

Let's Be Heard:

Sharing Respondents' Pandemic Experiences, Impacts, and Lessons to be Learned in Scotland

First Report | November 2023

Content Warning:

Please be aware that some parts of this report may be distressing or raise issues of concern for some readers. There are a range of services available if you require support after reading this paper, which can be found at the end of this document.

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Foreword

The Scottish COVID-19 Inquiry is Scotland's biggest-ever public inquiry. It is tasked with establishing the facts, and learning the lessons from, the devolved strategic response to the pandemic in Scotland.

Everyone in Scotland was impacted by the COVID-19 pandemic and many of us have experiences that we want to share with the Inquiry. Let's Be Heard provides a means for people affected by decisions made in Scotland to do that.

Since 22 May 2023, we have been collecting your experiences of the pandemic and the lessons you believe should be learned. The Let's Be Heard team has been travelling across the country to raise awareness of the project and help start conversations in your communities.

Some of you have been happy to share your name, others have preferred to submit to us anonymously. Either way, we are very grateful to everyone who has contributed so far. All your experiences are read by Inquiry colleagues and will help inform the Inquiry's investigations, reports and recommendations.

The report published today is a summary of the information we have gathered over the past six months. It is not a final report but sets out what we have learned to date. This interim report also highlights those communities and groups who we would like to hear more from. We want to ensure that the Inquiry also hears from minority and disadvantaged groups and from people living right across Scotland, including in rural and island communities.

I hope you find this interim report an interesting read and continue to engage with Let's Be Heard. The Scottish COVID-19 Inquiry is your inquiry and we want to hear from you.

Many thanks,

Ian Duddy Chief Executive and Secretary, Scottish COVID-19 Inquiry

Executive Summary

What is Let's Be Heard?

Let's Be Heard is the Scottish COVID-19 Inquiry's listening project.

The independent Inquiry is investigating the devolved strategic response to the COVID-19 pandemic between 1 January 2020 and 31 December 2022. It will establish the facts, identify any lessons that need to be learned and make recommendations to Scottish Ministers, so we are better prepared in future.

Let's Be Heard was established to give people living in Scotland or affected by decisions made in Scotland during that period the opportunity to share their experiences, and the lessons they believe should be learned from them.

It is the main way in which people can engage with the Inquiry to inform its investigations, reporting and recommendations.

Purpose of this report

This report shares the preliminary findings from the more than 4,000 responses Let's Be Heard has received since the launch of its National Engagement Period on 23 May 2023. This includes responses from individuals living in each of Scotland's local authority areas.

This is the first of a number of reports of key findings from Let's Be Heard which will be published during the lifetime of the Inquiry. By sharing its preliminary findings, Let's Be Heard hopes people in Scotland who have not already engaged with the project will recognise some of their experiences in those already shared by others and be encouraged to take part before the National Engagement Period ends on 20 December 2023.

Main findings: we asked and you said

During its National Engagement Period, Let's Be Heard is asking three core questions:

- 1. What were your experiences during the COVID-19 pandemic?
- 2. What were the impacts of these experiences on you or the people you know?
- 3. What lessons do you think should be learned from your experiences?

We asked: What would you like to tell us about your experiences during the COVID-19 pandemic?

You said: Experiences shared with Let's Be Heard described difficulty and isolation in not being able to see loved ones, especially those in care or nearing the end of their lives.

- Views regarding rules, restrictions, the provision of personal protective equipment (PPE), and Scottish Government communications were polarised, with many feeling they had received contradictory and inconsistent guidance.
- Key workers described difficulties in accessing vaccination and childcare and said they had faced incredible pressures.
- Health care was a prominent issue, especially in relation to communication challenges, delayed or missed diagnoses and the suspension of services.

• Almost every aspect of people's day-to-day lives changed. Homes became places of working and learning. Families were not able to meet or to be with loved ones at crucial moments, such as when family members and loved ones were dying.

We asked: What were the impacts of these experiences on you or people you know?

You said: Experiences differed across the country, nevertheless people experienced similar impacts. These include impacts on trust, mental health, life events, and financial security.

- Common impacts on children and young people included boredom and isolation, and many reported that their mental health and wellbeing had suffered.
- Older people were impacted predominantly by the isolation and loneliness caused by pandemic rules and restrictions. This included older people living on their own, as well as those living in care and nursing homes.
- Mental health issues, including anxiety, suicide and depression among people of all ages were reported frequently.
- Lockdown had significant economic impacts on both individuals and small businesses.
- Family dynamics were also severely impacted. While some enjoyed having more time together, others found it difficult to balance the competing responsibilities of working from home, parenting and supporting their children's learning from home. Many also found separation from loved ones incredibly difficult and experienced a feeling of extreme isolation.

• As a result of pandemic experiences, public trust in science, government and in others appeared to decline, a trend which appears to have continued.

We asked: What lessons do you think should be learned from your experiences?

You said: Several suggestions were made by respondents to ensure Scotland can more efficiently and effectively respond to future pandemics. Key lessons included:

- Having clearer plans in place for the strategic and emergency response to any future pandemic.
- Maintaining key services, such as primary health care, during a pandemic.
- Prioritising mental health and wellbeing, especially for key groups such as children, young people and those living alone.
- Public health messaging should be clear, consistent and evidence-based.
- Government must better balance protecting the population from the virus and avoiding unnecessary harm.

Call to action/next steps

Let's Be Heard is grateful to all those who have shared their experiences so far, and to the organisations which have supported and facilitated this engagement. A key focus for the Inquiry, and therefore Let's Be Heard, is investigating whether there were any unequal and disparate impacts for different groups and individuals. For this reason, it is important that Let's Be Heard hears from as wide a range of people as possible. The team is particularly keen to receive more responses from:

- Minority ethnic communities
- LGBTQ+ people
- Minority religious communities
- Men
- People aged under 20 and over 70
- People who do not feel financially secure

Let's Be Heard is also keen to hear more from:

- Frontline workers
- Migrant keyworkers
- Teachers and school staff
- Children under the age of six and people involved in early years care
- Students in higher and further education
- Unpaid carers
- Young carers
- Disabled people
- Small business and self-employed people

- People in receipt of welfare benefits
- People who were the subject of Do Not Resuscitate Orders (DNRs)/'Do Not Attempt Cardiopulmonary Resuscitation' Orders (DNACPRs) and their relatives
- The relatives of people who received end-of-life care
- People experiencing long COVID

Everyone's experience of the pandemic is important to the Inquiry, and it does not have to be particularly positive or negative. You also do not need to have had COVID-19 to participate. Let's Be Heard wants to hear from **you**.

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1. Introduction

Let's Be Heard is the Scottish COVID-19 Inquiry's listening project. It gives everyone affected by the devolved strategic response to the COVID-19 pandemic in Scotland between 1 January 2020 and 31 December 2022 the opportunity to share their experiences with the Inquiry.

It is the main way in which people can contribute to the Inquiry and aims to give a voice to as many people across Scotland as possible. Let's Be Heard allows people to tell the Inquiry about their experiences of the pandemic, how these affected them and any lessons they believe should be learned.

This report aims to set out the preliminary findings from experiences shared with Let's Be Heard to date. It is hoped people in Scotland who have not already engaged with the project will recognise some of their own experiences in those already shared by others and be encouraged to take part before the National Engagement Period ends on 20 December 2023.

Drawing on a random sample size of 675 experiences, from more than 4,000 responses collected from individuals and groups across Scotland, this report shares an initial thematic analysis from the three key questions Let's Be Heard has asked the public. These are:

- 1. What were your experiences during the COVID-19 pandemic?
- 2. What were the impacts of these experiences on you or the people you know?
- 3. What lessons do you think should be learned from your experiences?

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Structure of this report

The report will begin with some background on the Scottish COVID-19 Inquiry and the establishment and approach of Let's Be Heard. It will provide an overview of the project's aims, who Let's Be Heard has heard from, and the analytical approach taken to produce this report.

The main part of this report, comprising three sections, will share the early findings from experiences submitted to Let's Be Heard, focusing on experiences, impacts and lessons to be learned. Direct quotes from respondents are provided throughout the report to ensure lived experience is at the forefront of Let's Be Heard's preliminary findings.

It is important to note that the thematic findings represent the views of those who participated with Let's Be Heard. They do not represent, nor anticipate, the Inquiry's conclusions.

The analysis in this report is not exhaustive but provides early insights on the content of responses gathered through Let's Be Heard, and their value to the Inquiry.

The report will conclude by providing an overview of Let's Be Heard's approach and the next steps it will take, which include identifying the groups and communities which have not been adequately represented thus far in the project. It is hoped that people in Scotland who have not already engaged with the Inquiry via Let's Be Heard will be encouraged to do so and to help address the information gaps needed to understand any unequal impacts of the devolved strategic response. Let's be Heard and the Scottish COVID-19 Inquiry would like to express their sincerest gratitude to everyone who has responded so far, and the organisations which have facilitated those responses, as the findings from the accounts shared will be crucial to informing the Inquiry's investigations, reporting and final recommendations.

1.1 Background to the Inquiry and Let's Be Heard

The independent Scottish COVID-19 Inquiry was set up on 28 February 2022 and has been chaired by Lord Brailsford since 28 October 2022. The purpose of the Inquiry is to establish the facts of, and learn lessons from, the strategic devolved response to the COVID-19 pandemic in Scotland between 1 January 2020 and 31 December 2022.





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The Inquiry's **Terms of Reference** (ToR) set out the 12 broad areas it is investigating to identify the lessons that should be learned and make recommendations so Scotland is better prepared in future. These include areas such as the provision of health and social care, education, business, and welfare assistance and financial support.

To support the development of any recommendations the Inquiry might make, it needs to hear from the people who were directly impacted by the devolved strategic response to the pandemic in Scotland. That is why the Inquiry has established a listening project, Let's Be Heard: Sharing Scotland's COVID Experience.

Those who wish to take part do not need to have had COVID-19, as Let's Be Heard is interested in gathering all types of experiences. The information gathered through Let's Be Heard has equal value to that gathered in other ways, such as at the Inquiry's impact hearings.

1.2 Let's Be Heard's aims

Let's Be Heard has three principal aims:

- 1. To widen participation in the Inquiry by ensuring lived experience is included in its evidence base.
- 2. To provide guidance to the wider Inquiry and help steer the Chair's investigatory work from an early stage. This will ensure the experiences of those who take part play a crucial role in steering the work of the Inquiry.
- 3. To provide an evidence base to support the Inquiry's reports and recommendations.

A key focus for the Inquiry, and therefore Let's Be Heard, is investigating whether there were any unequal or disparate impacts for particular groups and individuals. Therefore, Let's Be Heard has been designed and implemented with inclusivity and accessibility at its heart.

To that end, the design of Let's Be Heard has been informed by several approaches, including trauma-informed, equalities and human rights-based approaches.

1.3 Who Let's Be Heard has heard from so far

A key part of the work of Let's Be Heard is to help the Inquiry determine whether the pandemic in Scotland affected people in different and unequal ways. To help it do this, Let's Be Heard is collecting equalities data alongside people's responses to the three core questions. People can choose to complete optional additional questions about protected characteristics, including age, sexual orientation and ethnicity. Collecting this data helps Let's Be Heard better understand the background, intersectionality and inequalities that surround people's experiences and report on them. This data will also be used during the Focused Engagement Period to identify what places, communities and groups Let's Be Heard should focus on engaging with next.

Demographic Summary

Age

Middle-aged people were the most frequent respondents to Let's Be Heard, with 46% of participants telling us they were aged 45-64. Children and young people accounted for 9% of participants.

Gender



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Of those respondents who told Let's Be Heard their gender, 68% were female. About 1% identified as nonbinary, trans or having a trans history.

Ethnicity



White Scottish/English/British people make up the majority of responses to Let's Be Heard, with 86% of participants identifying as such. 1% of submissions were from people who told us they were from a nonwhite/mixed race background.

Disability



The representation of disabled people has been broadly in line with population demographics, with 25% of participants telling us their disability is covered under the Equality Act 2010.

Occupation



Key workers have responded to Let's Be Heard in strong numbers, with 57% of respondents telling us they were a key worker during the pandemic. Of these, 27% were working in health and social care.



Those who have greater financial security have been more likely to contribute to Let's Be Heard. 74% told us they were either "very" or "fairly" financially secure. 26% told us they were "not very" or "not at all" financially secure.



58% of respondents told us they had, or continue to have, caring responsibilities. A third (33%) of these respondents cared, or continue to care, for their own children or dependents.

Localities

As shown in the two maps below, most of the responses received to date have been from people who identified the Central Belt of Scotland as being where their experiences of the pandemic took place. Fife (11% of total), Glasgow City (9%), and The City of Edinburgh (8%), were the three most frequently selected local authority areas.

Let's Be Heard has received proportionally fewer experiences from people in North Lanarkshire and West Lothian, and from people in rural areas compared to urban areas. People living in local authority areas in the Highlands and Islands account for 10% of responses.¹

¹ Highlands and Islands comprise Argyll and Bute, Highland, Moray, Na h-Eileanan Siar (Western Isles), Orkney, and Shetland.

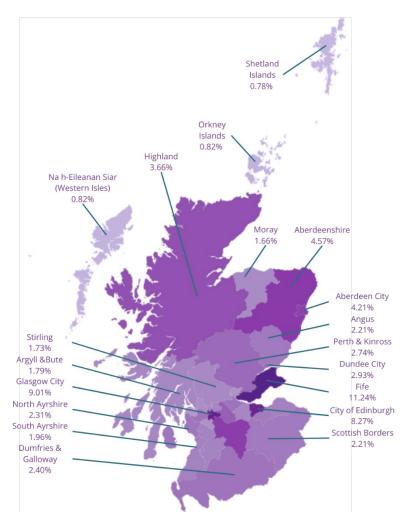


Figure 2: Scotland: Submissions by Local Authority

Figure 3: Submissions by Local Authority in the Scottish Central Belt



Who Let's Be Heard would welcome hearing more from

Let's Be Heard is keen to hear more from minority ethnic and marginalised groups, especially as it aims to present and emphasise findings in its future reporting on intersectional experiences of unequal and disproportionate impacts in Scotland.

