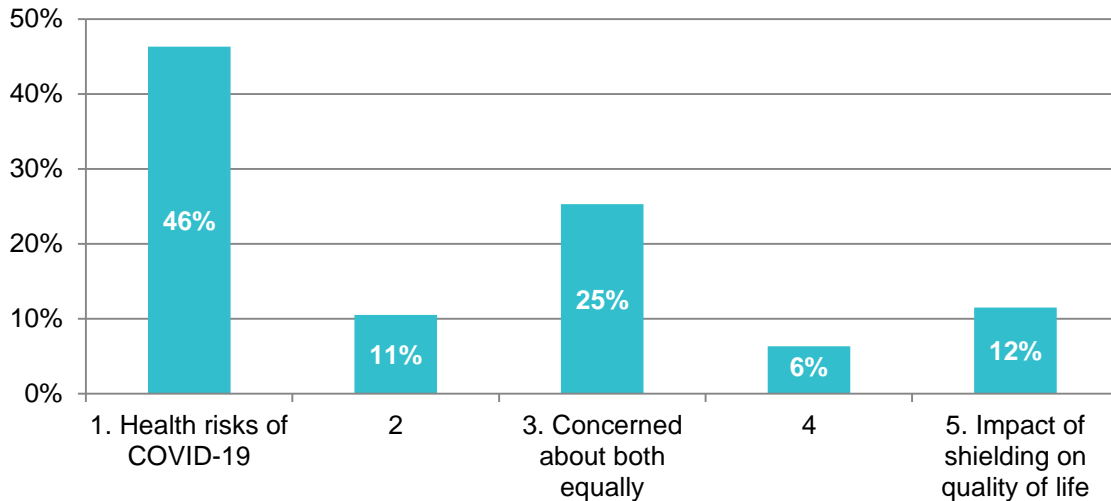
Figure 4: Perceived clarity of information over time (N=3,424)



3.3 Perceived COVID-19 risk vs. impact of shielding

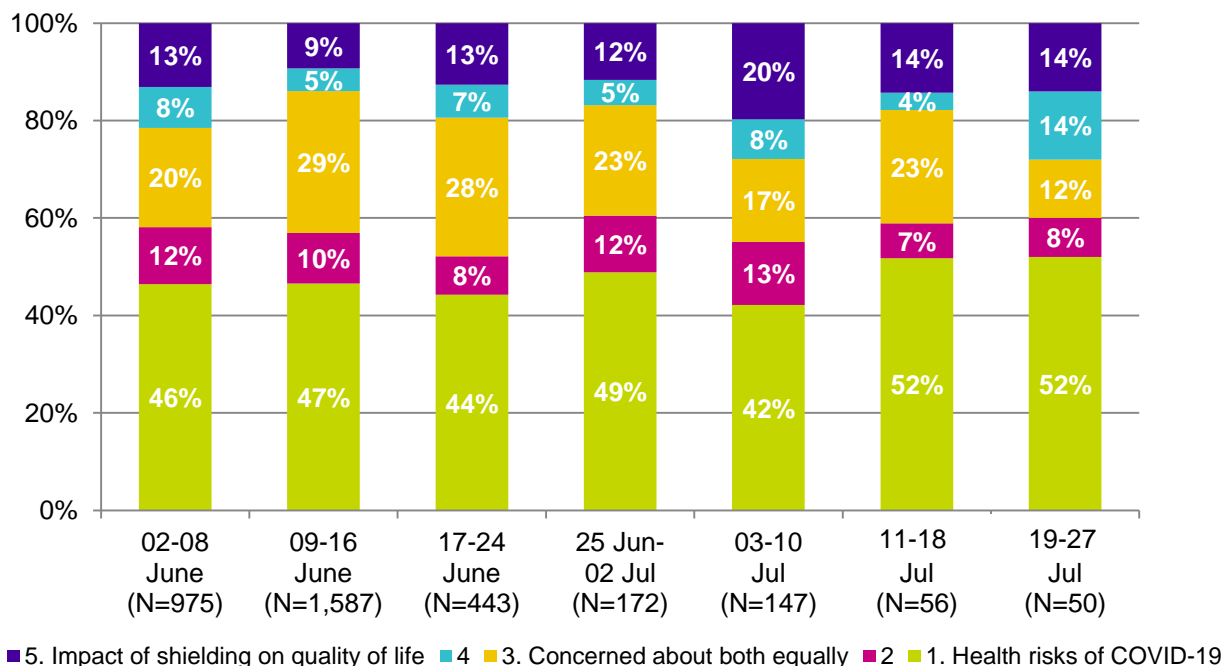
Q15a. What concerns you more: the health risks of COVID-19 or the impact of shielding on your quality of life? Please select a point on the scale below.

Figure 5: Perceived COVID-19 risk vs shielding impact 2nd June-31st July (N=3,430)



Those responding to the survey seemed to prioritise their physical health and the risk posed to them by COVID-19 more highly than any negative impact that shielding may have on their quality of life. Almost half (46%) of respondents stated unequivocally that they were more concerned about the health risks of COVID-19 (Figure 5), and this proportion did not vary over time (Figure 6). Around one in ten (12%) respondents were clear that the impact of shielding was of more concern to them, with no consistent change in this figure over the survey period (Figure 6).

Figure 6: Perceived COVID-19 risk vs shielding impact over time (N=3,430)



■ 5. Impact of shielding on quality of life ■ 4 ■ 3. Concerned about both equally ■ 2 ■ 1. Health risks of COVID-19

4. FREE TEXT RESPONSE THEMES

4.1 Impact of shielding

Q6. What IMPACT has shielding had on you (the person shielding), your quality of life and those close to you?

- Isolation

Feeling isolated remained by far the most commonly mentioned impact of shielding – around 44% of respondents mentioned **isolation or loneliness**. This applied equally to those shielding and those supporting or caring for someone shielding. Isolation was often attributed to the inability to see family or friends or, in a smaller number of cases, to living alone.

‘As time has passed I have found the isolation and loneliness unbearable, it’s like my worst fears are coming true’

Female, 55-64, Shielding

‘I live alone and the loneliness at times has been unbearable. I have one brother and he could not come to see me. He telephoned every day but when I heard his voice I just cried. I would have given anything to see my brother and his wife’

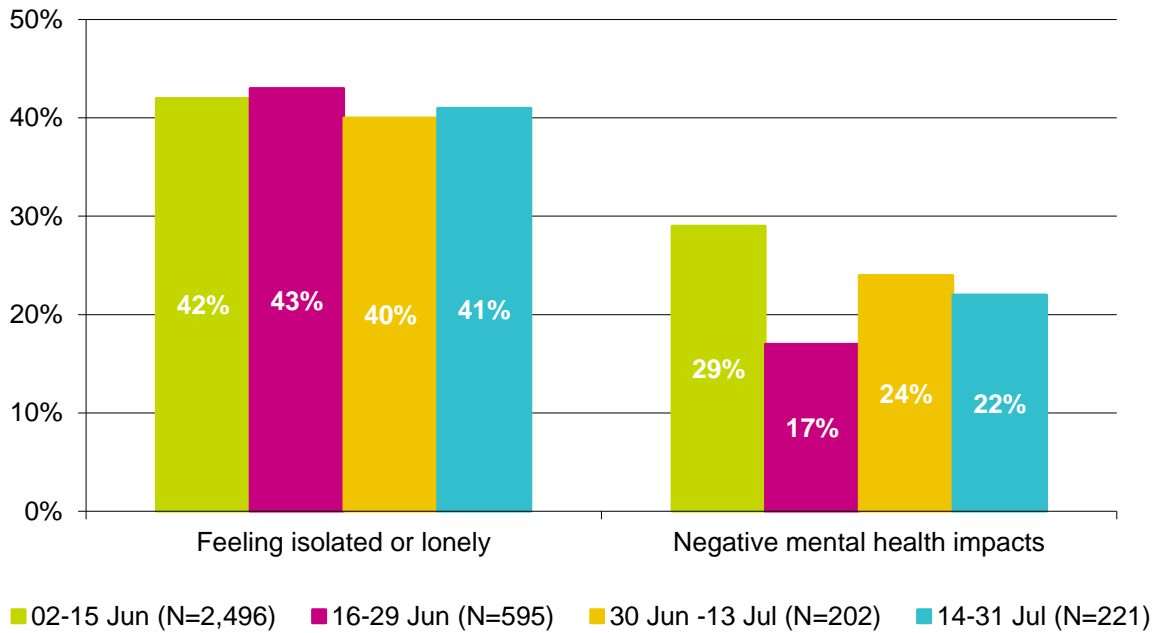
Female, 80+, Shielding

There were no notable differences across the different shielding categories¹ in the proportions mentioning loneliness or isolation as impacts of shielding.

