

OPUS2

Scottish Covid-19 Inquiry

Day 5

November 1, 2023

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Phone: 020 4518 8448

Email: transcripts@opus2.com

Website: <https://www.opus2.com>

1 Wednesday, 1 November 2023
 2 (10.00 am)
 3 THE CHAIR: Good morning, everybody. Mr Gale, when you are
 4 ready.
 5 MR GALE: Thank you, my Lord.
 6 My Lord, today there are two witnesses, both who are
 7 here in person. They represent organisations who, at
 8 present and during the pandemic, supported and continue
 9 to support, in particular, disabled people, organised
 10 and marginalised groups, and also unpaid carers during
 11 the pandemic.
 12 The first witness is Sara Redmond of the Health and
 13 Social Care Alliance Scotland, which is referred to
 14 simply as the Alliance. She speaks to a witness
 15 statement; the reference to that is SCI-WT0584-000001.
 16 The second witness is Tressa Burke. She speaks on
 17 behalf of the Glasgow Disability Alliance, which I think
 18 we will refer to as the GDA, and she also speaks to
 19 a witness statement, which is SCI-WT000862.
 20 So Ms Redmond, please.
 21 MS SARA REDMOND (called)
 22 THE CHAIR: Good morning, Ms Redmond. Please be seated.
 23 THE WITNESS: Thank you.
 24 THE CHAIR: Right, are you ready?
 25 Mr Gale.

1

1 Questions from MR GALE
 2 MR GALE: Ms Redmond, good morning.
 3 A. Good morning.
 4 Q. You provided the Inquiry with a statement, and that
 5 statement is on behalf of the Health and Social Care
 6 Alliance Scotland, which I think we are going to call
 7 the Alliance, and you are chief officer of development
 8 for that organisation; is that right?
 9 A. That is correct.
 10 Q. You don't need to tell us your date of birth, but could
 11 you just tell us your age, please.
 12 A. I am 40.
 13 Q. Thank you.
 14 The Inquiry knows the address of the Alliance for
 15 communication purposes.
 16 Your organisation has engaged with the Inquiry; we
 17 have had meetings with you, and you provided
 18 a considerable amount of information to the Inquiry.
 19 For those looking at your statement, if one goes to the
 20 end of your statement, there are a considerable number
 21 of references, all of which have links to documents that
 22 you have provided to the Inquiry, and I should say that
 23 the Inquiry is studying those documents and will be
 24 taking all those documents into account, albeit you do
 25 refer to them briefly as you go through your statement.

2

1 A. That's correct.
 2 Q. Now, if I can just take you to your statement.
 3 You are responsible, as you say in paragraph 1, for
 4 leading and continuing to shape the vision of the
 5 organisation and you are responsible for developing the
 6 strategic direction of the organisation, and also
 7 overseeing its portfolio of programmes. You then say:
 8 "Central to this is ensuring a strong voice for
 9 disabled people, people living with long term conditions
 10 and unpaid carers and [the] opportunity to influence
 11 change based on their lived experiences."
 12 Now, you are here really to tell us about the
 13 experience that your organisation had and the people who
 14 are associated with your organisation had during the
 15 pandemic, and you are also here to tell us certain of
 16 the lessons which you, based on that experience, suggest
 17 that we might, as an inquiry, wish to learn and to make
 18 possible recommendations in relation to.
 19 But first of all, can I just understand a little
 20 terminology. It may be — and I am sure it is — very
 21 obvious to you, but you mention on several occasions,
 22 and in particular in paragraphs 2 and 3, the "third
 23 sector". Can you explain to us what the third sector
 24 is, please?
 25 A. Yes, of course. So the third sector is a term that