Overall, the responses received from participants who self-identified as "non-white" had several notable characteristics, including some obvious intersections. Some broad findings include:

- 50% of non-white respondents were frontline key workers, which is marginally more than in overall responses (45%);
- 50% were also "not very" or "not at all" financially secure, significantly more than the average in overall responses (20%);
- 35% told Let's Be Heard they were disabled, more than average (20%); and
- 55% had caring responsibilities, several of whom spoke at length about the experiences and impact of being an unpaid carer. This was 10% higher than in the overall sample (45%).

What has been emphasised through Let's Be Heard's preliminary analysis is the underrepresentation of voices from minority ethnic and marginalised communities.

Let's Be Heard hopes to find more in-depth thematic findings on intersectional experiences and will therefore focus on reaching minority ethnic and marginalised groups for the rest of its National Engagement Period. This will also be a key objective during its Focused Engagement Period.

1.4 Let's Be Heard's Analysis

The Sample of Responses

For this report, Let's Be Heard has reviewed a sample of 675 response forms of the more than 4,000 responses received to date, with 224 of this sample being from children and young people. Organisational reports submitted to Let's Be Heard also inform these findings, but it should be noted that they do not represent all the reports gathered so far.

The sample comprises responses collected from Let's Be Heard's online platform and equivalent paper copy submissions, easy read and children and young people's forms. Responses used for this report were submitted to Let's Be Heard from May 2023 to September 2023.

Type of FormResponsesOnline Form331Paper Form115Easy Read5Children and Young People Form224

A full breakdown of these responses is shown in the table below:

These figures are broadly representative of the proportion of each type of form analysed by Let's Be Heard for this sample size. This is with the exception of children and young people's forms, which have been over-sampled because they contain far less detail about experiences than other forms. Let's Be Heard was keen to ensure the voices of children and young people were fairly represented in this report. It is important to note that everything shared with Let's Be Heard is done so in a selfselected manner, which means that the decision to participate in the project is left entirely up to individuals.

Children and young people

For this report, Let's Be Heard analysed a sample of 224 responses received from children and young people, as Let's Be Heard has created dedicated resources for children and young people up to the age of 14, this includes a bespoke response form, which is also available for those up to the age of 19. Most submissions came from those aged 10-19 (61.33%), with 1.78% of participants aged five to nine, and none under four.

Overall, responses from children and young people were brief. These focused on a few central themes: boredom, home-learning and the detrimental impact on mental health. These themes consistently overlapped to build a picture of children and young people in Scotland feeling anxious, under-stimulated and lonely during the pandemic. Often, these feelings were associated with inadequate home-learning arrangements and limited social interaction, which were often made worse by experiences of grief and loss.

2. We asked: What were your experiences during the COVID-19 pandemic?

You Said...

This section of the report focuses on the answers to the first of Let's Be Heard's core questions: What would you like to tell us about your experiences during the COVID-19 pandemic?

Key 'experience' themes have emerged from the responses analysed thus far, which present a broad picture of how people were impacted by the response to the COVID-19 pandemic in Scotland. These key themes include, but are not limited to: rules, restrictions and measures, Scottish Government communication, key workers, personal protective equipment (PPE), healthcare, care homes and nursing homes, social care, death and dying, school and education, and long COVID. Broader themes also emerged during the research team's analysis of responses. These include:

Inconsistency: Respondents indicated lockdown rules and restrictions seemed everchanging and were inconsistently enforced. Respondents expressed frustration that these rules were enforced completely, sometimes or not at all. In relation to healthcare, respondents observed inconsistencies regarding who required shielding and around how information was communicated between staff and patients in hospitals and health centres, as well as between different health departments.

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Polarisation: Respondents were divided in their opinions of lockdown. Some spoke in favour of, and others against, rules and restrictions such as staying at home, working from home and 'bubbling'. Respondents were also polarised about the performance of the Scottish Government and other public bodies during the pandemic. Some believed the Scottish Government did a good job, while others thought it had performed poorly, and both positive and negative comparisons were made in relation to how other governments responded to the pandemic.

Deep discontent: Some respondents directed dissatisfaction, in the form of frustration and anger, towards institutions they felt had failed them. For example, they expressed anger around decisions that exposed care home residents to COVID-19. Some respondents also expressed anger at the NHS for reasons including a lack of inperson appointments, services being cancelled, receiving late diagnoses and not being allowed to visit loved ones who were ill or dying. There was also anger and frustration expressed by healthcare and social care workers at not having sufficient PPE. Other respondents said anger was directed towards them in their professional capacity, such as NHS staff, police, teachers and retail workers.

Loss: The respondents in the analysed sample who experienced this most acutely were those who lost loved ones either directly to COVID-19 or due to circumstances related to the pandemic. Respondents whose lives were changed significantly by the pandemic also felt a sense of loss towards their previous way of life. This included students who could not continue or complete their education in-person, previously healthy people left suffering from long COVID and workers who lost their jobs due to the pandemic. More generally, loss was also felt by people who could no longer socialise and meet friends and family because of lockdown and other restrictions.

Concerns: Respondents raised concerns around the right to private and family life. This affected many key workers during the pandemic, for example care home workers who chose to live at their workplace to keep residents safe, and frontline workers such as police and firefighters who chose to live apart from their families in order to protect them. Many people were restricted from visiting family members in various healthcare settings, and in other local authority areas.

2.1 Rules, restrictions and measures

Most respondents in the sample group described their experiences of navigating the different pandemic rules, restrictions and measures in place during the period which is being investigated by the Inquiry. These rules, restrictions and measures were implemented by different public bodies such as the Scottish Government, the NHS and local authorities. Participants shared positive and negative experiences of these, identifying those they felt had been successful and others which created barriers and challenges. These can be understood in more detail below:

Navigating the pandemic response

The responses analysed suggest that people's experiences of, and views on, the pandemic rules, restrictions and measures fell broadly into three groups centred around positive sentiments, negative sentiments and those that were in between the two.

Some respondents voiced support for the rules and restrictions. They acknowledged the difficult task facing the Scottish Government and felt its response was appropriate and effective. This sentiment is exemplified by one respondent, who said "they did the best they could" under challenging circumstances. The rules and restrictions were described as "clear" and "determined by medical and scientific advice and free from influence by financial interests or public pressure."

On a similar note, another respondent commented: "Despite the confusion, I did feel that the message to stay at home, isolate and be really careful was clear." The mother of a baby said she was aware that lockdown would be isolating but she felt reassured by the restrictions and believed they were the right thing to do. Another person commented: "I was happy to take the precautions laid out by the government and played my part."

Respondents who were critical of lockdown rules and restrictions were sceptical about the apparent danger posed by COVID-19. One participant set out clearly one of the more widely held views:

"Lockdowns were never needed at all, and neither were masks or social distancing. Lockdowns have been proved to make no difference, masks are known to be pointless and unnecessary as is social distancing, and yet the government insisted on these useless measures for a virus which was a nonevent."

Distrust about the nature of the virus led people to question whether measures such as testing, vaccinations and other restrictions were necessary. Respondents from the sample group wrote about "being forced into lockdown, mask-wearing and forced jabs" and questioned the reliability of tests and vaccine safety. In several responses, both the Scottish and UK governments were accused of not telling the truth about the virus and of using the pandemic as a pretext to extend their political ambitions. A third group of people were neither overly supportive nor overly critical. Their appraisal of the measures taken was qualified, agreeing with some and disagreeing with others. Their feelings about the rules, restrictions and other measures were influenced by the consequences of lockdown. By far the biggest influencing factor was their experience of being separated from their families and loved ones and having to spend lockdown alone.

Respondents told Let's Be Heard how concerned they were about family members, particularly older family members:

"I understand the need to keep people safe and to stop spread of infection, but for families that have parents living alone and several miles away, this was very difficult and still has had an impact on my family to date."

Others said their family felt they sacrificed time together, which they "would never get back". Parents expressed concern about the closure of schools and the lasting impact it had on their children. Some respondents felt schools should have remained open at least one day a week to allow children to see their friends and receive support from their teachers.

Enforcement of rules and restrictions

Some respondents expressed frustration that rules were not properly enforced, while others questioned whether it was possible or realistic to enforce them all. An example of this was that respondents felt there was an expectation for people to 'police' others in their community. Other respondents highlighted what they saw as the "nonsense" (as described by one respondent) of employing people to stand outside public toilets to make sure only one person entered at a time.

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It was mentioned by a range of respondents that rules and restrictions were constantly changing and there were inconsistencies in their enforcement. This is exemplified by the response of a radiographer based in a large hospital during the pandemic, who described their experience of rules being adopted and enforced in different ways by departments in the same hospital:

"One day it would be full PPE and the next gloves and gowns. Some places would ask you to clean the machine within the Covid areas, other places outwith [them]."

Media reports of senior decision-makers and leaders breaking the rules were a significant factor in shaping respondents' views on this topic. For many, the response to this was a sense of anger and injustice. Respondents resented this "double standard", whether real or perceived, and condemned the apparent hypocrisy of those concerned.

Bubbles

Support bubbles offered people the chance to form extended households, in accordance with the rules at the time, to end isolation and make it easier to provide practical support to one another. This meant that individuals within one bubble no longer had to socially distance from each other and could visit each other's homes. Respondents from the sample group described the isolation they felt before the introduction of support bubbles as "inhumane" and "tantamount to abuse". The ability to visit family or have the option of living with others was described as a welcome measure. One parent explained that they had asked an older family member if they wanted to leave the bubble after their son returned to school because of the increased risk of infection. The answer was a resounding 'no'. Similarly, another respondent said: "I was able to live at my own flat through the week and visit my parents at weekends as part of my bubble." Bubbles extended beyond family groups and included friends and neighbours, as was the case with another respondent: "I stayed at home with my husband and had a very small bubble consisting of my neighbour and her two children."

Many respondents also described the introduction of bubbles as a relief, with one respondent saying they were, at last, able to receive "support and help". The only criticism was that bubbles were not introduced sooner than June 2020, as noted by one respondent:

"Adults living alone should have had bubbles from the start, including being able to see partners who lived in a different house. It is not humane to keep people isolated to that extent. I didn't see a single person for the first three weeks of lockdown."

Shielding

A small number of respondents shared experiences related to shielding. Shielding describes a set of measures introduced in March 2020 by the Scottish Government to protect people who were at the highest risk of severe illness or death if they caught COVID-19. People in the shielding category were advised to minimise contact with others to reduce the risk of being exposed to the virus. The programme also offered support services such as home visits, phone calls and online resources to help people stay safe and well.

The experiences shared with Let's Be Heard in relation to shielding fell into two categories: people dissatisfied because they were not included on the shielding list, and people talking about the impact of shielding.

Those who felt they should have been on the shielding list had a range of conditions, including asthma, myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). They felt shielding would have made it possible for them to work at home during the pandemic, reducing their risk of exposure. One person commented:

"I feel as though all ME/CFS sufferers who were in employment were thrown under a bus and I think it is unacceptable that anyone suffering from this disease was not protected or given shielding during the pandemic."

Another respondent, who was a healthcare professional, suggested the shielding category was not clear or well thought-out. Respondents also felt it was not clear who was considered high risk. The list was reviewed on a regular basis and clinicians were able to add people to the list if they deemed it appropriate.² One respondent spoke to their GP about their condition and was eventually placed on the shielding list, suggesting that this system had some flexibility, though this was not made clear.

Respondents who shared their experiences of being on the shielding list, or the experiences of family members, described it as a difficult period in their lives. One person said they were unable to get a supermarket delivery slot for six months and, as a result, were "forced to go out and be amongst people who may have been carrying COVID."

As shared by the Glasgow Disability Alliance and noted in its report, disabled people also faced barriers around the shielding list: "GP told me to shield but I never got a letter. Now my [food] parcels are stopping – but I'm still high risk!"³ Let's Be

² Scottish Government, *Shielding: A Way Forward for Scotland* (2020), p.7, URL:

https://www.gov.scot/publications/coronavirus-covid-19-shielding-way-forward-scotland/ ³ Glasgow Disability Alliance, *Supercharged: A Human Catastrophe Inequalities, Participation and Human Rights before, during and beyond COVID19* (August 2020), p.10. URL:

https://gda.scot/app/uploads/2020/09/GDAa_Supercharged-Covid-19Report.pdf

Heard respondents explained how having to work from home because they were in the 'high risk' category negatively impacted on their workplace relationships. One person commented: "This has affected my ability in a new role, especially trying to establish those office relationships."

Families of those shielding spoke of their anxiety at not being able to see loved ones. One person described how their sibling, who was diagnosed with terminal cancer, died in 2021 after months of shielding without being able to see their family: "He had no life from March 2020 till the day he died because of lockdown restrictions for those shielding."

Accessing services

For many people, accessing services was highlighted as a significant barrier across a range of critical areas such as healthcare, education, shopping, digital accessibility and employment support.

The most serious access issues that came from responses related to healthcare and dentistry. Many respondents said health conditions which predated the pandemic, or emerged during the pandemic, were compounded by the restrictions. For some, the consequences of not being able to access health services due to pandemic restrictions were stark, especially in relation to mental health, cancer journeys, and bereavement support. Notably, refugees and people seeking asylum in Scotland also found accessing health services a key barrier, as described by a cohort to Refugees for Justice in a 2022 report shared with Let's be Heard.⁴

⁴ Baroness Helena Kennedy QC, *Independent Commission of Inquiry into Asylum Provision in Scotland* (June 2022), pp. 26-27. URL:

https://static1.squarespace.com/static/62af1289a666c80e00b17253/t/636b9190408f81778746eaa7/1667 994032702/AIS+Phase+2+Report+Full.pdf

Several respondents highlighted how dependent they were on being able to access local community facilities and shops. This was even more critical for people living in small communities or in rural areas: "The value of the local shop and benefits of a rural lifestyle were massive positives."