It may have been expected that announcements about the relaxation of shielding advice and the imminent ‘pause’ in shielding would increase social interaction or optimism among those shielding about the prospects of seeing family and friends. However, there was no meaningful change over the survey period in the proportion of respondents mentioning the isolating impact of shielding (Figure 7).

¹ Based on self-reported reason for shielding

Figure 7: Most commonly reported impacts of shielding - over time



- Negative impact on mental health

The negative impact on people’s mental health was the second very common theme. 27% of those responding mentioned their mental health or emotional wellbeing, with many people stating that shielding had either brought on or exacerbated anxiety and/or depression. The severity of the reported issues varied from feeling ‘a bit down’ sometimes to people who were clearly struggling on an ongoing basis.

‘Shielding has been very tough to get through. I have started to go backwards with my depression and anxiety’
Male, 35-44, Shielding

‘It has been really hard not being able to go out after 12 weeks I am now very anxious and afraid to go out... I suffer from mild depression and it has been a struggle at times not to get overwhelmed completely’
Female, 55-64, Shielding

References to the detrimental impact of shielding on mental health tended to be more common in early responses, decreasing during June but becoming more common again during July (Figure 7).

Certain shielding groups – namely those shielding due to rare diseases or those with learning / physical / sensory disabilities – were much more likely to mention the mental health impact of shielding. Other groups (those living with cancer and people

who have undergone organ transplants) were much less likely to refer to mental health impacts.

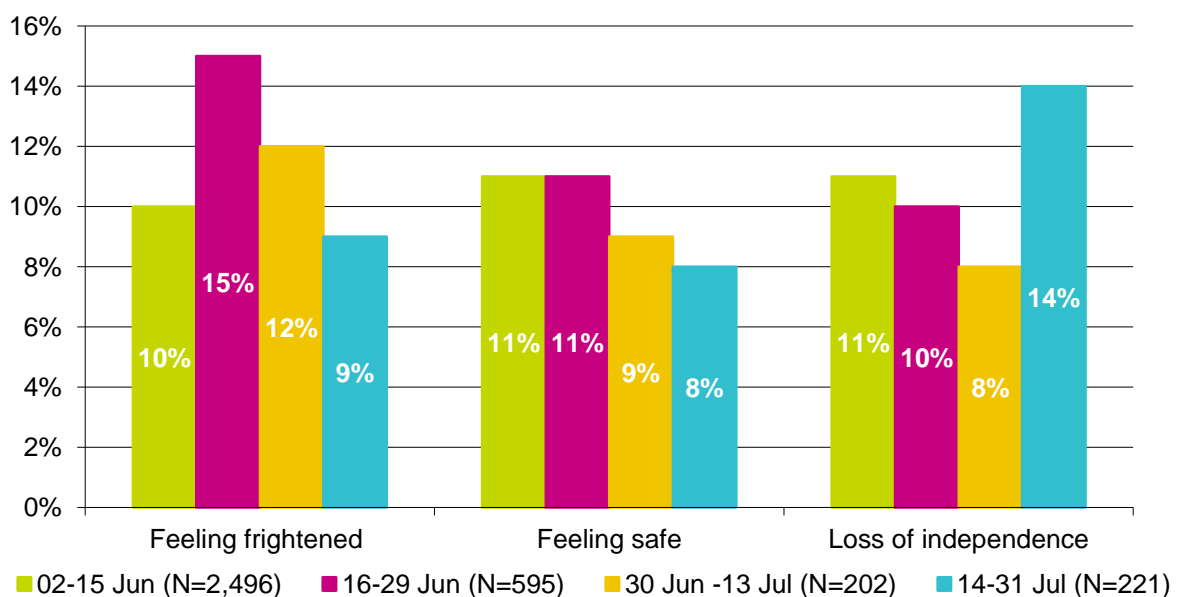
- Feeling frightened

Related to the theme of mental health, a smaller but still significant number of respondents (around one in nine) mentioned feeling **frightened** – of others bringing COVID-19 into their home or of going out, due to perceived poor public adherence to social distancing. Feeling ‘fearful of going out and worried about the future’ and ‘unsure if it will ever feel safe going out again’ was common among these respondents. Interestingly, these reported feelings of fear became increasingly common during the first month of the survey but the proportion was much lower among the later respondents (Figure 8).

‘I felt too frightened to go out so I’m still not leaving my home or garden... After all these weeks of isolation I do feel worried about going out and about again... The virus is everywhere and I don’t want to risk catching it after all these weeks of isolation’

Female, 65-79, Shielding

Figure 8: Other commonly reported impacts of shielding - over time



- Feeling safe

Conversely, the positive impact of shielding was also mentioned by around one in nine respondents. They indicated that shielding allowed them to feel safe and that it was manageable after they had adjusted and established a routine. As compared to individuals shielding for other reasons (e.g. cancer, organ transplant), a smaller

proportion of those shielding due to disabilities reported this positive aspect of shielding (3% compared to 9%). There is also some evidence that feelings of safety had diminished over time (Figure 8).

'It is limiting but at least I feel safe. I was extremely anxious about putting myself at risk, to the point of not sleeping. At least shielding has given me and my family peace of mind'

Male, 45-54, Shielding

- Loss of independence

A large group of respondents (11%) felt that shielding had caused them to lose their independence and to become more reliant on others than they wanted to be, though again far fewer than those who reported isolation or mental health challenges. These responses were often accompanied by reported feelings of **frustration**.

'It has been variable with good days and bad days but the main impact has been the loss of independence and not being able to go out and get things myself. Having to totally rely on others is very difficult'

Male, 45-54, Shielding

People living with disabilities appeared much *less* likely to report this as an impact of shielding, while those shielding due to organ transplants were *more* likely to mention loss of independence. There was no clear variation in the prominence of this theme over time (Figure 8).

- Impact on work or education

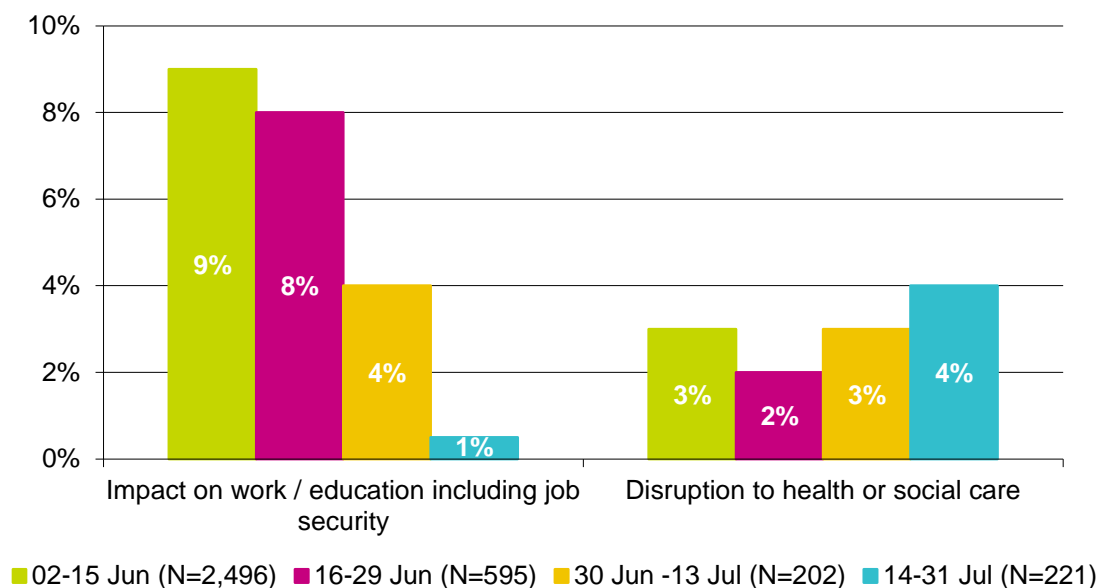
Around one in ten respondents saw the inability to attend work or education – and the associated impact on their financial circumstances and job security – as one of the main impacts of shielding. There is evidence to suggest that this impact on work or education was more common and much more severe where respondents and/or their family members were unable to work from home. This theme became much *less* common in later responses after peaking in mid-June (Figure 9). People who were shielding due to being on immunosuppression therapies appeared much *more* likely to perceive this as a key impact of shielding.

'As I had just started a new job as key worker, and am unable to work, and I am only entitled to statutory sick pay...this [has] caused a severe impact on my mental and financial state'

Female, 45-54, Shielding

People living with disabilities appeared much *less* likely to report this as an impact.