3

1 refers to charities, voluntary organisations, social
 2 enterprises, community groups; the groups and the
 3 organisations that would be working not for profit but
 4 for a social purpose, and who would be largely — who
 5 would reinvest any income or any funding that they
 6 generate back into the cause of that business.
 7 Q. We will come to your funding in a little. But in
 8 paragraph 3, you say that:
 9 "The ALLIANCE are the national third sector
 10 intermediary for health and social care, bringing
 11 together a diverse range of people and organisations who
 12 share our vision ..."
 13 Which is, as you say, that Scotland is somewhere:
 14 "... where everyone has a strong voice and enjoys
 15 their right to live well with dignity and respect."
 16 Right, "third sector intermediary"; intermediary
 17 with whom?
 18 A. So we are both a membership organisation and
 19 a connecting organisation. We operate almost as a bring
 20 between — particularly between Scottish Government and
 21 decision-makers and those members that we represent.
 22 So, you know, it's a terminology to reflect that we are
 23 there to represent the interests of our members.
 24 Q. In paragraph 4 I think you expand on that, where you
 25 say:

4

1 "We are a strategic partner with the Scottish
2 Government and have close working relationships with
3 many NHS Boards, academic institutions and key
4 organisations spanning health, social care, housing, and
5 digital technology."

6 I think these are all aspects that came into play
7 very acutely during the pandemic.

8 A. Yes.

9 Q. Could you just go to paragraph 5, and I am going to ask
10 you, if you don't mind, to read certain parts of your
11 statement.

12 At paragraph 5, could you just read on from there,
13 please.

14 A. Yes. So our purpose is to improve the well-being of
15 people and communities across Scotland. We bring
16 together the expertise of people with lived experience,
17 the third sector and organisations across health and
18 social care, and we inform policy, practice and service
19 delivery. Together our voice is stronger, and we use
20 that collective voice to make meaningful change at the
21 local and national level.

22 Q. Carry on, please.

23 A. Okay.

24 So the Alliance has a strong and diverse membership
25 of over 3,400 organisations and individuals. Our broad

5

1 range of programmes and activities deliver support,
2 research and policy development, digital innovation and
3 knowledge sharing. We manage funding and spotlight
4 innovative projects, and working with our members and
5 partners, we work to ensure lived experience and third
6 sector expertise is listened to and acted upon by
7 informing national policy and campaigns and putting
8 people at the centre of designing support and services.
9 Q. You set out your aims. Can you just read those, please.
10 A. Certainly. So our aims are: to ensure that disabled
11 people, people with long-term conditions and unpaid
12 carers' expertise and rights drive policy and sit at the
13 heart of design, delivery and improvement of support and
14 services; we aim to support transformational change that
15 works with individuals and community assets, helping
16 people to live well, supporting human rights,
17 self-management, co-production and independent living;
18 and we champion and support the third sector as a vital
19 strategic and delivery partner, and foster cross-sector
20 understanding and partnership.

21 Q. In paragraph 8, you refer to an inquiry; I take it this
22 is this inquiry?

23 A. That is correct.

24 Q. Can you explain why you felt an inquiry should take
25 place?

6

1 A. So based on the work that we delivered over the years
2 spanning the pandemic, the insights that we gathered,
3 our responses to public information, to guidance, to
4 policy developments, and quite extensive engagement with
5 people about their experiences of accessing health and
6 social care over that period, and the impact that that
7 period has had on people's health and well-being, we
8 felt strongly that there was a need to identify and
9 learn lessons from this experience.

10 We were concerned that, despite a commitment to
11 human rights principles and standards, decision-making
12 did not reflect, from some of the experiences shared
13 with us, human rights standards and principles; that
14 people's rights who were most at risk were not really
15 being considered when decisions were being taken;
16 information was not easily understood, was not easily
17 accessed for many people. And I think we felt that
18 there was also opportunity for us — health and social
19 care is not necessarily renowned for being particularly
20 quick to transform itself, and yet there was, you know,
21 really quite significant examples where change took
22 place at pace, and nationally, and we also thought there
23 was an opportunity to learn the lessons from good
24 practice that had happened so that we could apply those.
25 Q. I think you make the point in paragraph 8 that — and

7

1 this is something we have heard and I think we are going
2 to continue to hear — during the pandemic there were
3 examples of good practice that came about at pace.

4 A. Absolutely.

5 Q. But there were also examples of bad practice, and we
6 obviously need to recognise both.

7 A. Mm—hmm.

8 Q. Yes.

9 In paragraph 9, you go on to indicate how the
10 Alliance engaged with various committees of the
11 Scottish Parliament, and I think we can probably just
12 take that as read for present purposes.