A key concern for respondents during lockdown was the scarcity of online food delivery slots, forcing people to visit shops and potentially expose themselves to the virus when they would have preferred to stay home. This was particularly concerning for people living in rural areas:

"[It was] impossible to get delivery of food for many people in rural communities, as the supermarket delivery slots were booked up immediately, so people had to go to the shops, which is where transmission was rife."

This was even more concerning for people who had to shield. Some participants also raised concerns over the panic-buying they witnessed in some supermarkets and questioned why it was permitted for so long.

Testing

Experiences of testing varied amongst responses. Of those people who spoke about testing, most were either not convinced of the need for it or doubted its reliability. Some respondents described testing as "totally undependable", "pointless" and producing such "a high level of false positives as to be completely useless". For this group of respondents, it was felt that positive COVID test results were used to "drive lockdowns [and] mask wearing and generally terrifying the population for no reason".

There were fewer responses in the sample group supporting testing but those that did were complimentary about the process. One respondent praised the fact that tests were free and readily available:

"We were more than happy with testing arrangements. We found it simple to order test kits online and these were mailed out promptly. We also found it easy to arrange visits to testing centres."

A small number of respondents spoke about the challenge of accessing testing, though they did not raise any concerns about effectiveness. For people living in rural areas, access to testing centres was a concern because it required access to transportation and journeys took considerable time. If not feeling well, having to make this type of journey was an additional challenge. In the words of one respondent: "I believe I had COVID, but couldn't get tested as I was too ill to drive to the testing centre 50 miles away."

Testing also proved difficult for people who were blind and/or partially sighted, as highlighted by a 2022 Sight Scotland report, which found that "self-testing lateral flow and PCR kits are also very difficult for a blind or partially-sighted person to use unaided, and there is a lack of support available to support someone to take a test."⁵

Vaccine rollout

Experiences and views on the planning and rollout of vaccines were polarised among the sample group of responses. The delivery of the vaccination programme was seen by some as a success. One respondent said: "We got all our vaccinations smoothly and efficiently and have nothing but praise for the government info and organisations and

⁵ Sight Scotland and Sight Scotland Veterans, The Impact of the Covid-19 pandemic on blind and partially sighted people (2022), p. 7.

URL: https://sightscotland.org.uk/influencing-change/reports-and-consultation

NHS staff." A few individuals highlighted the benefits to them, and others, of being vaccinated either at home or close to home.

Others found it challenging to access vaccination clinics and centres. Distances to vaccination centres were cited as a barrier in some responses, particularly by those in rural areas, and for people who were vulnerable and/or reliant on public transport.

One particularly negative aspect of the vaccination programme highlighted by a number of participants was difficulty in booking and changing vaccination appointments. Particular health boards were mentioned as being especially good or especially poor in their delivery of vaccinations. There was a widespread feeling that people's experience of the vaccination programme depended on where they lived: "It is good that there is a vaccine programme but again there were inconsistencies between health board areas."

Respondents also spoke about the challenges of having a centralised system for accessing vaccination appointments in Scotland. They said call handlers did not understand local geography and would allocate appointments without considering how close or accessible the vaccination centre was for local people. One participant explained:

"The vaccination invite system was a mess and still is. Patients are invited via postcode to the nearest centre which means that they may be expected to get on 2 buses when there is a local option they cannot book for."

Some participants shared different views around vaccine hesitancy. A few criticised social and workforce pressures to be vaccinated and a lack of informed consent, undermining freedom of choice:

"My son was forced to have a full programme of vaccines in order to keep his job. What right have the government to enforce mass medication? They are supposed to protect us from harm, not jump to the wishes of the pharmaceutical companies."

Others described feeling stigmatised and isolated because they were reluctant to be vaccinated:

"I didn't want the vaccine but had the first two and then felt incredible pressure to have the booster, I felt bombarded with texts and adverts to have it - in the end I decided not to have it but felt like a total outsider for making that decision."

Respondents who shared experiences of delivering vaccines said most individuals they encountered appreciated being vaccinated. However, they also reported that their workplace felt unhospitable and unsafe at times because of the way members of the public communicated their hesitancy around vaccines to them.

2.2 Scottish Government communication

Respondents were polarised in their assessment of the First Minister's televised briefings and of Scottish Government communication more broadly. Positive evaluations by respondents identified communication from the Scottish Government as being trustworthy and measured, and favourable comparisons were made to UK Government communications. Speaking to the importance of communication and trust, one respondent commented: "These [communications] were much better in Scotland than in the UK as a whole, which really helped me and others to feel confident about the situation and what was being done." A similar sentiment was shared by another respondent, who said they "had much more confidence in the medical input from the Scottish CMOs [Chief Medical Officers] and Director of Public Health, a great communicator, than from those in England."

There was praise for the then First Minister, with comments such as "she did an amazing job in a very difficult time." Another stated: "The daily bulletin from Nicola Sturgeon was the only information I fully trusted." The daily broadcasts were described as targeted at the correct level and the information provided was seen as clear and succinct. The fact that the First Minister fronted a large number of the briefings was commented on and commended by one respondent: "I cannot fault Nicola Sturgeon's handling of a difficult situation."

On the other hand, many respondents felt the Scottish Government used its communications to score political points against the UK Government. One respondent said: "A decent politician would have put the welfare of the country ahead of partypolitical point scoring."

The relationship between the Scottish Government and the media was also a recurring theme. One respondent reported feeling that the Scottish Government and the media "belittle[ed] anyone who did their own research and decided they didn't need a vaccine". Several respondents felt members of the "public were bombarded with false reports" from the media with little room for dissenting opinions, with the perception, in the words of one respondent, that this led to more "public deaths and not once did the Scottish Government do anything about the media".

Several respondents felt it was useful to have up-to-date information about government rules and actions, but these became politicised by journalists asking non-COVID-related political questions. Others felt the daily press conferences became

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repetitive in their questions and answers. Respondents found this purported misuse of briefings as stressful, rather than informative. As one respondent put it, watching the news and the warnings felt like "fighting two battles for my life."

Similarly, some respondents felt the then First Minister relied on fear as a tool for changing public behaviours, expressing concern that "months of daily crisis warnings induced unwarranted fear." Other respondents criticised public information campaigns for implying "they could kill someone if they didn't follow these complicated, contradictory and constantly changing [rules]."

Some participants who expressed gratitude for the daily updates nonetheless said they had caused mental health issues, because people "suffered severe depression attributed to the briefings". One respondent said: "The TV campaigns were pure evil, creating fear and trauma," leading people to experience severe mental health challenges. Another respondent described the briefings as "the daily beating of negativity and doom", adding that they left them "in total despair".

2.3 Key workers

Key workers delivered essential services, supported the vulnerable and assisted community resilience during the pandemic. Those given this status included workers in health and social care, emergency services, prisons, education and supermarkets. There were many responses focusing on the experiences of key workers throughout the pandemic – both first-hand and observational. Responses that discussed key workers largely described challenging working conditions and the pressures they encountered from legislators, employers and the public. Many responses also expressed immense gratitude for the sacrifices made by key workers.

Access to vaccination

Although the rollout of vaccinations to key workers was often praised as efficient, particularly by NHS workers, some social care workers felt prioritising vaccinations for frontline workers – those who worked at the 'frontline' of the pandemic treating people with the virus – would have reduced the spread of COVID-19 in essential workplaces. For example, a few individuals reported slower than anticipated access to vaccinations for people working in social care:

"My wife is a carer and when the vaccine rollout came about December 2020/January 2021, she was meant to be a priority. After writing to our MSP, who didn't help and only replied many weeks later, we contacted other MSPs who did help and got this done."

Several police officers also expressed concern that they had not been prioritised for vaccination. These respondents reported feeling exposed while attending COVID-19 deaths, handling corpses, being spat at and having to physically engage with members of the public. An officer in a COVID-19 custody centre stated:

"Why police officers were not also prioritised for a vaccine I will never know. [I was] required to struggle with and restrain violent individuals with no option to maintain social distancing."

Access to childcare

The provision of childcare for the children of key workers was a significant theme in the sample group responses. NHS staff reported that their care responsibilities were overlooked, which put a huge burden on parents, often mothers. A pregnant doctor shared her experience:

"There appeared to be no joined up thinking about how the closure of childcare would affect people like me - in fact those in charge seemed not to consider that junior doctors being redeployed into acute areas might also have childcare responsibilities."

Accessing childcare was reported as "challenging". Where childcare was available, some described poorer conditions than before COVID-19, such as a lack of nappy-changing facilities. Others expressed frustration at precautions that got in the way of the wellbeing of children:

"We were not allowed into the nursery to settle her. I had to strap my baby into a pram and push her through an 'airlock' reception area, where they cleaned the pram handles before lifting her out. This is in direct contrast to everything we are taught about settling babies into childcare environments."

Key workers also felt they were burdened with "unreasonable demands at home and work" as they tried to balance their family and job responsibilities. Experiences varied between those who reported receiving help (such as with school placements) and those who felt completely unsupported: "The only way myself and my husband could actually look after our children was by having COVID and needing to self-isolate and be off work."

Some parents from the sample group mentioned arguments over childcare duties, especially when both were working. Many worried about the impact on their children's education, adding that they felt guilty and that they had failed as parents. One respondent said working from home "led to an even poorer outcome for our younger children as we were essentially there but not available to them".

Abuse from public

NHS/pharmacy staff, retail workers, police and teachers whose responses were analysed all reported some level of abuse specific to their roles. NHS/pharmacy workers mentioned increased paperwork, which directly impacted the amount of time they could dedicate to patient care. Overstretched GPs described being alone while facing angry (and sometimes violent) patients. GP practice staff felt threatened and unsafe dealing with people "demanding which vaccine they believed they should get". One respondent said:

"The media had convinced them that the AstraZeneca vaccine was going to give everyone a blood clot, and I literally had people screaming in my face that I was trying to murder them when I told them the AstraZeneca vaccine was what they were being offered. One of my colleagues was spit on."

Pharmacists who reported taking on additional duties to cover for shuttered health providers described significant public abuse: "I felt abandoned, and I will never forget the verbal abuse we faced at all stages of the pandemic."

Respondents working in retail recounted being "abused by customers on a regular basis". Retail employees highlighted safety concerns and expressed frustration with managers for not preventing customers from breaking regulations, such as shopping multiple times per day. However, shop managers said they felt unable to enforce these restrictions, or safety regulations, partly due to the abuse they received from customers when trying to do so.

Pressures of working on the frontline

Staff working on the 'frontline' of the pandemic were those whose jobs involved directly treating or dealing with people who had the virus. These workers were often exposed

to the virus for long periods of time. Many frontline workers from the sample group mentioned long shifts, staff shortages and fear of bringing COVID-19 home to their families. Care home workers and nurses, for example, spoke of inadequate preparation and changing or inconsistent guidelines. Many participants described having to take on additional duties at work to cover services that had been suspended:

"Our call volume was overrun with mental health calls, it felt like the mental health services were on their summer holidays during lockdown and it was left to the emergency services to captain the ship."

Some teachers from the sample group described online teaching as "a nightmare", with pupils lacking equipment and/or not participating in classes. They said they had not been given the time or tools they needed to make the transition to online teaching.

Frontline key workers said the pressures of conflicting responsibilities caused burnout and left them feeling they were being "treated like a robot". According to some respondents in the sample group, not all key workers had the same access to PPE, vaccinations and childcare, leaving them feeling resentful towards other key workers who were perceived to be receiving preferential treatment. Some respondents reported being so profoundly affected that they resigned from their jobs or took early retirement: "We have been profoundly damaged by the pandemic and neither of us feel able to work full time, ever again."

Key workers from minority ethnic backgrounds who were working on the frontline during the pandemic reported experiencing discrimination from their employers and members of the public. One respondent said that despite being at higher risk from COVID due to their ethnicity and a pre-existing health condition they were not supported by their employer. The respondent said their employer did not provide appropriate PPE or enforce social distancing in the workplace.

"I am from an ethnic background and have a health condition which put me at greater risk of serious complications should I have contracted covid. This had an adverse effect on my mental health and well-being. I had no help or understanding from my employer (public sector)."

A report on the treatment of lower-paid minority ethnic workers in health and social care, published by the Equalities and Human Rights Commission in 2022, found that they were at increased risk. When compared with white or British workers, minority ethnic workers reported being assigned higher-risk tasks and being redeployed to COVID-19 wards. The same report also found that minority ethnic workers were subjected to discrimination by some patients: "18% of ethnic minority staff in all pay bands across the NHS reported experiencing discrimination from patients or other members of the public, compared with 4.6% of white staff."⁶

2.4 Personal Protective Equipment (PPE)

Responses from the sample group which discussed PPE largely focused on key workers' access to, and use of, protective equipment.

PPE was mentioned by many key workers, including those in the healthcare sector, care home workers, and workers from other public-facing sectors such as retail, education, childcare, community work, policing and transport.

⁶ Equality and Human Rights Commission, *Experiences from Health and Social Care: The Treatment of Lower-paid Ethnic Minority Workers* (EHRC: June 2021), p. 8. URL: https://www.equalityhumanrights.com/publication-download/experiences-health-and-social-care-

treatment-lower-paid-ethnic-minority-workers

Respondents in the sample group frequently reported a lack of PPE available at the start of the pandemic and difficulties with procurement. One key worker said: "PPE was a disaster. It wasn't available in full for NHS staff."

Some healthcare workers in public-facing roles reported not being given PPE, which they said had been prioritised for hospital-based colleagues. The equipment they were given instead was described as "ill-fitting" and "of poor quality". Care home workers said PPE was rationed, reused and had to be borrowed or sourced privately by staff. One healthcare worker recalled: "During the initial phases of the pandemic, we had no PPE and were reliant on being able to beg or borrow masks."

Other respondents who worked in community social care settings (outwith hospitals or GP surgeries) said they felt deprioritised when it came to the provision of PPE:

"First the hospital was given good PPE and the staff were looked after well and supported. But when it came to the community workers, they had limited access to PPE. Somehow the lives and health of community staff were not as valued as those in hospitals."