Figure 9: Reported practical impacts of shielding - over time



- Disruption to medical care

A smaller proportion (around 4%) of respondents mentioned disruption to their routine health or social care – including domiciliary care – as a major impact of shielding. This theme was more common in responses from people living with rare diseases and people living with cancer, and *much* more common in responses from people living with disabilities (10% compared to 4%). There was no meaningful variation over time in how common this theme was (Figure 9).

4.2 Additional support accessed

Q7. Have you had any additional SUPPORT to help you cope with the impact of shielding?

40% of respondents stated that they had accessed ‘additional support’ to help them cope with the impact of shielding.

Q7a. Please tell us about the additional support you have had

Around 60% of all support mentioned involved deliveries of food, medicines and other essential supplies. These were accessed from a variety of sources but primarily family and friends or through priority supermarket slots. However, the proportion of respondents who reported that they had availed of priority supermarket delivery slots seemed relatively low (around one in six).

Smaller numbers reported receiving government 'food boxes' (7%), getting medical supplies delivered by pharmacies (3%) or getting deliveries from food banks (2%).

Others were being supported via regular check-ins from churches, care workers, nurses and community and voluntary organisations, including the use of befriending services. The proportion of all respondents availing of this type of support was relatively small (8%) but those who did seemed to benefit from it and were appreciative.

Various other sources of support were mentioned, including help from HSC staff and counselling, but the numbers referencing these were very small.

While the proportions stating that they had accessed additional support did not change markedly over time, those proportions who reported accessing government food boxes and befriending services decreased over the survey period. This is perhaps unsurprising given that the government food box programme ceased at the end of June 2020.

4.3 Additional support preferences

Q7b. What support would you have liked, if any?

Those who said they had *not* had any additional support to cope with shielding (60% of all respondents) were asked what support they would have liked. Around one third of those who had not accessed any support said that they did not need any. Among the remainder, the most common requests were for:

- Easier access to food deliveries or guaranteed priority supermarket slots

Of those who had not accessed additional support but who expressed a need for it, a significant proportion (28%) described having difficulties in getting supermarket delivery slots. These included very long delays in the registration process and struggling to get slots once registered) or in accessing food deliveries more generally. Requests for increased or improved support with food deliveries remained common over time.

'Very late into lockdown my daughter was able to book priority slots for our grocery delivery - this should've been in place much sooner as I have multiple complex health conditions'

Male, 80+, Shielding

- More and/or better information and advice

Around one quarter of those respondents who had not accessed additional support but who expressed a need for it stated that they wanted more information or guidance on 'how to shield'; on what support was available for those shielding and how to access it; and on when and how the government was planning to change shielding arrangements. This was often alongside feelings of having been '*forgotten*', '*ignored*' or '*abandoned*' after receiving the original shielding correspondence in March 2020.

The proportion of respondents asking for better information and advice decreased over time, with a notable drop between early and mid-June.

- More efforts from Health and Social Care to 'check in' with people shielding

There were suggestions that phone calls from GPs or from hospital staff to check how their shielding patients were coping would have helped. This was alongside feedback that people found it more difficult to get in contact with their GP at the time of responding. This theme became less common after being mentioned by almost one third of respondents in early June. Nonetheless, it remained a notable area of unmet need in later responses, being mentioned by around one in five respondents who had not accessed additional support but who expressed a need for it.

'I would have preferred that my GP practice had been more proactive with some kind of outreach programme for those in my position. I have had one call from a district nurse in April just to make contact. Since that there has been nothing further'

Male, 55-64, Shielding

- Psychological support or counselling

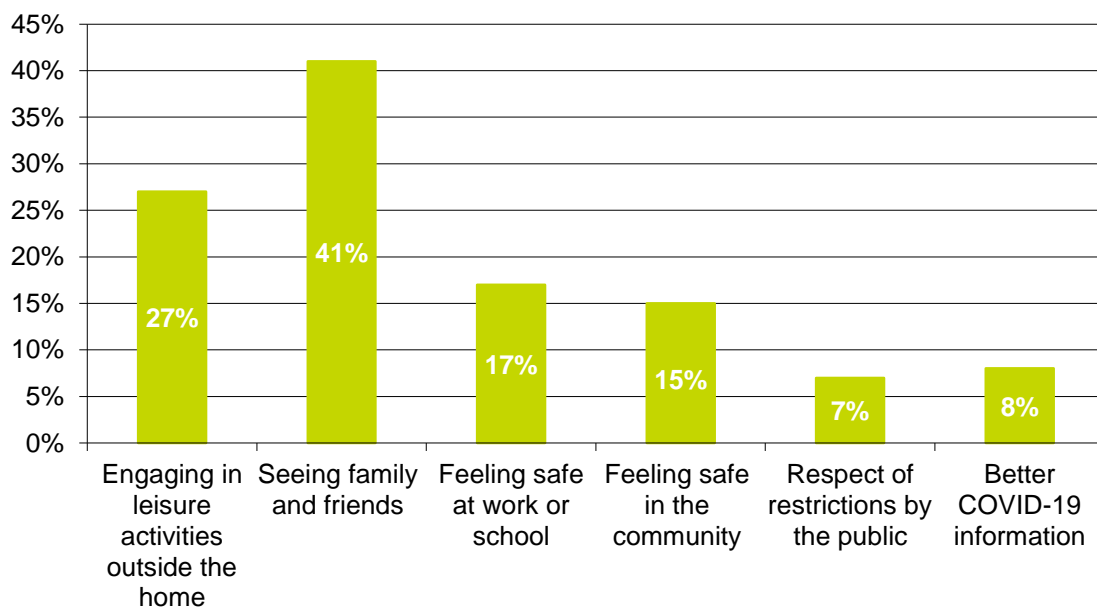
Around one in 20 respondents (who had not accessed additional support but who expressed a need for it) expressed a desire for emotional or psychological support. This was often about having 'someone to talk to' about the emotional impact of shielding outside their circle of family, friends or colleagues. The proportion of respondents requesting this type of support remained consistent throughout the survey period.

4.4 Priorities as shielding restrictions ease

Q16. What is most important for you as shielding restrictions ease? Please complete the following sentence: 'What would matter most to me, would be the ability to...'

The most important thing for people as shielding restrictions ease was seeing family and friends and having the opportunity for physical contact with others. Going out to engage in leisure activities, such as shopping or exercising, was also commonly mentioned (Figure 10). Almost 60% of those responding mentioned one or more of these as a priority.

Figure 10: Priorities as shielding restrictions eased (N=3,514)



However, in a large majority of cases, these hopes were caveated with a need to 'feel safe' before deciding to change shielding behaviours. The most common measures mentioned to this end were:

- Further reductions in infection rates;
- Steps to allow people to feel safe about returning to work or education. Around one quarter of those responding referred to the need for clarity around their rights as employees (and employers) as shielding restrictions eased. They specifically sought assurances that they – or those living or shielding with them – would not be pressured or forced to return to their workplaces before it was safe to do so. Some expressed fear that, if this happened, '*all my good work in shielding so far could be undone due to no fault of my own*'.
- Availability of clear, reliable information on the spread of COVID-19, ideally at a level where people can understand the risk in their own area. People felt that

this would give them more faith in government decisions and advice, and also that it would empower them to make their own decisions.

- Improved adherence from the public around lockdown and social distancing. There was a common perception that those *not* shielding were not respecting the restrictions and that society was opening up too much, too quickly. For many respondents, this created high levels of anxiety about emerging from shielding and going out among the public.
- Not rushing to ease restrictions, prioritising the development of a COVID-19 vaccine and promoting or providing personal protective equipment (PPE) were also important for some, albeit for much smaller numbers of respondents.

Smaller, but still substantial, numbers felt that they would benefit from:

- Access to psychological / emotional support. Some respondents felt that their mental health had been so severely impacted by shielding that they would need support to overcome the '*anxiety and fearfulness*' that had developed since beginning to shield. The proportion of respondents mentioning this was again relatively small (around one in 20) but the severity of the issues described suggested a significant level of need.
- Getting back to receiving necessary or routine (i.e. non COVID-19 related) healthcare was a priority. The types of services mentioned ranged from physiotherapy to blood tests to cancer screening.

'[What would matter most to me, would be the ability to attend] routine GP / dentist / eye appointments, going back to normal services. Being able to see your own GP face to face again. People being able to get cancer screening and treatment like before'

Female 35-44, Shielding

4.5 Suggested changes if shielding continues

Respondents were asked what changes would make their lives 'easier or more enjoyable while still allowing you to feel safe' if they were required to continue shielding.

4.5.1 Public services and the government

Q19. If you (the person shielding) are advised to continue shielding, what changes to your day-to-day life would make it easier or more enjoyable while still allowing you to

feel safe? What things could public services or the government (e.g. Dept of Health, councils) do?