13 At paragraph 10, you tell us what the Alliance did
14 in terms of what is called the People at the Centre
15 Engagement Programme.

16 Perhaps if you just read paragraph 10 so that we
17 understand that, please.

18 A. Certainly. So in 2020, the Alliance undertook the
19 People at the Centre Engagement Programme. This was
20 a programme of engagement looking at short and
21 longer-term reform of the health and social care system.
22 So it was an engagement programme to learn lessons from
23 people's experiences following the COVID-19 pandemic
24 outbreak in Scotland. The programme captured the lived
25 health and well-being experience of the COVID-19

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1 pandemic. Over 1,000 people across each of Scotland's
2 32 local authority areas were engaged with and their
3 experiences captured, and those were collated and
4 analysed and the prominent themes were drawn out in
5 a final report.

6 Q. And, again, you provided us with that report. It is
7 referenced in your statement, and the link is provided.

8 Now, going on, you say:

9 "We continue to hear and gather evidence on the
10 lasting impact ... from our members ..."

11 Perhaps, again, could you just read that so we have
12 that in context?

13 A. Absolutely. So we continue to hear and gather evidence
14 on the lasting impact of COVID-19 from our members,
15 including for those living with long COVID. In 2022, we
16 published commissioned research on accessing social
17 support for long COVID. The research aimed to build
18 understanding of the live circumstances of people with
19 long COVID in Scotland, as well as their experiences of
20 accessing social support. We also commissioned research
21 into the lived experience of COVID-19 of marginalised
22 communities, as a member of the Inclusion Health
23 Partnership and the CLEAR partnership, which is the
24 Community Lived Experience Action Research partnership.
25 We have also published research exploring disabled

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1 children and young people's and their carers'
2 experiences of accessing healthcare services and support
3 during the pandemic.

4 Q. Can I just ask you about long COVID. You may be aware
5 that the Inquiry does have a remit to consider
6 long COVID in particular circumstances, and we have
7 issued guidance and advice on that.

8 Can you just indicate why it was that, in 2022, you
9 commissioned research in accessing social support for
10 long COVID? Can you explain why you did that?

11 A. So during the 2020 engagement programme, we had
12 a particular focus group and gathered information from
13 people living with long COVID at the time. In the
14 subsequent years, we were continuing to hear from people
15 living with long COVID through a range of different
16 forums and groups that we were members of that the
17 experiences that they had had then had continued, so in
18 terms of the support they were receiving, the challenges
19 they were finding in terms of the awareness of the
20 condition, you know, really the range of symptoms, and
21 those experiences being believed and understood. And
22 also, despite some of the policy developments around
23 long COVID service across Scotland, people weren't
24 necessarily describing that they were then experiencing
25 that support as available in their local areas.

10

1 So we commissioned this research really to
2 understand in a bit more detail what people's
3 experiences were, you know, further on, so a couple of
4 years since the onset of pandemic.

5 Q. Can you perhaps just very briefly explain what the
6 outcome of that research was.

7 A. Yes. I mean, I think the things that really stood out
8 from that research was that people were very much,
9 I think, shocked by the experience they had of being
10 diagnosed with a long-term condition, and the challenges
11 that they had encountered with having that experience
12 believed by the healthcare system. They raised concerns
13 about just, you know, battling to receive a diagnosis,
14 the range of symptoms that they were experiencing not
15 really being accepted as part of the condition. They
16 talked about the significant impact that it was having
17 on their daily life, many people having to leave work,
18 having to rely on friends and family for support with
19 the caring responsibilities that they had in life, that
20 they were having to spend a huge amount of time
21 researching support and treatment options, some
22 describing having to look for private support and
23 treatment.

24 Some did describe support they were receiving from
25 the Health Service, and, you know, good support from GPs

11

1 and others. They typically tended to refer to
2 themselves as being lucky for having that experience,
3 and when they were discussing wider support, they spoke
4 at length about the difficulties they had had navigating
5 the social security system, and none that we — that
6 were involved in the research that I can recall had had
7 any experience of accessing social care support. It had
8 not been a route that they had found accessible for
9 themselves.