Police officers in the sample group also reported a lack of PPE: "During the initial stages of the pandemic, I was required to attend suspected COVID deaths unvaccinated and without adequate PPE."

Other key worker respondents referred to lax enforcement of mask-wearing in public settings. A teacher stated:

"Mask wearing was never compulsory in schools. As soon as one pupil didn't fancy it, management refused to enforce it... My own anxiety around dying was deemed irrelevant." There were mixed feelings across the responses analysed about the effectiveness of facemasks in preventing infection. These views were not limited to key workers. Some respondents felt colleagues and members of the public did not wear facemasks properly or re-used them. A small number of respondents expressed the view that some varieties of facemask did not provide adequate protection. One respondent said: "The so-called disposable surgical masks used by so many could never provide the protection alluded to in the advice issued by the government."

2.5 Healthcare

Although a small number of respondents in the sample group expressed positive views on the NHS during the pandemic, many felt the NHS had failed to meet the standards they expected during the pandemic, was unprepared and had failed to communicate effectively: "The NHS was unprepared for [a] pandemic situation. It was chaotic, badly managed and badly organised."

Communication challenges

Many respondents said poor coordination between different areas of the healthcare system affected their care and risk assessment for COVID-19. As mentioned previously, some respondents who expected to be assessed as being at high risk from COVID were not. Others noted that arranging prescriptions and making appointments to see a doctor were unnecessarily complex and stressful for patients and staff.

Patients and their families faced challenges trying to adapt to new ways of communicating with healthcare staff. Respondents spoke about the restrictions in place between January 2020 and December 2022, which meant they were unable to

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have a face-to-face conversation with their doctor. Respondents felt guilty about asking a nurse to check on a patient or asking them to speak with a patient who did not have access to a mobile phone. Test results and diagnoses, which would have normally been shared in person, were communicated by telephone, leaving some patients feeling "devastated". One respondent recalled their father being happy to receive a call from his mother, who had recently been admitted to hospital, "only to realise a consultant was sitting with her. They Facetimed my father to let us know my mother had cancer."

Communication within hospitals also became challenging, according to many healthcare workers from the sample group: "There was uncertainty and lack of clear instructions, particularly when most policy changes were spread by word of mouth from managers rather than the usual channels." Many felt this way of communicating led to confusion as to how guidance should be implemented. This meant that guidelines were implemented differently across departments, according to the responses. A few participants noted these communication challenges resulted in a lack of oversight in keeping COVID-19 infected patients separate from other patients.

Delayed and missed diagnoses

Several respondents described missed or late diagnoses with tragic consequences, often attributed to the inability of GPs to schedule face-to-face appointments – an issue that many report has continued. The Scottish Association for Mental Health also noted in its 2021 report, which was submitted to Let's Be Heard, that the move away from inperson appointments was particularly problematic for the public.⁷ One respondent described how telephone consultations with a relative meant "the surgery [team] missed out on the fact he has diabetes. He had to have emergency surgery to have his leg amputated." The inability to make an appointment meant that another

⁷ Scottish Association for Mental Health, *Still Forgotten? Mental Health Care and Treatment During the Coronavirus Pandemic* (March 2021).

URL: https://www.samh.org.uk/documents/Still_Forgotten.pdf

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respondent's wife received a late diagnosis of lung cancer and she subsequently succumbed to the disease. Another respondent stated: "We believe that our mum may well have lived longer had the diagnosis come sooner."

Coping alone

Many respondents recounted how they, or loved ones, were forced to travel by ambulance, attend hospital appointments, have major surgery, undergo cancer treatments or give birth alone due to COVID-19 restrictions. This was often described as deeply traumatic. One person noted: "My father-in-law went from cancer diagnosis to death almost completely alone, except for the final week." A paramedic recalled: "I watched, often holding back tears as relatives said goodbye to loved ones as if it was their last time, every time we took someone to hospital." Respondents described how families were not allowed to be with critically unwell patients but were briefly admitted to see them when they were near to death or had died. Many felt these restrictions lacked logic and compassion.

Suspension of services

Responses frequently reported treatment being suspended due to COVID-19 restrictions, often continuing to the present. As one GP put it:

"The worst part of the Covid pandemic for me, as a GP, was not the virus itself, but the compromise to daily service that our patients required then and still require now, with waiting lists and delays to investigation and treatment that have not yet recovered in 2023."

All NHS dental services stopped at the start of the pandemic in 2020 and some have resumed but without informing registered patients, according to respondents. One participant noted: "My children to this day have not had any of the normal periodic dental checks that were the norm before the pandemic." Another respondent stated: "Health services were too focused on covid to the detriment of other services." The severe negative impacts of delayed or cancelled medical treatment were also noted by the ALLIANCE and Age Scotland in reports shared with Let's Be Heard.⁸

2.6 Care homes and nursing homes

There was a mix of experiences shared among responses around care and nursing homes, including a focus on rules and restrictions, care of residents, transfer of residents from hospitals and the experience of losing loved ones in these settings. Care homes, in this context, are organisations which provide residential care for people who need extra support in their daily lives, such as older adults and people with additional support needs. Nursing homes, in this context, provide nursing/medical care in addition to personal care. The experiences in this section are shared from three different perspectives: those living in homes, those with family members living in homes and those working in these homes during the COVID-19 pandemic.

Rules and restrictions in care and nursing homes

Several respondents discussed the ever-changing rules and restrictions placed on nursing and care homes in Scotland during the early months of the pandemic. While some described the guidance as "complicated and confusing", others felt it was "wellcommunicated and sign posted". A few responses from staff in care and nursing homes suggested it was difficult to put guidance into practice when it was "constantly changing" and there was not enough time to think about how best to implement it.

⁸ The Alliance, *Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future* (2021) URL: https://www.alliance-scotland.org.uk/lived-experience/wp-

content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Executive-Summary.pdf; The ALLIANCE, Humans of Scotland: Stories from people during COVID-19 (2021); Age Scotland, *The Big Survey 2021: A Snapshot* (2021). https://www.alliance-scotland.org.uk/humansofscotland/stories-from-people-during-covid-19/

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Respondents with family members living in more than one care or nursing home also found it difficult to understand how the same guidance led to different practices in different homes. One respondent said she was allowed to visit her brother through the window at his care home but her mother, who was living in a different care home, "was not allowed to even see us on her 95th birthday, not even through her window or a video call".

Numerous respondents said the implementation of rules and restrictions led to many residents in care and nursing homes feeling isolated. Several respondents considered the rules to be particularly distressing when patients were unable to understand their purpose, for example patients with dementia. A respondent who worked in a care or nursing home setting during the pandemic said:

"We had to ask people who often had limited insight to become even more isolated from family and friends, and while we all knew that this was a necessary part of keeping people safe, it often felt cruel."

Family members described how restrictions left their loved ones isolated and with "a very poor quality of life". Adaptations such as window visits were described as beneficial when residents had capacity to understand the need for them, but confusing and distressing when they did not.

There was concern expressed from a few staff members that the rules and restrictions placed on care and nursing homes were developed specifically for elderly patients. Some said the rules did not cater to the needs of other groups of people living in residential care, such as disabled people or those recovering from addictions. A member of staff who worked in a residential home for autistic adults said: "We had to follow all the legislation that an older age care home would, despite us catering for a different clientele therefore were much harder to follow. We struggled to communicate with non-verbal and verbal clients due to mask wearing. A lot of our clients display physical touch for reassurance and were denied this and they didn't understand why."

Care of residents

The experiences shared of care during the COVID-19 restrictions were mixed. Some participants said they felt staff were doing their best under difficult circumstances, showing appreciation for the care their relatives received: "I felt the care home staff were so sensitive and respectful even in the middle of a pandemic." Others, however, felt the treatment of their relatives was poor: "The treatment she received in the nursing home was at best mixed. I will regret to my dying day allowing her to enter that care home."

Much of the poor treatment of residents was attributed to the restrictions put in place and staff shortages, limiting the ability of staff to provide the optimal standard of care. In their responses, people who worked in these care settings reported poor working conditions such as staff shortages, poor access to PPE, a lack of information and rules they did not feel able to implement:

"What I witnessed in the nursing homes I can only compare to a war zone. There were minimal staff as many of them had become ill themselves and minimal medical care for the residents. They were acutely unwell and were left there to be cared for by staff who were struggling."

While the conditions were challenging, staff also reported the sacrifices that were made to maintain a decent standard of care for their residents: "In another care home they had a resident sent back who had Covid and went on to infect three other residents. The care home manager moved in to care for the infected residents on their own to try and protect the other staff in the care home. This is only one story of self-sacrifice that we heard as we went around the different care homes."

Transfer of residents

Many respondents had negative experiences surrounding the transfer of residents from hospital to care and nursing homes without adequate testing. Only one response in the sample group felt the transfers were "something any sensible manager would do", considering it an appropriate decision to make space in hospitals for patients requiring acute care. The remaining responses considered the decision to bypass testing at best "thoughtless" and at worst a "criminal" decision: "Sending untested elderly people from hospitals into care homes to 'seed' the virus there is unforgiveable."

Loss and death

Many respondents shared the experience of losing family members in care and nursing homes. People shared the pain of being unable to be with their loved ones prior to their death or as they were dying. One respondent described watching their father pass away while "standing outside his window". Other experiences related to death and dying are described in more detail later in this section.

Staff in the sample group spoke of the significant loss of life they bore witness to:

"I had watched while our nursing home was reduced from 50 people to less than 10, our LD [learning disability] support home reduced to only 2 young people- all dead due to Covid." Staff said that these challenges were exacerbated by loved ones being unable to visit. One staff member recalled the emotional toll of having to repeatedly telephone relatives to notify them of a death:

"Also under stress, as we had to deliver news of death over the phone to relatives, who were barred from visiting their loved ones. I now find this job a mental/emotional drain, rather than a positive one."

2.7 Social care: care at home and unpaid carers

Within the analysed sample, there were a limited number of responses from people providing unpaid care to family and loved ones and from people receiving care in their own homes. Unpaid carers are defined as a person of any age who provides unpaid help and support to wife, husband, partner, son, daughter, parent, relative, friend or neighbour who cannot manage without the carer's help.⁹

Respondents who did speak on this topic reported the emotional strain of caring alone for someone. One respondent, who was already caring for her husband, who had dementia, explained how difficult it was to get support during the pandemic when she also began caring for her sister:

"Getting help from doctors and social work was almost impossible. About a year into covid I finally got help after threatening to leave my husband sitting on their doorstep. Within a week we had carers."

Some unpaid carers reported they were unable to care for family members living far away due to their own health conditions and other caring commitments at home. They also spoke of the financial burden of not being issued with PPE as unpaid carers, and not qualifying for support if the person they cared for was not on the shielding list.

⁹ NHS Western Isles, Are you a carer? Information and advice for carers in the Outer Hebrides. URL: https://www.wihb.scot.nhs.uk/i-am-a-carer/what-is-an-unpaid-carer/

It should be noted that the experiences and views of individuals who identify themselves as unpaid carers are under-represented in this sample, and that future findings would be enriched by more submissions from this group.

2.8 Death and dying

Respondents shared experiences relating to death, dying and end-of-life care. There were some mentions of deaths related to COVID-19 but in many cases the deaths were attributed to other conditions, with several related to cancer. Individuals described how restrictions impacted their access to GPs and specialist care, delaying diagnoses. Participants also highlighted how restrictions had left them unable to provide comfort and care to sick and/or dying loved ones, as well as identifying an inability to provide support through grief.

Respondents also shared very personal stories, recounting their experiences of losing loved ones, and the heartache of watching them deteriorate over video calls or through windows. One participant described how her daughter, in her late 20s, was diagnosed with advanced cancer and died three weeks later without them being able to visit her in hospital. The only contact they had was through Facetime: "To watch your child slowly dying over Facetime is something no parents should ever have to go through."

Several respondents shared similar stories of loved ones dying alone. In some cases, family members lived far away and were prevented from travelling to visit, while others were limited by hospital and care/nursing home restrictions: "Nobody should ever have to die on their own when they have a loving family desperate to be by their side." While most responses discussed negative experiences in relation to end-of-life care, some also spoke positively about the care and attentiveness that healthcare and medical staff had provided to their loved ones.

Grieving

Many people described the severe impact lockdown rules and restrictions had on their ability to gather with family for funerals and celebrations of life, and grieving after the loss of a family member or close friend.

"Not being able to attend the service for my Uncle's funeral and the family not being able to gather or grieve together will forever be a source of pain."

Families and friends being unable to gather to grieve together is described in responses as having ongoing impacts. These are described in more detail later in this report.

Do Not Attempt Cardiopulmonary Resuscitation

'Do not resuscitate' (DNR) and 'do not attempt cardiopulmonary resuscitation' (DNACPR) are medical orders that instruct healthcare providers as to whether they can intervene if a patient's heart or breathing stops. Many participants expressed concern about the perceived pressures being placed on patients and their family members to sign DNR and DNACPR orders without being given appropriate information, or time, to consider the implications. The importance of DNRs was acknowledged by some, but they also stressed the importance of allowing a patient time to make an informed decision.

"The way in which patients or relatives were being asked was inappropriate. It came across entirely as a financial relief for the hospital or a release from additional workload to attempt resuscitation. A deeply offensive way to approach a practical discussion during a time of clinical need."

Additionally, within the sample group, there were a few respondents who expressed concern that DNRs were being assigned without any prior knowledge or patient consent. For example, some respondents shared instances of people finding out upon recovery that a DNR had been assigned without any consultation. One participant recognised that it might be "practical" to discuss DNRs in future, but the way in which the subject was raised was "inappropriate". The same person commented that in one hospital "both doctors and nurses [were] asking patients/relatives to sign a DNR rather than consider putting one in place".

2.9 School and education

COVID-19 also had an impact on early years/pre-school, primary school, secondary school, and further and higher education. Responses in the sample group analysed include the perspectives of parents and pupils/students submitted by adults and children and young people.