When people were asked what public services and the government could do differently to make their lives easier and more enjoyable if they were required to continue shielding, one in nine respondents (11%) stated that they were happy with the response to date, with many people specifically very positive about the approach taken by health and social care bodies/professionals.

It is notable that approval for the approach/management to date was less common among those living with rare diseases and people living with disabilities (3% and 4% respectively). Relative to the wider shielding population, these two groups were also more likely to request improvements across a range of themes, most notably:

- More 'checking in' from HSC professionals;
- Increasing or improving financial support;
- Designating space / time for those shielding to go outside, visit shops, leisure centres, GPs, etc. without the perceived risk of coming into contact with the general public; and
- Greater effort to educate the public about the shielding community and the risks they face.

The remaining 89% of respondents touched on a range of themes in the changes or actions they suggested, but the provision of more and better information was the most frequently mentioned concept (by about one third of all respondents to this question). These suggestions cut across both:

- Shielding-specific information, with many people (around one quarter of respondents) again mentioning a lack of information to date, unclear guidance, poor communication of the rationale/scientific basis for the guidance, and difficulties in finding out when and how the guidance is likely to be updated. Addressing this was a clear priority for many respondents and there was a feeling that the increased certainty from having regular, clear, consistent updates would help address many of the other issues and challenges people were experiencing.
- General COVID-19 information, with people wanting clear, regular and *localised* updates on the current COVID-19 situation (infection rates, deaths, R number, etc.) so that they could feel equipped to make informed decisions about emerging from shielding.

'[They could] keep us in the loop and updated. Lack of information causes stress. Even though it is a difficult time for everyone, there is the additional stress level for shielded patients'

Female, 55-64, Shielding

There was some evidence that communication and information provision had become less of an issue over time (Figure 11), in keeping with improved perceptions of feeling informed and receiving clear information and advice (Figures 2 and 4). However, this was clearly still a major area for improvement from the perspective of people shielding.

Other suggestions relating to the remit of Health and Social Care bodies/professionals included:

- More efforts from Health and Social Care to 'check in' with people – see Section 4.3 above. Overall, 7% of respondents mentioned this and this proportion has remained steady over time (Figure 11).
- Safe return to accessing necessary or routine healthcare – see Section 4.4 above. Around one in fourteen people made this suggestion, with the proportion seeming to increase over time (Figure 11). Specific ideas included making access to GPs, dentists and Emergency Departments easier and safer, opening day centres, increasing domiciliary care provision and taking steps to start treating people on waiting lists. People living with rare diseases more commonly raised this issue (15%); those living with cancer were also more likely to mention it (12%).

Figure 11: Changes to make life easier when shielding (HSC) - over time

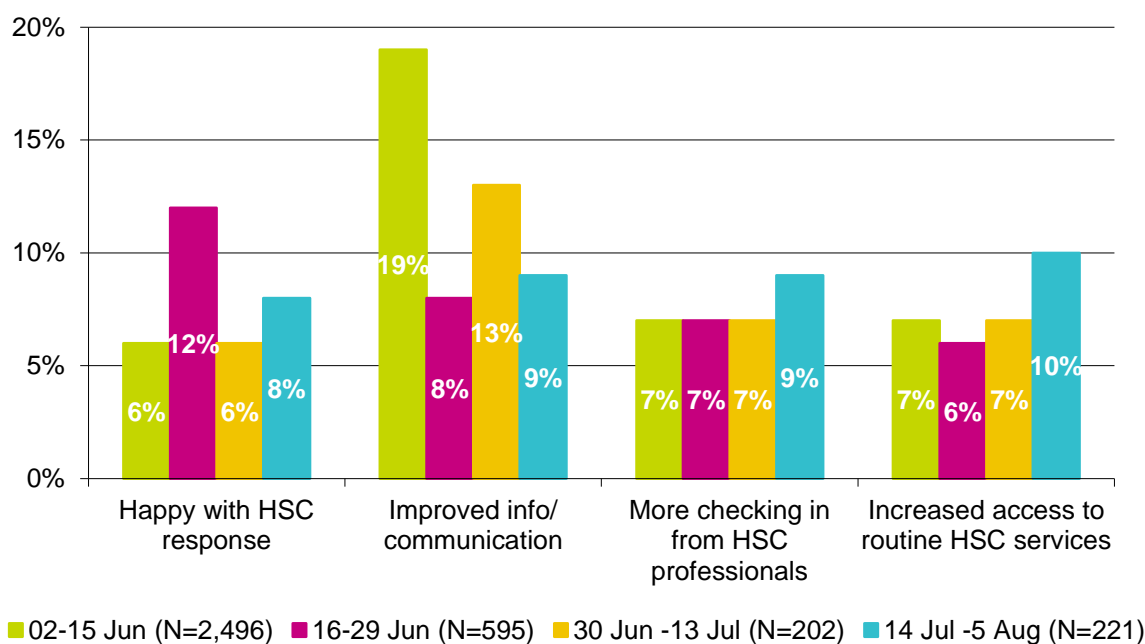
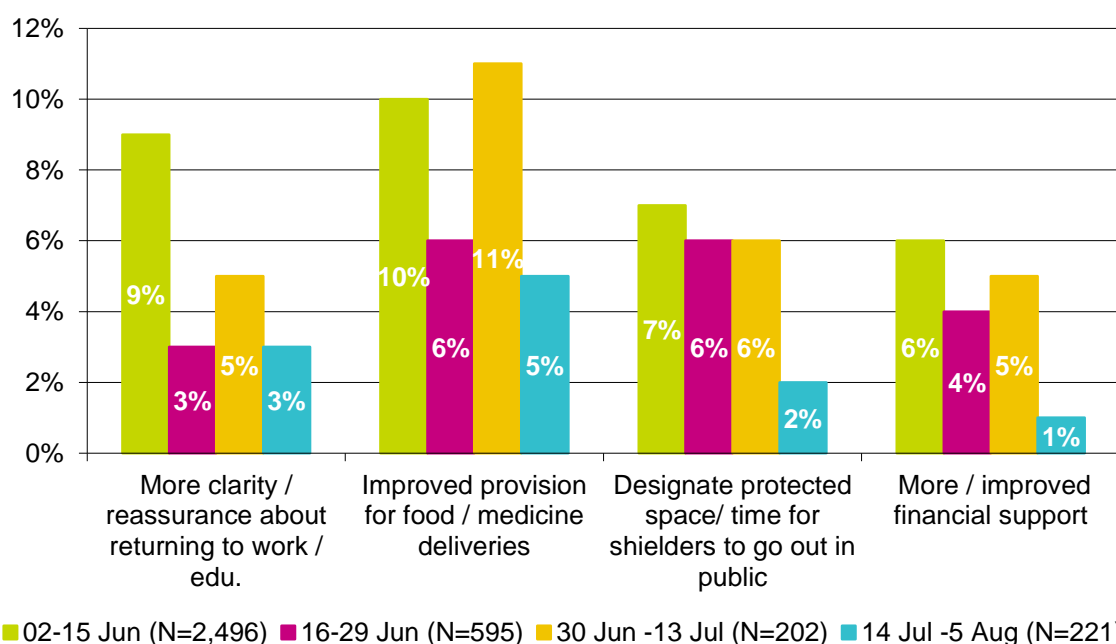


Figure 12: Changes to make life easier when shielding (non-HSC) - over time



Outside of respondents' health or social care, other proposed changes included:

- Increased clarity and assurances about returning to work and education. As they emerged from shielding, a substantial group of respondents (10%) appeared uncertain and anxious about their rights and status, specifically around whether they (or those with whom they lived) could be 'forced' to return to the workplace, what measures would be put in place to ensure their safety

when commuting and working, and what the arrangements would be for returning to school for children living in shielding households. This theme however became less common over the survey period (Figure 12).

- Improved provision for getting essential supplies delivered, with many people (9%) reporting issues with priority supermarket delivery slots, and many others apparently unaware that these were available to them. A smaller number mentioned the importance of government food boxes, and voiced concerns about this support ceasing at the end of June.
- Designated times for people shielding to go to public places, use shops, attend the GP, etc. without other members of the public. This suggestion was made by around 7% of all respondents; again, there is evidence that this proposal became less common toward the end of the survey period (Figure 12).
- Continued or improved financial support (6%), including specific requests for those shielding or those living in shielding households to be automatically eligible for furlough – or for alternative financial support – as more areas of the economy started to open up and more people were asked or required to return to work. Smaller numbers felt that they should be given more flexibility in using Self Directed Support payments (e.g. to pay informal carers or to purchase extra items to make shielding more manageable). Requests for improved financial support more commonly came from people living with rare diseases and/or disabilities compared to other respondent categories (12% and 17% respectively), and had in general become less common over time (Figure 12).