Early years and pre-school

There were limited responses that discussed the experience of early years and preschool care for children under five. The few respondents who did speak to these experiences reported that the closure of baby and toddler groups increased isolation for both parents/guardians and their children: "I and others with small children could not restart the toddler groups, drop-ins and other gatherings that are a lifeline to isolated people." Furloughed parents/guardians, or those with free time, described enjoying the time spent with their young children during lockdown. A Place in Childhood, a report shared with Let's Be Heard, also found inequalities between parents who were furloughed and parents who were not.¹⁰

Responses from staff often described high levels of stress due to their perception that guidance for early-years settings was not prioritised. They also described last-minute changes to working practices, insufficient access to PPE and poor communication from local authorities. As one respondent noted: "Staff are still dealing with stress/anxiety/depression stemming from the immense pressure we were under."

Many staff also expressed concerns about the negative impact of pandemic restrictions on the social and emotional development of young children, with one staff member stating that delayed speech development and sleep problems are common among children born during lockdown.

Primary and Secondary Education

While a few respondents noted that schools tried their best, many felt the move to online learning was harmful to children's educational, social and emotional development, and that gaps in learning and socialisation would be difficult to overcome: "Those who had support at home for learning have lost less learning than others, but all have lost the social skills." In another report shared with Let's Be Heard, A Place in Childhood also reported that remote schooling was taking a toll on children's well-being.¹¹

¹⁰ A Place in Childhood, *COVID-19 for Children and Young People: Learning from Primary School Children* (2022).

¹¹ Hamilton, J., & Wood, J., *Children and Young People's Participation in Crisis: A Research Report'* (A Place in Childhood: 2020). URL: https://aplaceinchildhood.org/covid-19-research-report-children-and-young-peoples-participation-in-crisis/

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Adults and children and young people from the sample group reported that the quality of online teaching was "inadequate". However, some teachers noted that their efforts were not sufficiently recognised. One said: "We have been lambasted as 'lazy' and doing nothing during the two lockdowns. We worked very hard through it all, yet we haven't had that acknowledged."

In discussions about learning from home, some respondents felt it was unfair to expect families to teach children at home when many did not have the capacity or resources to do so. Other parents commented that furlough gave them the opportunity to support their children in learning from home. The wider impacts of these competing demands are discussed in the 'changing family dynamics' section of this report.

Many responses emphasised the impacts on educational attainment and social development, as well as students' increased anxiety around exams and attending school. One respondent said: "I don't feel education was prioritised enough, or the potential long-term effects on children given enough consideration, educationally, socially and mental health."

Those with children with additional support needs reported a lack of adequate support. A respondent stated: "Both of my children are autistic. The lockdown broke our routine and has affected schooling beyond repair."

It should be noted that Let's Be Heard only received a small number of completed forms from school staff and that future findings would be enriched by more submissions from this group.

Further and higher education

Further and higher education in Scotland refers to post-secondary school education, typically in colleges or universities. Many students reported their studies had been disrupted due to factors such as family care needs (e.g., returning home to look after younger siblings) and being on the shielding list. Many respondents felt online learning was insufficient to meet student needs. Many also noted that students living alone experienced isolation, whereas those in busy households struggled to concentrate. Some felt this contributed to failing exams or modules, or to delays in completing their courses:

"I was studying my HNC [Higher National Certificate] for nursing and having to carry out all coursework from my box room at home. As a result of this I failed one test on my unit and failed that year all together, thus setting me back a year from being able to move forward closer to becoming a nurse."

Online learning was particularly damaging for students in practical subjects, according to respondents. As one lecturer explained:

"Learners had went months with no practical learning then, we were given very little time to get them through their qualification before the new intake of learners started. Some learners dropped out and others simply did not pass through no fault of their own."

Other staff respondents outlined how hard they worked to support students, and the toll this took on their mental health.

2.10 Long COVID

Long COVID signs and symptoms are defined as those which "develop during or after an infection that is consistent with COVID-19 [and] continue for more than four weeks and are not explained by an alternative diagnosis".¹² Respondents described their experiences of living with long COVID and detailed how the condition had transformed their day-to-day lives. As one participant stated:

"I was fit and healthy, working full-time, attending 3-4 exercise classes each week, running a home, caring for relatives and socialising with friends. I am now essentially housebound. I use a stick indoors and a wheelchair or mobility scooter outside. My life is unrecognisable now."

Respondents suffering with long COVID overwhelmingly reported that they felt "abandoned" by health services. Many struggled to have their condition diagnosed or even recognised by health practitioners. One respondent said: "I had lasting symptoms of memory loss, fatigue, breathlessness which have now lasted over 3 years, but I was only recently told I have long COVID."

When respondents were diagnosed with long COVID, many felt health services offered little support with the condition. Responses often conveyed a sense of hopelessness around how to continue with long COVID.

"I contracted covid in October 2020 and had horrendous experiences with staff of the NHS and continue to do so as I have never recovered and have long covid as a result of the virus. There is absolutely no support, treatment, further investigations or interest in my health. The best I have been offered is antidepressants because my mental health has taken such a bad turn."

¹² SIGN, Healthcare Improvement Scotland, *Managing the long-term effects of COVID-19*, URL: https://www.sign.ac.uk/our-guidelines/managing-the-long-term-effects-of-covid-19/

Some respondents with long COVID stated they were key workers and had contracted the virus at work. They expressed frustration and disappointment at what they perceived was a "lack of recognition for the sacrifices they had made".

"I am in considerable pain every day. I do not have a family life or a social life. [...] All thanks to succumbing to Covid in my workplace as a Key Worker. A Key Worker! I don't feel [...] that I have been treated as a Key Worker since January 2022. We have all been forgotten about and left to fumble through what remains of our lives which have been very much changed for the worse."

Those on the frontline who were from minority ethnic communities were also at risk of contracting COVID-19 and were more likely to be hospitalised, compared to people who described themselves as 'white Scottish'.¹³ One participant noted that they were at particular risk because they were from a minority ethnic background, and that many minority ethnic doctors had died from COVID-19. They said they had contracted COVID-19 at work, struggled to return and when they did their manager refused to make any adjustments for their long COVID symptoms:

"I met with my manager, they flatly refused to adjust my job. This added to my long-suffering. I felt like an animal. No one supported me. My long COVID was called an agenda when I asked for help."

Responses detailed that further hostility was apparent when respondents from minority ethnic communities with long COVID received threatening feedback about their work performance, and questions about their plans to remain in Scotland after retirement.

¹³ Public Health Scotland Monitoring ethnic health inequalities in Scotland during COVID-19 (2022), p. 9 URL: https://publichealthscotland.scot/media/11979/pra_annual-monitoring-report-on-ethnic-healthinequalities.pdf

Participants also mentioned that contracting long COVID had made them unable to work and had forced some into financial hardship or early retirement. One respondent said: "I am likely to lose my job soon and am worried about using my savings and being unable to pay my mortgage."

3. We Asked: What were the impacts of these experiences on you or the people you know?

You Said...

This section of the report focuses on Let's Be Heard's second question: What were the impacts of these experiences on you or the people you know?

Responses show that despite there being a diverse range of experiences throughout the pandemic, the *impacts* of COVID-19 across Scotland were broadly similar. Previously, this report looked at people's individual experiences. This section relates to the impacts of those experiences, and discusses some of the broader thematic impacts that were experienced. These include impacts on:

- older people;
- children and young people;
- family dynamics and relationships;
- people's level of trust;
- life events such as birth and death;
- financial security; and
- mental health and wellbeing.

3.1 Older People

As discussed previously, many respondents felt isolated and lonely during lockdown. One group significantly impacted by this was older people living in care and nursing

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homes. Respondents described how, for long periods of time, care homes prohibited friends and family from visiting. When visitors were allowed, they were only able to meet their relatives or loved ones through a window. One person spoke about her 98year-old mother and how hard this period was for her: "She did not understand why she could not see her family. Luckily, we continued to visit at her window until that was stopped."

A few respondents highlighted the additional challenge of moving their parent(s) into care for the first time during the pandemic. They said they were neither allowed to go inside the home to settle their parent(s) nor were they allowed to visit, due to restrictions at the time. Describing their experience of moving their father into care and the impact this had, one participant explained: "He was isolated and alone and dealing with a massive change with no family support." In addition, a few participants said this left their parent(s) feeling "abandoned", "hurt", "lonely" or "distraught".

While some respondents shared the benefits of using online tools and mobile apps, such as WhatsApp, Zoom and Facetime, to stay connected with family members, others said using video conferencing technology was not always easy or possible. Many people across Scotland are affected by digital exclusion, which can occur when people do not have access to affordable or reliable digital services or do not have the requisite skills to use them.¹⁴

During the pandemic, digital exclusion particularly impacted older people who were less likely to be familiar with using digital devices and services or had impairments which made accessing them more difficult. As one respondent noted: "Technology is

¹⁴ Tim McKay, *The Digital Divide - inequality in a digital world, Blog: Digital Exclusion,* (September 2021), URL: https://www.audit-scotland.gov.uk/publications/blog-digital-exclusion

not helpful when someone has eyesight problems and hearing difficulties and doesn't necessarily understand how it actually works."

Some older participants explained how this left them feeling isolated: "The isolation and shame of not being confident with the technology was awful."

3.2 Children and young people

This section provides an overview of the key impacts on children and young people during the pandemic in Scotland, as described in Let's Be Heard responses. Let's Be Heard provided a response form specifically designed for children and young people. Adults, and children and young people, are quoted and referenced in this section.

Boredom and home learning

Common themes identified in the sample responses from children and young people included feelings of boredom and monotony during lockdown. Many said they initially felt happy at the prospect of school closures, but as the weeks and months passed they began to miss attending school. Sentiments such as the following were common: "At first, I was glad to miss school but then I felt trapped at home. I was just waiting for it to be normal again." This common sentiment was also highlighted in a 2021 report by the Children's Parliament, which was shared with Let's Be Heard. It noted that children can feel "stuck" inside, and that this is felt most acutely by children who do not have access to a safe outside space or private garden.¹⁵

Online learning arrangements did not appear to alleviate these feelings of boredom for children and young people, according to the responses. The vast majority of children and young people who discussed home learning felt the arrangements put in place

¹⁵ Childrens Parliament, Corona Times Journal Edition 1 (2020),

URL: https://www.childrensparliament.org.uk/news/childrens-journal-1/

were inadequate, unengaging and did not effectively maintain their education during lockdown. Many felt the work provided was insufficient or poorly explained, while some felt overwhelmed with trying to focus on learning at home. As one respondent noted in their children and young people form:

"The whole thing was a fever dream, I did literally 1 piece of schoolwork the whole time and was not motivated to do any more. I was constantly on tiktok and netflix. I feel I missed key parts of school and when I returned it was straight into exam prep."

As discussed in a previous section, many adults expressed the view that learning from home resulted in a poorer standard of education for their children. Parents also found it difficult to help with home learning. A few children and young people also said that not having access to laptops or other resources had a negative impact on their home learning. The A Place in Childhood report also noted the increased stress on family resources and an overload of screen-time had a negative impact on children's development during this time.¹⁶

Children and Young People's Mental Health and Wellbeing

Both adults and children and young people indicated in their responses that the pandemic had had a detrimental impact on the mental health of children and young people, as well as on their social and emotional wellbeing. One respondent said: "The impact on our young people (under 25) of lockdown absolutely dwarfs any health impact from Covid."

Adults expressed concern in their responses about a perceived deterioration in the development of children and young people, as well as high levels of anxiety around the

¹⁶ Hamilton, J., & Wood, J., *Children and Young People's Participation in Crisis: A Research Report'* (A Place in Childhood: 2020). URL: https://aplaceinchildhood.org/covid-19-research-report-children-and-young-peoples-participation-in-crisis/

long-term impacts: "I volunteer in a school with many vulnerable families in it - the deterioration for many in behaviour and emotional maturity is staggering."

Many children and young people mentioned experiencing isolation and loneliness because they were unable to see friends or family. Fears around loved ones catching COVID-19, particularly elderly relatives or family members who were key workers, were also cited by some children and young people: "I felt very lonely and I started to become an anxious person due to the fear of my family and friends getting covid."

Children and young people also talked about experiencing bereavement and their sadness at not being able to say a proper goodbye to loved ones due to restrictions on care-home/hospital visits and funerals at the time.

Children and young people's responses also discussed experiencing considerable and debilitating anxiety during the pandemic. A few respondents in this age group said this manifested as anxiety around catching the virus and excessive concern with hygiene. A few described overall feelings of helplessness, loss of confidence and lack of motivation, as the following response explains:

"I was alone a lot doing schoolwork which, looking back now was useless, I didn't learn anything anyway, I don't think I was capable to, I was so lonely and I remember just sitting staring at the computer screen doing nothing, I was quite sad and would cry over little things like if I burnt my food or lost something, I was miserable, my mental health was declining."

Responses from adults and children and young people indicated that some children and young people struggled to return to school after lockdown or did not return at all. Both age groups also acknowledged that due to the pandemic children and young people had missed out on years that were educationally, socially and emotionally formative:

"I used to be involved in a climbing club and had started to go to competitions before the pandemic but it closed for two years and now I don't feel confident to take it up again so I feel the closure has changed my future path."

"Lockdown and school closures have caused a generation to fall behind with education which many will never catch up."

These adverse impacts on mental health were compounded by a lack of access to mental health services, according to some respondents. The Scottish Association for Mental Health also noted this in a 2021 report shared with Let's Be Heard, which stated that mental health services were very thinly stretched and there was insufficient capacity to respond to mental health needs during the pandemic.¹⁷

Positive outcomes for children and young people

Some children and young people said they found certain aspects of the pandemic and lockdown rules enjoyable or that they had had a positive impact. Respondents who already found socialising or attending school emotionally challenging said they were grateful for extended periods of being at home and changes to schooling, with some also pointing out that learning from home allowed them to sleep for longer. Some of these responses also said that being at home allowed them to spend more time with their family, or pursue other activities they enjoyed:

"My life didn't really change because I still had football I also kept in good contact with friends I knew. I felt amazing because I had more time to play football and play more sports. I had more and more football practice as I got better at it. It

¹⁷ Scottish Association for Mental Health, *Still Forgotten? Mental Health Care and Treatment During the Coronavirus Pandemic* (March 2021). URL: https://www.samh.org.uk/documents/Still_Forgotten.pdf

changed because I spent more time with my family. I feel good about what happened in covid."

The impacts of caring for children aged up to five

Only a small number of responses in the sample group referred to experiences related to having children up to the age of five. Of these, many – especially of those who identified themselves as key workers – discussed the difficulties around balancing childcare arrangements with work. Managing learning from home with young children was also recognised as difficult, especially for families with more than one child in the household. On the other hand, some respondents said home-working or furlough allowed them to spend more time with very young children, especially those in early and formative years: "One positive was that my husband was able to work from home, which was probably helpful re my mood and ability to cope in the early months of having the new baby."

3.3 Changes to family dynamics

Lockdown restrictions had a significant impact on family dynamics, according to respondents. For some, being locked down at home with their family was a positive experience, while for others it was stressful and challenging. Respondents also reported that lockdown led to them being separated from family members, which caused its own stresses:

"My son who was 14 at the time [and] had to make a decision where he was going to stay. With his Dad & step-mum (she had to shield as vulnerable) or me." "We all thought it would be better sense to stay at his Dads & keep him safe too. He was there for 13 weeks & 3 days. The impact this has had on myself is awful. We facetimed for the 1st 6 weeks then he came for garden visits for an hour which was all that was allowed. We did not hug as we couldn't. I coped with it at the time, but afterwards the affect it had on my mental health & anxiety which I'd never suffered much with was awful. I will never do that ever again."

Lockdown families

Many respondents found that periods of lockdown spent at home were positive, "bringing us closer together" and had helped improve mental wellbeing as a result of "slowing the pace of life to a more manageable level". The furlough scheme provided relief for some households, allowing parents to manage childcare responsibilities while working from home. One respondent reported that since her husband was furloughed, he was able to teach their children under the same roof while she worked at home. Another respondent said: "COVID helped me change my view and perspective of how I see life. Now I cherish every moment I get with my family and friends."

For others, balancing work and learning at home was challenging. For example, one respondent reported that the strain of shielding, combined with working from home while teaching two young children, led to the breakdown of her marriage and created a very stressful situation at home. Parents also described the stress and guilt they felt trying to balance looking after their children with working and managing home or online learning.

Several participants were concerned they had created long-term mental health issues for their children by not spending enough time with them during lockdown. Between their work and other life pressures, participants said their levels of stress were unlike anything they experienced before.

Key workers with young children described the additional stress of working away from home and trying to care for their children. A senior nurse described the guilt she felt being away from home and then trying to support her children's learning when they were at home: "I was unable to be their mum and teacher and boundaries were very blurred and I felt like I failed at both jobs."

Another key worker described living apart from their family to protect them from infection, leaving their partner to cope with raising their children alone and having limited contact with them:

"I spent months 'playing' with my daughter though a window - my daughter perched on her windowsill with some of her toys, and me standing outside feeling like an observer of my own life. I will never get that time back."

In some cases, lockdown meant children and young people had to take on extra responsibilities, such as food shopping and collecting prescriptions. A child of a key worker described the impact this had on them: "I also spent a lot of time looking after my siblings as my mum worked nightshift and would sleep during the day." Another young person described the pressure to help their mother after she came home with a new baby one day during lockdown: "Gran wasn't allowed to visit to help mummy so I felt I had to help but I didn't know what to do."

Family separation

As highlighted previously, one of the most significant impacts of the pandemic was family separation. Respondents told Let's Be Heard how concerned they were about family members they were not able to be with, particularly older family members:

"I understand the need to keep people safe and to stop the spread of infection, but for families that have parents living alone and several miles away, this was very difficult and still has had an impact on my family to date." One respondent reported that the difficulties she experienced caring for her mother, who lives on her own hundreds of miles away, still have an impact on her family. Another family from the sample group could not visit their mother as they would have done before the pandemic. One family member recalled how a sibling who lived some distance away was unable to see their mother before she died: "Her mild dementia deteriorated quickly, and she died without him being able to see her during her final four months."

Isolation

When Scotland's lockdown restrictions eased in the summer of 2020, people were allowed to form 'bubbles', which went some way to addressing concerns about social isolation, according to respondents. While many welcomed these social bubbles, for some respondents it meant choosing between family members, such as between seeing their parent or child, if all three lived separately. Respondents also described being unable to be in social bubbles with relatives who lived further away as very difficult, adding that this still has an impact on their family.

3.4 Trust

Respondents reported that the pandemic had an impact on their trust in government, science and other people.

Questioning the science

Among responses which referred to declining trust, one of the key factors was scepticism around the science behind lockdown. A small number of respondents indicated a distrust in science itself, but most distrusted what they saw as the "particular" or "partial" science followed by the Scottish Government. One respondent

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said: "At no time was any scientific evidence for the efficacy of masks or lockdowns or social distancing or shielding ever given." Others doubted the credibility of experts, saying: "We should not be exposed to so-called 'experts' pontificating government policy based on 'modelling' or rather guesswork."

Inconsistent rules

Some respondents' distrust of government stemmed from inconsistencies in the rules and restrictions. Respondents reported that these inconsistencies often made alreadychallenging experiences even more difficult or led to people feeling overlooked in decision-making. This was sometimes compounded by encounters with people in positions of authority who were unwilling or unable to modify protocols. Some felt the restrictions were not sufficiently flexible and resented the idea of having extremely low-risk, outdoor activities shut down due to blanket restrictions across Scotland.

One response in the sample group was from the grieving parents of a man who took his own life during the pandemic. Their grief was exacerbated by rules which did not allow them to identify his body together, despite the fact they lived together: "It was traumatic enough to have to identify our son but because of these ridiculous conditions and restrictions the ongoing pain of losing our son is worsened."

Betrayal

Several respondents were angry and felt betrayed that they had obeyed the rules when others did not. Their sense of betrayal was even greater when it was reported that government officials were breaking the rules. Many respondents recounted being willing to sacrifice visiting their elderly parents, or not attending the funeral of loved ones for the public good early on, and feeling that they had been made a fool of upon learning that rule makers had become rule breakers: "I agree rules [are] required to be put in place, but the upsetting thing is us the public stuck to those rules even during very emotional periods such as the loss of loved ones and funerals when the Prime Minister and members of the Government did not."

Trust in others

Respondents from the sample group reported some instances in which their trust in others had grown. For example, some reported positive encounters with friends, neighbours and strangers as well as feelings of community spirit and solidarity. These included accounts of people, such as healthcare workers, who went out of their way to offer compassionate care despite extremely challenging circumstances. As one respondent noted: "I have encountered individuals who tried their best to ensure humanity and compassion were provided to those in their care."

In contrast, several respondents also described experiences of suspicion and abuse, as well as their own lack of trust in others. Lockdown was described as horrible and led to people judging others, according to some responses. Several participants also noted the negative impacts of the pandemic on their trust in strangers and wider society for a range of reasons, including a fear of strangers instilled during lockdown, political disagreements and the sense that people had become more selfish and less trustworthy.

"Asking neighbours to report on their neighbours was another scandalous idea. One hardly likely to improve neighbourhood relations in already strained situations."

Future trust

Many respondents said they would not be willing to abide by similar restrictions in future, citing their recent experiences as well as concerns about the lack of preparedness for another national or international public health emergency. This theme appears to cut across opinions in the responses that questioned the severity of the COVID-19 virus and the necessity or effectiveness of restrictions in reducing its spread. Many responses referenced politicians from both the UK and Scottish governments breaching the rules as a reason for their scepticism and why their trust in government had diminished. For some, this was the first time in their lives they had felt this way. One respondent commented:

"If this was to happen again, I would do things differently, I would not stick to any rules and go and collect my mum or other family members that would be alone in this situation. [...] A precedence has been set by government, especially in Westminster so I can say a lot of people would do this differently and have the same thoughts as myself."

3.5 Life Events

Many respondents referenced the impact lockdown had on being able to engage with, and take part in, significant life and cultural events, such as births, funerals, weddings, birthdays, graduations and holidays. A few respondents acknowledged that they understood why the rules were in place, with some highlighting their importance. Several others identified these lockdown rules and restrictions as "inhumane", "disgraceful", "heartbreaking" and "unacceptable". The life events spoken about in the most detail were funerals, pregnancy and birth.

Funerals and life celebrations

One of the most common impacts mentioned by respondents were the limits imposed on the number of people allowed to attend these important life events. Even if the event took place outdoors and people were socially distancing, the numbers permitted had to remain low to adhere to COVID guidelines at the time. This placed considerable pressure and additional stress on families who were required to choose who was allowed to gather to grieve and say their goodbyes in person. Not being able to gather with family and celebrate the lives of loved ones placed additional stress on people who were trying to navigate grief and loss:

"I was so sad at the loss of my mum, she was the centre of our family and extended family. In her will she stipulated that at her funeral, 'make sure everyone gets a cup of tea'. I couldn't even get to do this small gesture for her friends."

Participants from the sample group emphasised the importance of having time to gather in person and share stories of loved ones, as well as being able to support one another as part of the process of saying goodbye. From the responses, it was commonly felt that not being able to gather in these circumstances prolonged the grieving process, and people described the long-term impact it has had on them and their family members.

Several participants questioned the value and necessity of some of the rules and restrictions imposed on funerals during the pandemic, such as being required to sit two metres apart. In opposition to these restrictions, one respondent stated: "Such overly simplistic interpretations of social distancing caused significant harm to our family and no doubt to many others, without in any way reducing perceived risk." Respondents felt the rules around funerals were particularly unfair because in other contexts people could gather in groups. One participant pointed out: "A limited number of people were allowed in the crematorium yet at the same time people were queuing closely together outside Primark." Participants struggled to understand the contradictory nature of the restrictions.

Pregnancy and births

A number of respondents recounted the experience of pregnancy and giving birth during the COVID-19 pandemic in Scotland. The earlier period of lockdown in March 2020 was highlighted as a particularly challenging time because of the strict restrictions in place. Some participants described having to miss appointments or scans before and after the birth of a baby, as only the pregnant person/mother was allowed to attend. Describing a high-risk pregnancy and traumatic delivery, followed by surgery for their infant son, one person described the negative impact these experiences had on him and his wife: "This caused us great distress and was the wrong policy in our opinion." He added: "My having to wait in the car for hours at a time whilst my wife took him in was not the right call for our family's wellbeing."

Respondents who were pregnant at the time described the impact of being alone and isolated during pregnancy, labour and delivery. At times, partners were not allowed in the hospital at all, or were only allowed to visit when their partner was in the labour ward. Once the baby was born, the partner was often not allowed to visit at all or only allowed into the hospital for a limited time, as exemplified by this response: "My husband was only able to attend the birth once I was in labour which was 1.5 days later. I was in hospital for another 1.5 days with no visitors."

The impact of these lockdown rules and restrictions was felt more widely by family members who were prevented from meeting newborn babies. People spoke about grandparents waiting months or even a year before being able to hold their new grandchild. Others described the impact of not having social and family support during those first few months as new parents. In addition, a few people spoke of the fear and uncertainty about how COVID-19 could affect newborn babies, which led them to further isolate themselves from visitors, even once the lockdown restrictions had been lifted. One person said:

"We initially didn't let grandparents hold our new baby for almost their first year due to concern of the lack of knowledge of how COVID may affect children both acutely and long term."

Several people emphasised the mental and emotional toll lockdown restrictions had on them, and the negative long-term impact they had on their experience as new mothers and parents.

3.6 Economic impacts

Only a small number of responses in the sample group dealt directly with economic impacts of the pandemic. Let's Be Heard will address this gap in responses during the focused engagement period starting in 2024. However, some more detailed responses around the themes of long-term economic impacts and the economic impacts on individuals can be seen below.

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Long-term economic impacts of COVID-19

Several respondents in the sample group commented on the economic impacts of the pandemic, and most suggested that the current cost of living crisis is a direct result of decisions made during lockdown. One respondent spoke of friends who:

"...couldn't afford heating last winter and are struggling to feed their children. This is a result of the appalling lies, misinformation and lockdowns which the government is responsible for."

Respondents who were business owners during the pandemic also identified how working from home had a negative impact on their business and the economy in general. The impact on nurseries, takeaway sandwich shops, bars and restaurants was highlighted by some as particularly acute. The impact on other sectors, such as agriculture, hospitality and community businesses, was also highlighted, with some participants expressing a sense of injustice and loss regarding their own experiences in this area.

Economic impact on individuals

Responses in this area largely focus on the impacts on the self-employed, with the key issue being a lack of support. One respondent detailed how not having access to business support left them in a terrible financial situation which, in turn, has negatively impacted their mental health:

"Because I was self-employed, I never received a penny and am £14k in debt with my mortgage, about to have my home repossessed. Other bills piled up, and it's a debt I won't be able to climb out of and will need to file for bankruptcy because my mental health is shot." Another person explained that their business was not eligible for support because it opened just before lockdown. Because of this, they had to give up the business and move away to get work, leaving family and friends behind. A self-employed personal trainer shared their experience of failing to receive government support:

"I was left with no income and basic information from the Scottish Government no help was being offered due to not having premises. Eventually I got selfemployed income support but had to wait until May to receive it. I struggled to pay my bills. I used all of my savings to keep a roof over my head and eat."

3.7 Mental health

The COVID-19 pandemic in Scotland positively and negatively impacted people's mental health across a range of contexts. Participants shared their experiences in relation to mental health during the pandemic through a variety of interconnected themes discussed below, including isolation, anxiety over catching or spreading COVID-19 and suicide.