As discussed, around one in ten respondents suggested each of the above changes. Less common proposals (raised by around one in 20 respondents) included:

- Greater individualisation as shielding restrictions were eased, so that the most vulnerable people were kept as safe as possible without imposing unnecessary restrictions on those at lower risk. This reflected the perception from some respondents – particularly younger adults, children or those caring for children – that they had been overlooked and that everyone shielding was assumed to be older.
- Efforts to deter the public from breaching restrictions through stricter enforcement of lockdown, including harsher penalties. Another suggestion was for a specific campaign to raise awareness of shielding among the public and to educate people about the risks to which people shielding were exposed if the public did not adhere to restrictions. People living with cancer, rare diseases and/or disabilities were more likely to prioritise continued public restrictions and enforcement. This theme peaked in early June but was a consistent concern, with around 6% of respondents mentioning it during the last month of the survey.

The numbers of respondents mentioning other public health measures to make their lives easier during shielding (e.g. contact tracing, expediting a vaccine, promoting / providing PPE) were relatively very small. Around 8% of respondents mentioned one or more of these interventions. Proportions had remained steady over time.

4.5.2 Family and friends

Q17. If you (the person shielding) are advised to continue shielding, what changes to your day-to-day life would make it easier or more enjoyable while still allowing you to feel safe? What things could your family do (in making choices)?

In terms of things that their family could start doing or do more of, the most common response (given by around ¼ of those participating) was that **family members were already doing enough** – or doing too much. The sentiment that the families of those shielding were ‘making a lot of sacrifices on my behalf’ was common.

Also of note was that one in 20 respondents **could not avail of family support** due to having no family, having no family nearby or having family members who were frontline workers or who were already over-burdened.

Among those who provided substantive responses, proposed changes relating to family behaviours included:

- **Visiting more frequently** (while taking necessary precautions) or **taking trips or meeting up** in open, public places (while taking necessary precautions). Around ¼ of respondents made one or both of these suggestions, and they were mentioned more frequently in later responses. This suggests that, as more time elapsed since the COVID-19 peak, those shielding became more open to having visitors and going out in public;
- **Adhering to COVID-19 restrictions** around social distancing and hygiene (7%);
- **Staying in more regular contact** remotely via video or phone calls, or just generally checking in with them more (4%).
- **Providing more practical help** with delivering essential supplies, housework or gardening (4%); and
- **Better understanding and acceptance of shielding**, and particularly of how it affects the person shielding (3%).

Many of these suggestions became less common in the later response data.

4.5.3 Local community or neighbourhood

Q18. If you (the person shielding) are advised to continue shielding, what changes to your day-to-day life would make it easier or more enjoyable while still allowing you to feel safe? What things could your local community or neighbourhood do (in providing support)?

Suggestions around what the local community or neighbourhood could do differently echoed responses on family: in particular, 47% of those responding to this question stated that they did not need anything – or did not need anything more – from their local community.

Among those who did make suggestions for how their local community or neighbourhood could make their life easier, proposed changes included:

- More practical support with collecting and delivering essential supplies, etc. This was suggested by around one in six respondents who indicated that their community could do more.
- ‘Checking in’ more regularly with people shielding and their families, giving valuable opportunities for social interaction (27%).
- People respecting the lockdown restrictions and having consideration for those shielding (21%), reflecting the above finding that many of those shielding feel threatened and worried when they see increasing numbers of people congregating in public. Suggestions included good hygiene, routine use of PPE and respecting the guidance around social distancing in public.

Almost all of the themes relating to help from the community had become less common in the more recent response data; this may indicate a reduced reliance on community support among those shielding.

Reviewing the response data by reason(s) for shielding showed that people shielding due to learning / physical / sensory disabilities were much more likely to request additional community support across almost all themes. These requests tended to focus on support with getting deliveries and having people to ‘check in’ on or ‘look out’ for them. This group was also much *less* likely to say that they did not want or need any support from their community.

5. SUMMARY OF PALLIATIVE CARE RESPONSES

The analysis presented here is based on the responses from the 209 survey respondents who indicated in the survey that they were receiving palliative care support based on the response to the survey question below:

Q10. Do you (the person shielding) receive palliative care support as part of the management of your health condition(s)? This could be from a district nurse, palliative care consultant, social worker or others. Palliative care is the care of patients with advanced progressive illness including pain management and other symptoms as well as psychological, social and spiritual support

5.1 Sample characteristics

Table 1: Characteristics of respondents reporting use of palliative care

Characteristic	Percentage (N=209)
<i>Respondent category*</i>	
Person shielding	65%
Person supporting someone who is shielding	35%
Person whose relative / loved one is shielding in residential care	4%
<i>Gender</i>	
Female	63%
Male	34%
Missing	2%
<i>Age (years)</i>	
0-34	10%
35-54	24%
55-79	51%
80+	16%
<i>Ethnic group</i>	
White	98%
Other	2%
<i>Reason(s) for shielding*</i>	
Severe respiratory condition/s	34%
Other	33%
Cancer	26%
On immunosuppression therapies which significantly increase risk of infection	18%
Learning / physical / sensory disability	14%
Rare diseases that significantly increase the risk of infections	7%
Living in a care home / supported living environment	3%
Prefer not to say	2%
Organ transplant	1%
Pregnant with significant heart disease	1%

*More than one selection allowed per response

Survey participants who answered 'Yes' to the above question were predominantly white (98%), tended to be older (67% were 55 years of age or older), and approximately 1 in 3 were male. The most common reasons for shielding were severe respiratory conditions (34%), cancer (26%) and receiving immunosuppression therapy (18%). The majority of respondents were themselves shielding (65%) (Table1). Around 10% of responses were received via post, with the remainder submitted online.

5.2 Advance Care Planning

Respondents who indicated that they were using palliative care support were asked a series of follow-on questions:

Q11. Have you (the person shielding) discussed your future wishes/preferences for care (known as Advance Care Planning) with your GP or another health or social care professional?

Q12. If 'yes', did you have this discussion before you began shielding?

Q13. If 'no', would you like the opportunity to discuss your future wishes/preferences for care?

Q14. What would be the best, most appropriate way to have this discussion in your circumstances?

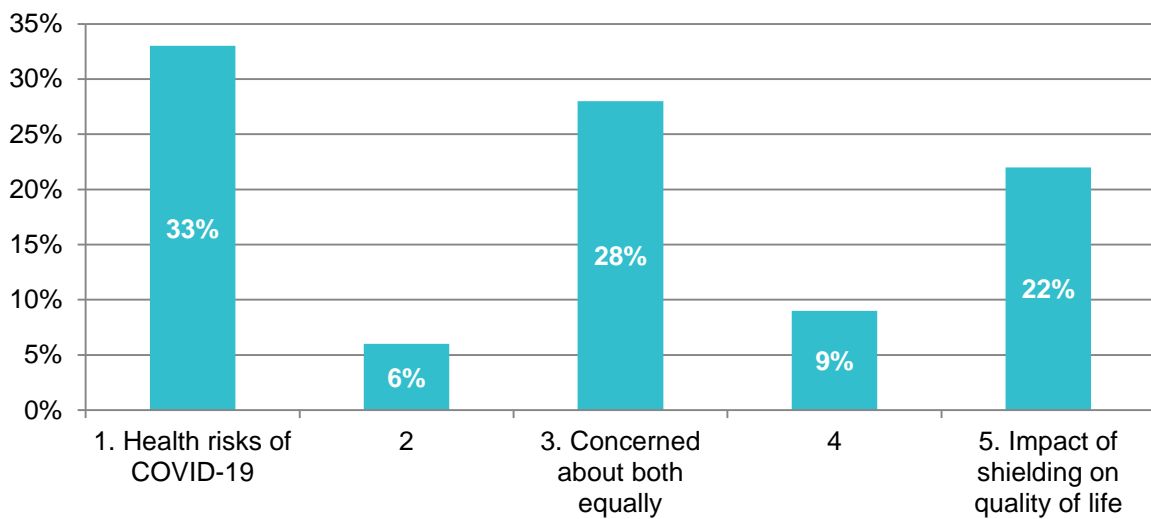
It is noteworthy that, despite their serious health conditions, only 24% of the 209 respondents who reported receiving palliative care support indicated that they had discussed Advance Care Planning (ACP) with a health professional. A large majority of respondents (72%) indicated that they had not discussed ACP with a health professional.

Of those who had discussed ACP with a health or social care professional, the majority (68%) had done so prior to the start of shielding.

Of those who had *not* discussed ACP with a health or social care professional, 41% reported that they would like the opportunity to discuss these issues. However, several respondents reported that being asked about ACP by a health or social care professional during a pandemic would make them feel as though their lives were less valued than those of other ill or well persons.