Isolation

As discussed previously, many participants shared their experiences of isolation during the pandemic and the resulting impact on their mental health and wellbeing. Respondents highlighted the lack of contact with family and friends, combined with interruption to normal routines, including important recreational activities. One respondent summarised the experience of isolation:

"I cried almost every day because of the isolation. I lost my confidence, my love of nature and reading. I felt that the world as I knew it had come to an end. I felt cut off from my support network, alone and lost all interest in everyday activities." The impacts of isolation and loneliness were particularly difficult for older people and people living alone, and this was highlighted by several respondents.

Anxiety of catching or spreading COVID-19

Many respondents in the sample group said their mental wellbeing was strained by the anxiety of potentially catching or spreading COVID-19. This was particularly concerning for those living with vulnerable people or with large families in the same household: "This was a terrifying time at work with the thought of what you could have been bringing home to your family." For people who could not work from home and had to go into an office or other workplace, especially key workers, this led to intense and demanding routines to try and prevent the spread of COVID-19 within their households. Some people who found themselves in this situation described their daily patterns of removing clothing and rigorously washing hands, as well as showering before greeting their children and other family members. Such repeated actions put immense mental strain on these individuals, which several noted has had a lasting impact: "I would say this is still affecting me as I am still very paranoid about bringing illnesses into my home when I never was before the pandemic."

Key workers and mental health

While the pressures placed on key workers, such as increased workloads, lack of PPE, stressful interactions with the public and worries about childcare and/or learning from home are highlighted throughout this report, this section focuses on how these pressures affected their mental health. Many respondents who fall into this category described how exhaustion and burnout gradually took its toll. As one participant noted: "I started to become scared to go to work and look after my patients. As a result, I started to have panic attacks."

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Along with these impacts was a constant exposure to traumatic events while at work, such as caring for patients who died from COVID-19. Some respondents reported there being a lack of emotional or wellbeing support for key workers in Scotland to help them deal with the effects of stress, trauma and poor mental health in these situations:

"Nurses held the hands of dying patients day after day and supported them as best they could. We are burnt out and broken, many with PTSD and yet we are still come to work for others but who actually cares for us?"

Key workers who said their mental health deteriorated during the pandemic also felt this impacted the quality and quantity of services they provided, due to increased absences and working hours. Some respondents reported being so profoundly damaged – physically, mentally or both – that they either resigned or took early retirement. The impact on the mental health of the carers of disabled people (as well as disabled people) was noted in a 2020 report which Inclusion Scotland shared with Let's Be Heard.¹⁸ This report indicates that lockdown resulted in increased levels of stress as carers took on additional responsibilities when support services were reduced or withdrawn.

Suicide and suicidal thoughts

In some cases, respondents reported that the pandemic increased their experiences of suicidal thoughts and/or increased the incidence of suicides by their peers or family members. Some responses highlighted the role that lockdown isolation had on their experience of suicidal thoughts. Several other participants described the stress of having a business fail during the pandemic as a major contributor to suicidal thoughts. One respondent shared the story of their brother who died by suicide during the pandemic. Their brother had his own business which failed during lockdown. The

¹⁸ Inclusion Scotland, *Initial Findings of Inclusion Scotland's Covid-19 Survey* (2020).URL: https://inclusionscotland.org/wp-content/uploads/2021/05/Initial-Findings-Report-.pdf

respondent said their brother had written in his suicide note that: "covid restrictions destroyed his business he worked hard to build and being locked down made him depressed."

Some other respondents said stress associated with the pandemic, such as loss of income or anxiety around catching the virus, also significantly contributed to them contemplating taking their own lives.

Ongoing mental health impacts

Some participants wrote about the impacts on their mental health after lockdown restrictions ended. They said they felt as though they had "lost years" of their lives to the pandemic, and that little support was available to help process the trauma after the pandemic ended. For some, lingering anxieties and associated disorders, such as agoraphobia, which emerged during the pandemic, continue to affect them today:

"I am still anxious about being in large groups of people. The impact the pandemic had on my mental health was huge and now we're expected to carry on as though it never happened."

For others, it was as simple as not being given the time or resources to process the impacts of this period.

4. We Asked: What lessons do you think should be learned from your experiences?

You Said...

This section of the report focuses on the answers to Let's Be Heard's third core question: What lessons do you think should be learned from your experiences?

Respondents provided many suggestions as to how Scotland can be better prepared to respond to future pandemics. Key lessons included:

- having clearer plans in place for a future pandemic and emergency response;
- maintaining key services, such as primary healthcare, during a pandemic;
- prioritising mental health and wellbeing, especially for key groups, such as children and young people and people living alone;
- providing clear, consistent and evidence-based public health messaging; and
- finding a better balance in future government pandemic responses between protecting the population from transmission of a virus and avoiding unnecessary harms.

It is important to note again that the suggestions provided in this section represent the views of those who participated in Let's Be Heard, and do not represent, nor anticipate, the conclusions of the Inquiry.

4.1 Pandemic preparedness

Respondents overwhelmingly expressed frustration that the Scottish Government was not adequately prepared for the pandemic and its consequences. Several recommendations were suggested to help Scotland be better prepared for future pandemics. These included:

Put clear plans in place for future pandemic and emergency responses:

- Many respondents felt that the Scottish Government's credibility has been damaged. They wanted proof and reassurance that lessons have been learned, and that rigorous plans for different scenarios will be put in place and regularly reviewed.
- Some participants called for a coordinated approach to a future pandemic response. Respondents who navigated multiple systems, such as hospitals, GP practices and social care, frequently referred to the lack of a "joined up" approach and recommended establishing better communication channels across departments and institutions that need to work together during public health emergencies.

Invest in public services, equipment and training as the foundation for future preparedness:

 Many respondents reported experiencing increased harm because major public institutions, such as the NHS and schools, were operating on a "skeleton system" even before the pandemic. They recommended investing in Scotland's public services and infrastructure during non-crisis times to increase capacity and resilience during public health emergencies.

- Many recommended more attention to sourcing and distributing equipment, particularly PPE, and updating regulations to ensure reserves were well-stocked with a buffer during normal times.
- Staff shortages, as well as inconsistencies in staff training, especially in schools and hospitals, resulted in uneven service provision and hampered institutions' ability to run effectively, or to adhere fully to the regulations. Furthermore, some participants suggested a focus on improved staff training in these public institutions and investment in staff retention, ahead of any future public health emergencies.

4.2 Care homes

Many respondents expressed concern around the handling and treatment of residents in care homes throughout the pandemic, and that the restrictions around care homes were overly strict.

Respondents highlighted several areas where lessons could be learned and made recommendations as to what could be improved:

Greater planning and preparedness for access to, and distribution of, PPE:

- Some participants believed that if more health and social workers had had access to PPE sooner, it would have significantly prevented the spread of COVID-19 in care homes.
- It was considered vital among respondents in the sample group that care homes stock suitable PPE as standard in preparation for future pandemic outbreaks or public health emergencies.

More transparency around the risk assessment for restricting visitors to care homes:

- Participants stressed that rules and restrictions around families being able to see loved ones in care homes should be more flexible and compassionate in future.
- Several participants also expressed concern about the detrimental impact on the mental health and wellbeing of elderly people living in care homes who were prevented from seeing family.

Implement testing policies for all patients being transferred from hospitals to care homes:

• The decision to send patients to care homes without being tested for COVID-19 was highlighted by respondents as a significant error that should never have happened.

Have flexible guidance for different types of care homes:

 A few participants highlighted that not all care homes are for elderly patients. They noted that there are care homes for recovering addicts, or for disabled adults, etc. Respondents suggested these homes have different rules and restrictions in future, tailored to the needs of their residents. According to respondents, the COVID-19 rules and restrictions were targeted to care and nursing homes for the elderly and were not always suitable to these other groups of care home residents.

4.3 Health and social care

Respondents also made a few key recommendations related to access to health and social care services:

Health and social care services should continue during lockdown to reduce the risk of late diagnoses and misdiagnoses, and to minimise the deterioration of people's health.

- The services most frequently referred to in the responses are health services, including GPs and dentists. Respondents' concerns centred around health conditions either being missed or misdiagnosed during lockdown.
- People expressed the view that not being able to have a face-to-face consultation with a GP seriously compromised the quality of the care received.
- Formal and informal carers shared concerns that restrictions on home visits made it difficult to provide appropriate support and care for older people. The effectiveness of doorstep visits or phone calls was questioned in some responses, with family members finding it challenging to support loved ones during the pandemic.

4.4 Vaccine rollout

Many respondents described the rollout of the COVID-19 vaccine in Scotland as efficient and well organised, but other responses suggest there are lessons to be learned and several areas for improvement, including:

More clarity around who is prioritised for receiving the vaccine:

- Some health and social care workers felt that receiving the vaccine sooner could have prevented the transmission of COVID in their respective workplaces.
- Several respondents who were police officers during the pandemic questioned why they were not among those prioritised to receive the vaccine early.

Better consideration for where vaccines are being administered:

- While some respondents praised being able to receive vaccinations at home, others stated the process for getting a vaccine at home was quite challenging to access.
- Respondents also said specific consideration is needed for rural populations and for people who rely on public transport to access clinics.

Consider how to staff vaccination clinics:

 Some respondents said there were retired medical staff willing to work or volunteer in the vaccination clinics but there was no mechanism to bring them onboard.

4.5 Education and children and young people

Lessons learned around education and children and young people are derived from both adult forms and children and young people forms. Suggestions and lessons to be learned in this theme, as identified by respondents, include the following:

Schools and early years institutions should be kept open:

- Adults responding to this survey, and children and young people responding to the children and young people form, largely expressed the view that schools should have been kept open during lockdown, as it was felt that learning from home was insufficient to support children's learning, and social and emotional development.
- Children and young people expressed the view that keeping schools open would have helped avoid feelings of loneliness and isolation.

• Some adults also felt that families could be better supported by keeping early years and pre-school institutions open to help with childcare.

Improved support for pupils and students learning at home:

- Respondents, including children and young people, expressed the view that learning from home should be better supported by schools and further/higher educational institutions. Parents/guardians in the sample group said they struggled to keep up with the demands from schools to facilitate learning at home, and both adults and children and young people noted that inequalities between households would mean some children would find it more difficult to learn at home than others, depending on access to laptops/tablets and internet.
- Some respondents felt schools in Scotland should have continued to implement grade allowances longer to take account of the disruption to pupils' education.
- Respondents also stated that more support should have been given to further and higher education students studying from home.
- They also expressed the view that further/higher education institutions should have provided more academic accommodations such as deadline and funding extensions to accommodate working from home.

Prioritise mental health, wellbeing and activities for children and young people:

- There was a general view particularly among adults that children and young people's mental health needs to be better supported in recognition of the detrimental impacts of the pandemic on their mental health.
- Some respondents, including children and young people, expressed the view that, overall, children and young people's needs were deprioritised in the response to the pandemic. They highlighted the closure of educational

institutions, and the perception that spaces and events which catered to adults were reopened sooner than those for children and young people.

4.6 Scottish Government communication

Respondents identified instances where communication from the Scottish Government could have been improved. The data from the sample group suggests two key areas for improvement:

Messaging should be clear, consistent and evidence-based:

- Respondents said rules and restrictions were inconsistent throughout the pandemic. They wanted clear communication around how and why decisions were being made. For example, driving lessons were not allowed, even when drivers and instructors were wearing masks, but the rules and regulations meant a person could travel on a bus with multiple people if they wore a mask.
- Respondents also wanted clearer, evidence-based messaging when rules were changed or adapted.

More consistency in messaging across the whole of the UK (respondents highlighted differences between the rules in Scotland and the rest of the UK):

- There was a call for a "one message and one response" across the four nations, with some people stating restrictions in Scotland seemed stricter than in the rest of the UK.
- The differences were especially stark, according to responses, for people in Scotland who had family in England and those who travelled between the two nations regularly for work. For example, masks were not required for train travel

in England, but they were required in Scotland, meaning passengers travelling across the border found this rule confusing.

Communication could have been more balanced (respondents were divided over the Scottish Government's daily briefings):

 Respondents' views of the daily briefings were divided, with some commenting on a tendency towards political "point-scoring", while others praised the briefings.

4.7 Scottish Government decision-making: balancing risks and harm

Several respondents said any future Scottish Government must seek to strike a better balance between protecting the population from transmission of the virus and avoiding unnecessary harm. Some of the specific suggestions voiced by participants included:

- More consideration be given to the impact on people's mental health and wellbeing in pandemic planning and response. For example, protective measures such as bubbling should have been introduced sooner to reduce potential harm to people living alone, and for family groups living in different households.
- Consider developing and implementing a more holistic needs assessment when making or lifting lockdown restrictions. For example, some respondents questioned why venues such as pubs and football stadiums reopened long before children's activities and playgroups.

5. Do the interim findings in this report reflect your experiences?

Let's Be Heard wants to know if the responses in this report represent your pandemic experience in Scotland and invites you to add to these voices and share your own unique experience.

What would you like to tell the Inquiry to ensure your voice is heard?

Let's Be Heard invites you to answer three questions around experience, impacts and lessons to be learned by visiting its online platform lbh.covid19inquiry.scot, emailing **LetsBeHeard@covid19inquiry.scot** or writing to the project at Freepost SCOTTISH COVID-19 INQUIRY.

Paper forms (also in large print and braille), easy-reads and forms in Scotland's most commonly spoken languages are all available and other versions or formats are available on request. BSL and audio submissions can also be submitted through Let's Be Heard's online platform.

For Scotland to be better prepared in future, it is important the Inquiry hears directly from people about what happened to them during the pandemic and understands the lessons they believe should be learned.

6. The Let's Be Heard approach and methodology

This section describes Let's Be Heard's organising principles and practical methods for collecting and analysing experiences shared.

6.1 Let's Be Heard principles in action

Let's Be Heard has adopted the Inquiry's wider human rights-based and traumainformed approach since its inception. These have also been built into its design and underpin its operational decisions. By working in this way, Let's Be Heard has ensured the needs of the people sharing their experiences are at the heart of its work.

Let's Be Heard has done this in a number of ways. It has:

- consulted representative organisations and members of the public in its design and testing ways of engagement;
- embedded the PANEL principles in the design of its overall public participation approach;¹⁹
- developed an approach underpinned by choice so people can decide both how and what to share with the Inquiry;
- offered financial assistance and general support to facilitate group discussions with colleagues, peers, family or friends;
- created several accessible response options, alongside standard options, to meet different preferences and needs;
- created dedicated resources and a bespoke response form for children and young people in consultation with children's organisations;
- revised its online form in response to feedback from the public;

¹⁹ PANEL stands for Participation, Accountability, Non-discrimination and equality, Empowerment and Legality.

- developed an internal equalities assessment tool to review the impacts of its approach on different audience groups;
- regularly monitored and evaluated progress; and
- written an internal research framework to embed human rights considerations in its approach to analysing responses.

It is important Let's Be Heard is responsive to feedback and continually reflects the above approaches. Let's Be Heard values the time people spend sharing their experiences of the pandemic and their experience of engaging with the Inquiry's listening project. From a trauma-informed perspective, Let's Be Heard is committed to maintaining a feedback loop with those who have (as well as those who have not) participated so they know how the experiences they share are feeding into the work of the Inquiry. This report represents the first example of this feedback loop.

6.2 Let's Be Heard engagement methods

Let's Be Heard focuses on people's lived experiences of the pandemic and therefore relies on personal accounts from individuals and groups.

The three core questions used during National Engagement are purposefully openended to encourage participation on a wide range of topics and to allow people to tell the Inquiry what is important to them.

Similarly, the approach to engagement has been designed to raise awareness of Let's Be Heard across Scotland, and to provide support to ensure that anyone who wishes to participate can do so. Individuals and groups can get involved in the National Engagement Period in a variety of ways, depending on their needs and preferences. These include, but are not limited to, participating:

- individually or as part of a group using Let's Be Heard's bespoke Engagement Guide;
- via Let's Be Heard's online platform or through digital uploads;
- using a paper form available in various formats/accessible versions/languages;
 or
- by submitting an organisation's existing report of a past engagement event(s) that collates people's experiences.

We would like to thank those groups and organisations who have already contributed existing reports detailing their members' experiences. The reports are a rich source of information and a way to capture the voices of communities which may not yet have contributed to the National Engagement Phase. They also provide detail as to how groups may have been disproportionately impacted by the pandemic. The reports cited here have been shared with Let's Be Heard and are already proving beneficial to its analysis and understanding of people's experiences of the COVID-19 pandemic in Scotland.

Let's Be Heard is open to exploring alternative approaches to allow people to share their experiences. The team can offer support by email or by phone to identify the best possible solution to meet individual circumstances.

More detailed information on how people across Scotland can engage with Let's Be Heard can be found in **ANNEX A**.

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6.3 Let's Be Heard timeline

Let's Be Heard undertook a two-phased pilot between November 2022 and March 2023 to inform its design and approach. This involved gathering feedback on its proposed approach to engagement, testing materials and resources, and ensuring these met the needs of a diverse audience. More than 23 representative organisations took part in the pilot with expertise in a range of areas, including human rights, equalities, workers' rights, healthcare, disability, gender, age, ethnicity, care homes and lived experience of COVID-19 bereavement.

Let's Be Heard's ongoing National Engagement Period was launched on 23 May 2023, enabling people across Scotland to share their experiences of the pandemic, describe the impacts of these experiences and suggest lessons they believe should be learned.

Following the conclusion of its National Engagement Period on 20 December 2023, Let's Be Heard will begin a period of Focused Engagement, during which it will seek to build on the broad base of information gathered. This will give people the chance to participate in more targeted engagement activities such as focus groups and workshops, allowing Let's Be Heard to fill any information gaps and to provide a more detailed information base to support the Chair with specific information needed for investigative work.

Figure 4: A visual timeline of Let's Be Heard



6.4 Engaging with children and young people

Let's Be Heard is keen to hear directly from children and young people in Scotland to capture their experiences of the pandemic.

To support this engagement, Let's Be Heard has created dedicated resources for children and young people up to the age of 14, this includes a bespoke response form, which is also available for those up to the age of 19. The form was developed in collaboration with children's organisations to ensure it is accessible to this cohort and can be completed by young people themselves, or an adult on their behalf.

7. Let's Be Heard: next steps

Let's Be Heard's National Engagement Period is open until 20 December 2023. During this period, Let's Be Heard will continue to ask everyone in Scotland for information relating to the Inquiry's Terms of Reference in the form of experiences, impacts and lessons to be learned. It encourages everyone to contribute to ensure their voice helps steer the work of the Inquiry's investigations.

Next, Let's Be Heard will begin its Focused Engagement Period, where it will conduct more specific engagement and research activities, such as focus groups and workshops, as requested by the Inquiry's legal team, Counsel, and the Chair to:

- fill any gaps in terms of information and representative groups; and
- provide a more detailed information base.

7.1 Where you can support the Inquiry

The Let's Be Heard team is grateful to everyone who has taken the time to share their experiences. The team feels privileged to read the thoughts and experiences of people in Scotland during the pandemic. Each response received is important.

Every contribution to Let's Be Heard is valued and helps created a fuller picture of Scotland's COVID-19 experience. For this project to provide a complete and accurate account of what took place during the pandemic, Let's Be Heard needs to hear from people across every part of Scotland's diverse society, particularly from those who consider they were disproportionately impacted by the pandemic. Please note, participants do not need to have had COVID-19 to share their experiences.

The work of Let's Be Heard is underpinned by a human rights-based approach with an onus on breaking down barriers to participation. This means ensuring the project finds ways to engage with individuals and groups who may be less likely to take part in a public engagement project.

Throughout the National Engagement Period so far, and through the analysis of responses for this report, Let's Be Heard has identified some key groups that it feels are missing or are underrepresented. These include:

Children and young people:

- Care experienced children and young people, including children in foster care.
- Young people living in shared accommodation during the pandemic.
- Students in higher and further education.
- Young carers.
- Adults who have experiences of living with, or looking after, children aged up to five.
- Adults who were foster or kinship carers during the pandemic.
- Adults who would be willing to support a child or young person to complete a Let's Be Heard children and young people form.

Minority Ethnic and Minority Religious Communities:

- Experiences of those living in Scotland during the pandemic from any minority ethnic, cultural or religious groups.
- Experiences of minority ethnic key workers.
- Experiences of religious leaders or cultural community leaders.

Migrants, refugees/asylum seekers

- Migrants living in Scotland during the pandemic, including those for whom English is not their first language.
- Refugees or asylum seekers living in Scotland during the pandemic, or those with experience navigating the asylum process while in Scotland during the pandemic.

Representatives and individuals from the following groups:

- LGBTQ+.
- People over 70.
- People who don't feel financially secure.
- Disabled people.
- Men.
- People who worked in the emergency services during the pandemic.
- Key workers in social care.
- Key workers working in frontline services, such as retail and hospitality.
- Unpaid carers.
- Patients in hospital or residents in care/nursing homes or their family members.
- Those in management roles across health and social care.
- Those who were asked to shield in Scotland during the pandemic.

Additional experiences Let's Be Heard would like to hear:

- The mental health and wellbeing impacts of lockdown on adults and children.
- Being self-employed or managing a small business during lockdown.
- Being diagnosed with a serious health condition during the pandemic.
- Receiving healthcare during lockdown, including people who were cared for in hospital.

- Navigating end-of-life care for family members during the pandemic.
- Ante-natal and post-natal care, including experiences of having a baby during the pandemic.
- Experience of working in primary, secondary or further and higher education during the pandemic.
- The treatment and management of long COVID that took place from 1 January 2020 to 31 December 2022, from the experiences of those living with the condition and those treating or supporting those with the condition.
- Experiences of people receiving welfare benefits.

8. Acknowledgements

Thank you.

Let's Be Heard is grateful to all who took the time to share their experience with the Inquiry.

Let's Be Heard expresses its sincerest thanks and gratitude to Scottish Covid Bereaved and Care Home Relatives Scotland and other representative organisations for supporting the project during its design and piloting phases, and for raising awareness of the Inquiry's listening project in their communities.

We would also like to thank the following organisations for the wealth of expertise and feedback that helped inform this public engagement:

- Age Scotland
- Alliance
- BEMIS (Black and Ethnic Minority Infrastructure in Scotland)
- Black Professionals Scotland
- British Deaf Association
- Care Home Relatives Scotland
- CEMVO (Council of Ethnic Minority Voluntary Organisations)
- Children and Young People's Commissioner
- Childline
- Children's Parliament
- Educational Institute of Scotland
- Equality and Human Rights Commission

- Engender
- Glasgow Disability Alliance
- Human Rights Consortium Scotland
- Inclusion Scotland
- PBW Law
- Refugees for Justice Scotland
- Scottish Action for Mental Health
- Scottish Commission for People with Learning Disabilities
- Scottish Council of Jewish Communities
- Scottish Covid Bereaved
- Scottish Human Rights Commission (SHRC)
- Scottish Trades Union Congress (STUC)
- Young Scot

Finally, we would like to acknowledge and thank all those organisations and community groups that have helped raise awareness of Let's Be Heard or used our resources, such as the Engagement Guide, to host their own experience-sharing events on behalf of Let's Be Heard. We are extremely grateful to all the individual hosts for the work they have put in and to the people that have taken time to attend and share their personal experiences.

ANNEX A: Let's Be Heard engagement methods

The five primary methods used for National Engagement include:

- Online platform:
 - o digital response forms and information resources; and
 - o digital information videos and upload options available.
- Paper forms:
 - o paper response forms and information resources; and
 - \circ a Freepost address to ensure people do not incur a cost to participate.
- Engagement guide and resources:
 - A guide aimed at supporting people to host group discussions with colleagues, peers, friends or family members to submit a summary of the conversation.
 - The guide is promoted to organisations so that they can use their established and trusted relationships in their communications, which will encourage and provide a safe space for engagement.
 - Support, including expenses, has been made available to help people interested in hosting or facilitating discussion group events.
 - Let's Be Heard has been attending events, when invited, to answer questions and take notes. The team cannot host or facilitate discussions.
- Pop-up information stands:
 - Let's Be Heard has attended conferences, public spaces and community events to raise awareness of the Inquiry and Let's Be Heard.
- Phone support:
 - Let's Be Heard is providing telephone support to people who may have requests or queries about the best way for them to get involved.

Accessibility has played a critical role in developing these engagement methods. Let's Be Heard ensured a range of accessible formats was made available from the public launch, on 23 May 2023. As standard, Let's Be Heard created the following, with other materials made available on request:

- braille response forms;
- large print response forms and information resources;
- easy read response forms and information resources;
- translated response forms and awareness-raising materials including:
 - o Gaelic;
 - o Polish;
 - o Punjabi;
 - Simplified Chinese; and
 - o Urdu;
- BSL information videos, and audio and video upload options; and
- dedicated digital and paper materials for children and young people.

In summary, during the National Engagement Period people can respond to Let's Be Heard's three core questions individually, as part of a group, online, through digital uploads, on paper or by sharing existing reports. If these methods are not appropriate for you, the team is keen to offer telephone support to identify the best possible solution to allow people to share their experiences.

ANNEX B: Help and Support

If you have been affected by the COVID-19 pandemic, there may be organisations which can provide support, including the organisations listed below. All of these organisations are independent of the Scottish COVID-19 Inquiry.

Breathing Space

Link: <u>www.breathingspace.scot</u>

Contact Breathing Space when you're feeling low. They are a free, confidential, phone and webchat service for anyone in Scotland over the age of 16 experiencing low mood, depression or anxiety. Call 0800 83 85 87 for support. Visit their website for opening hours.

Chest Heart Stroke Scotland

Link: www.chss.org.uk/coronavirus/coronavirus-information-and-support/longcovid/

If you, or someone you know, is living with long covid, Chest Heart & Stroke Scotland is here to help. Call the CHS Scotland long covid advice line on 0808 801 0899 for advice about how to manage your condition, and information about the services and support available – including their long covid peer support group.

Childline

Link: www.childline.org.uk

Childline is a free, confidential, 24-hour helpline for children and young people up to the age of 19. Childline can be contacted about any concern – online or by calling 0800 1111.

Citizen's Advice Scotland

Link: <u>www.cas.org.uk</u>

Scotland's Citizens Advice Network is an essential community service that empowers people in every corner of Scotland through local bureaux and national services by providing free, confidential, and impartial advice and information. People can get advice in local bureaux, through online advice pages or interactive self-help tools. Go to CAS.org.uk to find out more.

Cruse Scotland

Link: <u>www.crusescotland.org.uk</u>

Cruse Scotland offers support to people who are bereaved throughout Scotland. Services include information and advice; immediate support via the helpline on 0808 802 6161 and webchat services on their website; one-to-one listening support & counselling; support groups; specialist support for children and young people; and training and group support for workplaces and organisations.

Marie Curie Scotland

Link: www.mariecurie.org.uk/help/support

Marie Curie is Scotland's leading end of life charity, with frontline nursing and hospice care across Scotland. For help with practical information and support on any aspect of life with a terminal illness, dying and bereavement, contact Marie Curie on 0800 090 2309. This includes bereavement support.

Money Advice Scotland:

Link: <u>www.moneyadvicescotland.org.uk/help-for-people-with-money-worries</u> Money Advice Scotland is Scotland's money charity. It exists to help people in debt, support money advisers and influence policy. Visit their website for more information or email info@moneyadvicescotland.org.uk.

Samaritans Scotland

Link: www.samaritans.org/scotland

Samaritans is here, day or night, for anyone who is struggling to cope or who needs someone to listen without judgement or pressure. Samaritans is available 24 hours a day, 365 days a year. Call 116 123 for free or email jo@samaritans.org.

Scottish Association for Mental Health

Link: <u>www.samh.org.uk</u>

SAMH (Scottish Association for Mental Health) is Scotland's national mental health charity. For more information on mental health, you can use the SAMH information service to find helpful information on general mental health problems at <u>samh.org.uk/info</u>. For support, call 0344 800 05<u>50 (Monday to Frid</u>ay 9am to 6pm) or email info@samh.org.uk.