Among those open to having a conversation about ACP, shielding appeared to influence how they would like to be approached. Around half of these respondents reported that they would prefer to have such discussions over the phone or by email, with some specifically attributing this to their need to shield. It is of interest that a small number of respondents, while open to discussing ACP, felt it was too early for them to be having such discussions.

Figure 13: COVID-19 risk vs shielding impact - palliative care respondents* (N=205)



* Due to missing responses, percentages do not sum to 100%

5.3 Impact of shielding

5.3.1 Impact on the person shielding

Respondents reported greater concern for the risk of COVID-19 as compared to the impact of shielding on their lives (Figure 1). Approximately 1 in 5 (20%), of the 209 respondents who reported receiving palliative care support felt that shielding had either little or no impact on their lives or that they had found ways to minimise its impact.

However, the majority of respondents felt that shielding had a markedly negative impact on their emotional wellbeing. Almost 1 in 5 (20%) respondents reported that shielding specifically led to depression, and / or anxiety, and / or stress. The most commonly-reported reasons for impact on mental health were:

- Isolation and loneliness

Respondents specifically reported missing social interactions such as church, dinner out and having visitors to their home. Interactions with family and close friends were most commonly mentioned:

'It has been incredibly challenging mentally being confined to my home. I feel I have already fallen into periods of depression as it's hard to remain focused and motivated. I have found this has made it more difficult to adhere to my treatment schedule and exercise requirements to stay healthy'

Male, 25-34, Shielding

- Disruption of Health and Social Care services

Respondents receiving palliative care support reported that the disruption to their healthcare and social care had been detrimental in several ways:

- Perceptions that their general health had deteriorated;
- Concerns that their illness would worsen or, for those in remission, that their illness would return;
- Concerns that they would not be able to access essential healthcare;
- Concerns that the process of recuperation would be stalled or that they would lose function or mobility due to the inability to engage regularly in physiotherapy or occupational therapy; and / or
- Concerns regarding overburdening family members now performing the services that care workers had previously provided.

'My last 3 cycles of chemo have been postponed due to COVID-19. I was very disappointed and a bit scared about how this would affect my recovery from cancer'

Female, 55-64, Shielding

- Loss of independence

Concerns associated with feelings of vulnerability and fear were also common among those receiving palliative care support, with specific references to:

- Fear of leaving home or allowing others into the home, often due to a lack of confidence in the general public's willingness to follow COVID-19 prevention practices;
- Fear for safety when restrictions were eased;
- Not knowing what will happen; and / or
- Uncertainty over the implications of family members returning to their workplaces, both in terms of the increased risk of contracting COVID-19 and the loss of care provision.

A small number of survey respondents identified themselves as being terminally ill and approaching end of life, but those with a short time to live were consistent in their responses. They found it very difficult to be separated from their loved one(s), and to be unable to 'make memories' or to engage in things that brought them joy:

'It's destroying my mental health. I have terminal cancer and I'm spending what could be my last spring indoors'

Female, 35-44, Shielding

'I am coping with the effects of stage four (terminal) cancer with no sense of how long I have left, yet I can't spend my remaining hours with people I am close to'
Female, 55-64, Shielding

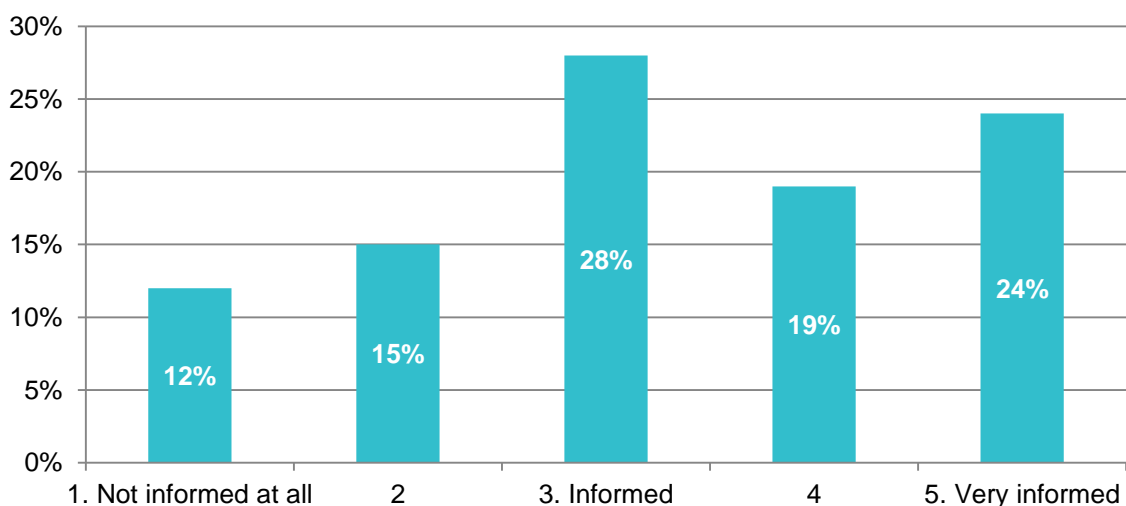
- Impact on family / loved ones

Excluding the 20% who felt that shielding did not have a significant impact on their lives, almost all respondents who spoke about those close to them indicated that the added work of caring for the person shielding was an excessive burden.

Carers themselves described being exhausted, worrying about maintaining the pace, and the need for a program / service to provide them with some respite.

5.4 Information and advice

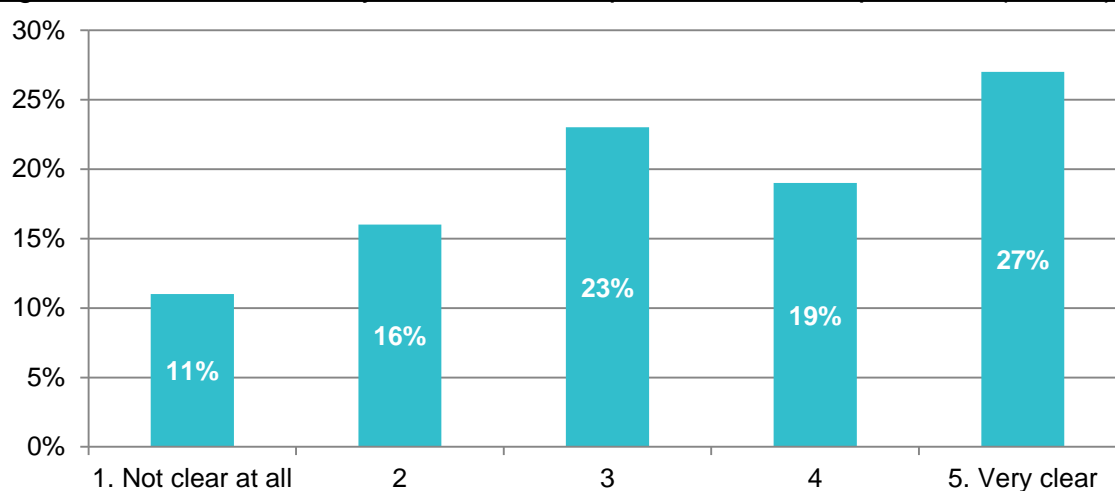
Figure 14: Perceptions of feeling informed - palliative care respondents (N=205)*



* Due to missing responses, percentages do not sum to 100%

Most respondents receiving palliative care support (71%) indicated that they felt informed or very informed regarding COVID-19 (Figure 14). Consistent with this finding, 69% of respondents found the information they had received to be clear or very clear (Figure 15).

Figure 15: Perceived clarity of information - palliative care respondents (N=202)*



* Due to missing responses, percentages do not sum to 100%

While these findings are positive, it is important to note that 27% of respondents could not obtain information that they felt they needed. In the free text section of the survey, participants provided valuable insight into the types of information they would find beneficial (see Section 5.5 below).

5.5 Role of government

Across multiple survey questions, respondents accessing palliative care support were often critical of how shielding had been handled by government and provided suggestions for how their experience could be enhanced if it proved necessary to continue shielding or to reintroduce it at a later point in time. Examples of recurring themes included:

- Guidance regarding shielding not being clear or timely;
- Insufficient information provided regarding resources for people shielding;
- Not being well informed about what to expect when shielding;
- Insufficient government guidance for shielding in special populations, e.g. shared supported living houses for adults with learning disabilities;
- Unreasonable government expectations, e.g. asking a parent simultaneously to work remotely, home school their children, and take over carer responsibilities for shielding family members;
- Insufficient assistance provided with basic needs such as buying food, acquiring medication, cleaning the house for those who had no support from family or friends, or who were dependent on assistance from charities that had closed; and / or
- Not being informed regarding the plan for what would happen after the end of the 12 week shielding period or for how shielded individuals would be expected to re-enter society.

6. DISCUSSION

Shielding had clear detrimental social and psychological effects on a significant number of respondents. However, relatively very few mentioned a need for professional support or counselling. This may indicate that the emotional impact of shielding was temporary for most people. However, this cannot be assumed, particularly given the uncertainty about how long shielding (or some form of it) will need to continue and the apparent reluctance of many of those shielding to return to a normal, less isolated life as shielding restrictions eased. The lack of expressed need for professional emotional support may also be due to a lack of knowledge or experience of such support.

This fear of COVID-19 and the risk it represents to clinically extremely vulnerable people was a central concern. There was a sense from many respondents that this fear would prevent them from changing their shielding behaviour even when shielding advice changed. It was often accompanied by a perception that the rest of the world had gone back to 'normal life' and that going out in public therefore posed too much of a risk until such times as a COVID-19 vaccine becomes available. Concerns about contracting COVID-19 may help explain why the proportion of respondents voicing frustrations or hopes around accessing routine or necessary healthcare was relatively low, although this still equated to a large number of people.

Several areas of unmet need were mentioned by substantial numbers of respondents and recurred across responses to a number of questions.

Many people shielding in Northern Ireland due to COVID-19 appeared to prioritise being kept informed above other areas of unmet need. There was a strong desire to be given clear guidance on what they should and should not do. There were also clear messages that people wanted to see and understand any available information on COVID-19 infection rates – ideally at as localised a level as possible – and on the actual risk posed to them as individuals. Respondents expected that having access to this information would empower and support them to make their own informed decisions about whether and how to emerge from shielding.

In reviewing the categorical and free text response data, it seemed apparent that there was more to be done in this area. Although people shielding were much more likely to have positive than negative perceptions about the amount and clarity of information they were receiving – and these figures had become more positive over time – one in five still seemed to feel uninformed. One third of all respondents also identified information provision and communication as an area where they could be better supported by the government. There were specific requests for clear, concise, consistent and regularly updated advice to the shielding population, along with the scientific rationale for such advice. A considerable number of respondents made

specific reference to the daily COVID-19 briefings and explained that they felt that the shielding community was often ‘forgotten’ or ‘ignored’ as changes to guidance and restrictions for the wider population were announced.

Another recurring theme was around increased contact with HSC services and professionals. It was common for respondents to request more proactive ‘checking in’ from their GPs or consultants, for reassurance but also, in many cases, for opportunities for social interaction.

Many respondents asked for improved access to food deliveries, because they were unaware of or had not tried to access priority supermarket delivery slots at the time of responding. Another reason was that, in many cases, they had experienced major issues or delays in the process of registering for these. References to these problems were less common in more recent responses. However, the proportion of people mentioning priority supermarket deliveries as part of the support they had accessed remained relatively low (around 20%) across most of the survey period. This may indicate low awareness or uptake of this service among those shielding.

The practicalities and challenges of returning to work or education after (or during) shielding cut across several questions. This was a major source of uncertainty for people and one of the areas in which respondents were most likely to demand clarity from the government as shielding restrictions eased. Common questions included whether those unable to attend work would be expected to go on Statutory Sick Pay and whether people shielding (and their family members) could or should be furloughed or exempted from attending school. These queries were again strongly linked to respondents’ fear of exposure to COVID-19 and the tension this was creating as they were expected to return to normal activities. References to work and education were also often accompanied by perceptions that people shielding were too often perceived as all being older and that younger people with jobs and families had been ‘forgotten’ as a result.

Comparing response data across different shielding categories (based on self-reported ‘reason for shielding’) produced some valuable insights. In particular, two groups (those living with learning, physical and/or sensory disabilities and those living with rare diseases) were consistently more likely than other groups to report negative impacts of shielding, to identify areas where they needed additional support to help cope with shielding, and to suggest changes that would make their lives easier should shielding restrictions continue. This intelligence and the detailed breakdown by impact/issue may be of use to organisations or professionals supporting these groups.

7. RECOMMENDATIONS

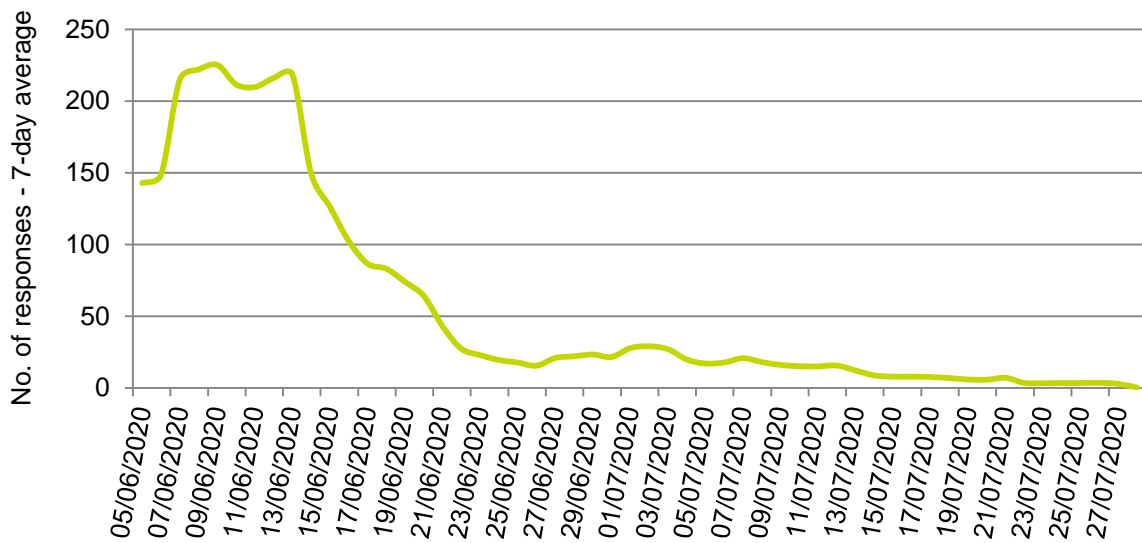
Based on survey findings, the PCC identified several key areas for action in the event of further restrictions for clinically extremely vulnerable people, with a number of specific recommendations under each. These are presented below.

Table 2: Survey themes and recommendations for improving experiences of clinically extremely vulnerable people

Theme	Recommendation
1. Information (including volume, quality, stratification)	Provide more and / or better shielding-specific guidance
	Provide more and / or better general COVID-19 information (e.g. localised rates of infection or death)
	Increase clarity and assurances about returning to work and education for clinically extremely vulnerable people and those in their households
	Introduce stratified tiers for different groups as shielding restrictions are eased or reintroduced, based on risk
2. Increased awareness of / adherence to public health guidance and restrictions	Increase effort to educate the public about clinically extremely vulnerable people and the risks they face
	Increase effort to deter the public from breaching restrictions
3. HSC support	Increase effort from Health and Social Care to 'check in' with clinically extremely vulnerable people
4. Access to services	Provide easier access to food deliveries or to guaranteed priority supermarket slots
	Designate space / time for clinically extremely vulnerable people to go outside, visit shops, leisure centres, GPs, etc. without the perceived risk of coming into contact with the general public
5. Financial support	Continue or improve financial support for clinically extremely vulnerable people and those in their households
6. Access to routine health care	Make arrangements for safe return to accessing necessary or routine healthcare
7. Psychological support	Make emotional or psychological support available to those who need it

APPENDIX 1 - Information on responses and respondents

Response volumes and format



*For postal responses, 12 days have been deducted from the date responses were inputted, to account for time in transit and between responses being received and inputted by PCC staff

Response format	Online	3,192	90.8%
	Postal	269	7.6%
	Phone	56	1.6%
		3,517	

Respondent demographics

Age group	0-17 years	143	4.1%
	18-24 years	73	2.1%
	35-44 years	485	14.1%
	25-34 years	292	8.5%
	45-54 years	639	18.5%
	55-64 years	770	22.3%
	65-79 years	822	23.8%
	80+ years	222	6.4%
	Not applicable	1	0.0%
	Prefer not to say	3	0.1%
		3,450	

Gender	Female	2,387	69.3%
	Male	1,045	30.4%
	Other	1	0.0%
	Not applicable	5	0.1%
	Prefer not to say	4	0.1%
		3,442	

Ethnic group	<i>White</i>	3,408	98.9%
	<i>Chinese</i>	1	0.0%
	<i>Irish Traveller</i>	3	0.1%
	<i>Pakistani</i>	1	0.0%
	<i>Indian</i>	6	0.2%
	<i>Mixed ethnic group</i>	6	0.2%
	<i>Black other</i>	3	0.1%
	<i>Other ethnic group</i>	6	0.2%
	<i>Prefer not to say</i>	13	0.4%
		3,447	

Respondent shielding profile

Shielding reason(s)	<i>On immunosuppression therapies sufficient to significantly increase risk of infection</i>	1,249	36.2%
	<i>Severe respiratory conditions including all cystic fibrosis, severe asthma and severe chronic obstructive pulmonary disease (COPD)</i>	1,173	34.0%
	<i>Cancer</i>	451	13.1%
	<i>Learning disability / physical disability / sensory disability</i>	179	5.2%
	<i>Rare diseases that significantly increase the risk of infections, e.g. severe combined immunodeficiency (SCID), homozygous sickle cell</i>	177	5.1%
	<i>Organ transplant</i>	146	4.2%
	<i>Diabetes</i>	105	3.0%
	<i>Heart problems</i>	96	2.8%
	<i>Prefer not to say</i>	61	1.8%
	<i>Living in a care home / supported living environment</i>	44	1.3%
	<i>Splenectomy</i>	35	1.0%
	<i>High blood pressure</i>	33	1.0%
	<i>Old age</i>	29	0.8%
	<i>Asthma</i>	28	0.8%
	<i>Arthritis</i>	27	0.8%
	<i>Multiple sclerosis</i>	26	0.8%
	<i>Kidney problems</i>	17	0.5%
	<i>Stroke</i>	17	0.5%
	<i>Pregnant with significant heart disease, congenital or acquired</i>	13	0.4%
	<i>Dementia</i>	10	0.3%
<i>Autoimmune disease</i>	6	0.2%	
<i>Motor Neurone Disease</i>	3	0.1%	
<i>Other</i>	232	6.7%	
	3,451		

*More than one selection allowed per response

Respondent category	<i>Person shielding</i>	2,825	81.7%
	<i>Person supporting someone who is shielding</i>	720	20.8%
	<i>Person whose relative / loved one is shielding in residential care</i>	48	1.4%
	<i>No response</i>	7	
	<i>Person ineligible to respond</i>	55	
		3,457	

**More than one selection allowed per response*

Consent to contact for further involvement?	Yes	1,800	52.0%
	No	1,662	48.0%
		3,462	

APPENDIX 2 – Shielding survey questionnaire

Patient and Client Council - Shielding Survey

Dear Stakeholder

The health, social and economic impact of COVID-19 (coronavirus) cannot be understated. Our lives have had to change causing significant impact to individuals and their families who have been advised to 'shield' on account of their condition/s.

You, or someone you know, may have received a letter from your doctor or hospital clinician to advise that you are at higher risk of becoming seriously ill from COVID-19; as such you need to be 'shielded'. In giving you this advice the priority has been to protect those most likely to be acutely affected by coronavirus and their families, in turn helping to protect the National Health Service (NHS). By applying this to everyone this has ensured equity for all affected.

The Department of Health recognises that from your direct experience of shielding, you have a unique insight into its impact and the measures required to support the transition from shielding to public engagement. As such, we kindly call upon your support with our consultation on this subject. The evidence and insights gathered will assess the level of impact that shielding has had and will inform the Department of Health on the key issues for consideration in planning the further easing of restrictions. The survey covers:

- How you have been affected by shielding;
- What are the most important things to you;
- What support you have had to help you deal with the impact of shielding;
- What measures of support are required if you are advised to continue to shield in some way;
- What information is needed to support you to safely ease the restrictions on shielding and what is a priority

The research will be conducted through a self-completed survey. The report will outline key themes for consideration to assist the Department of Health.

It is estimated that the consultation questionnaire will take approximately 15 minutes to complete. Please return your questionnaire to Freepost, Patient and Client Council or email it to info.pcc@pcc-ni.net. Alternatively this survey can be completed online at www.patientclientcouncil.hscni.net or over the phone by calling our freephone number 0800 917 0222

We thank you in advance for your time and responses.

Section 1 - Demographic Information

Q1 Which of the below describes you? (Please select all that apply)

- I am shielding
- I am supporting someone who is shielding
- My relative / loved one is shielding in residential care
- None of these

If 'None of these', thank you for your interest, however, at this time we only wish to engage with those who are shielding or those who are supporting someone who is shielding.

Q2 Which gender do you (the person shielding) identify as? (Please select one option only)

- Male
- Female
- Transgender
- Other
- Not applicable
- Prefer not to say

If Other, please specify:

Q3 Which age group applies to you (the person shielding)? (Please select one option only)

- 0-17 years
- 18-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65-79 years
- 80+ years
- Not applicable
- Prefer not to say

Q4 What is your ethnic group?

- White
- Black African
- Bangladeshi
- Chinese
- Irish Traveller
- Pakistani
- Indian
- Black Caribbean
- Mixed ethnic group
- Black other
- Roma Traveller
- Prefer not to say
- Other ethnic group

If other ethnic group, please specify:

Q5 What was the reason for you shielding? (Please select all that apply)

- Organ transplant
- Cancer
- Severe respiratory conditions including all cystic fibrosis, severe asthma and severe chronic obstructive pulmonary disease (COPD)
- Rare diseases that significantly increase the risk of infections, e.g. severe combined immunodeficiency (SCID), homozygous sickle cell
- On immunosuppression therapies sufficient to significantly increase risk of infection
- Pregnant with significant heart disease, congenital or acquired
- Learning disability / physical disability / sensory disability
- Living in a care home / supported living environment Motor
- Neurone Disease
- Prefer not to say
- Other

If other reason, please specify:

Section 2 - Your EXPERIENCE of shielding

Q6 What IMPACT has shielding had on you (the person shielding), your quality of life and those close to you?

Q7 Have you had any additional SUPPORT to help you cope with the impact of shielding?

- Yes
- No

If 'Yes', please tell us about the additional support you have had:

If 'No', what support would you have liked, if any?

Q8 Do you feel you have the INFORMATION you need to help you make decisions about shielding? Please indicate on the scale below how informed you feel.
1. Not informed at all 5. Very informed

Q9 How clear has the information and advice you have received about shielding been?
1. Not clear at all 5. Very clear

Q10 Do you (the person shielding) receive palliative care support as part of the management of your health condition(s)? This could be from a district nurse, palliative care consultant, social worker or others. Palliative care is the care of patients with advanced progressive illness including pain management and other symptoms as well as psychological, social and spiritual support
 Yes
 No

If 'Yes', please go to Q11; if 'No', please go to Q15.

Q11 Have you (the person shielding) discussed your future wishes/preferences for care (known as Advance Care Planning) with your GP or another health or social care professional?
 Yes
 No

If 'Yes', please go to Q12; if 'No', please go to Q13.

Q12 Did you have this discussion before you began shielding?
 Yes
 No

Please go straight to Q14.

Q13 Would you like the opportunity to discuss your future wishes/preferences for care?
 Yes
 No

Q14 What would be the best, most appropriate way to have this discussion in your circumstances?

Section 3 - Next steps

Q15 What concerns you more: the health risks of COVID-19 or the impact of shielding on your quality of life? Please select a point on the scale below.

1. Health risks of COVID-19 5. Impact of shielding on quality of life

Q16 What is most important for you as shielding restrictions ease? Please complete the following sentence: 'What would matter most to me, would be the ability to...'

Section 4 - LIVING WITH shielding

If you (the person shielding) are advised to continue shielding, what changes to your day-to-day life would make it easier or more enjoyable while still allowing you to feel safe?

Q17 What things could your family do (in making choices)?

Q18 What things could your local community or neighbourhood do (in providing support)?

Q19 What things could public services or the government (e.g. Dept. of Health, councils) do?

Section 5 - Further Information

This survey is part of a wider consultation on relaxing current restrictions for those who are shielding due to COVID-19.

Q20 Would you be happy for us to contact you about being involved in future stages of the process? (By selecting "Yes" and providing your details, you consent to the Patient and Client Council securely retaining these details on file in order to contact you at a later date to ask about your experiences of shielding).

- Yes If Yes, do you require an interpreter? Please specify what language _____
- No

To allow us to contact you again, can you please provide the following details:

Q21 Full name:

Q22 Email address:

Q23 Phone number:

Q24 If you would also like to become a member of the Patient and Client Council's Make Change Together movement to further influence and shape the future of health and social care in Northern Ireland please tick the box below and we will be in contact in due course.

- Yes, I would like to become a member of the Patient and Client Council's Make Change Together Movement

Please post your completed questionnaire to Freepost, Patient and Client Council (no stamp required) or email it to info.pcc@pcc-ni.net

Thank you for your participation and feedback

Remember you can contact us by

Telephone

0800 917 0222

Email

info.pcc@hscni.net

Post

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