10 Q. One of the things I think we will hear more about, and
11 I think you have hinted at, is that there was, so far as
12 long COVID is concerned, at various stages some
13 scepticism about the condition.

14 A. Yes.

15 Q. And that seemed to permeate both the medical profession
16 and the wider public.

17 A. Yes.

18 Q. I think you go on to deal with this later in your
19 statement. I think it is useful to just get that point
20 across now.

21 If we go back to your statement, you move from that
22 group of impacted people to a reference to Engender.
23 Now, you probably are aware that the Inquiry is going to
24 hear from a group of women's rights organisations
25 tomorrow, and Engender is one of those organisations, so

12

1 you can be assured that we are aware of that. But
2 perhaps you could just indicate the partnership that you
3 had with Engender and what that partnership brought to
4 you.

5 A. Yes. So the Alliance worked in partnership with
6 Engender to undertake research to look at the
7 experiences of pregnancy and maternity services across
8 Scotland during COVID—19. We worked to capture
9 qualitative experiences from people who were accessing
10 pregnancy and maternity services and we were able to
11 capture over 200 responses, and that covered the period
12 from March 2020 to November 2022.

13 The research aimed to get a better understanding of
14 access related to pregnancy, fertility, maternity,
15 abortion, miscarriage and postpartum care during
16 COVID—19, and the report that we published from the
17 analysis of those experiences drew together some of
18 those key findings and made some recommendations for
19 Scottish Government and relevant health bodies.

20 Q. I think you quote from one of the participants in the
21 research, and perhaps you can just read that quote,
22 please.

23 A. Certainly:

24 "It is essential that Scotland learns from people's
25 experiences during the pandemic to improve maternity

13

1 services and public health messaging. To do otherwise
2 would be to fail, and further compound the trauma, of
3 thousands of parents over the last few years."

4 Q. Thank you.

5 You then go on to talk about, to a certain extent,
6 one of the points we have already touched on:
7 long COVID. You also go on to talk about discussions
8 that you had with the Scottish Government on shielding,
9 vaccination and long COVID.

10 I think it is right that we recognise that you
11 worked closely with the Scottish Government throughout
12 pandemic.

13 A. Yes.

14 Q. I think much of that work was very positive.

15 A. Yes, yes, we were able to be involved in a range of
16 groups, such as there was a communication group to —
17 that involved health boards and others, ourselves and
18 there was another health and social care intermediary
19 represented, and it was to both feed in information to
20 Scottish Government about communication needs and public
21 health messaging, but also to help with dissemination of
22 that as well. And involved in other similar groups as
23 those referenced around — we were involved in
24 an evaluation advisory group when Public Health Scotland
25 were looking at people's experiences of shielding and

14

1 being on the high risk list, and other similar ...

2 Q. Yes. I think you also tell us that you had direct
3 liaison with Scottish ministers and Directorates — this
4 is at paragraph 15 of your statement — and your former
5 chief executive is a member of the Mobilisation Recovery
6 Group. Just tell us what that group was, please.

7 A. Yes. So this Mobilisation Recovery Group was set up by
8 the then Cabinet Secretary for Health and Social Care,
9 and even in 2020 there was a consideration about: how
10 will we, you know, look to remobilising health and
11 social care services? So at the time there was
12 obviously a particular focus on care and treatment for
13 people with COVID, but equally there was that view to:
14 how will we start to recover and remobilise health and
15 social care services?

16 So the group involved a range of stakeholders: there
17 was, as you were saying, our former chief executive as
18 a representative from the third sector; there was also
19 representatives, I believe, from the independent sector,
20 representing those working in care homes; and a range of
21 health boards and members of Scottish Government
22 Directorates as well.

23 Q. Within that group, what was the particular input that
24 your organisation was intending to give or could give?

25 A. So our involvement was really to help ensure that the

15

1 experiences of people, particularly people accessing
2 health and social care, people living with long—term
3 conditions, disabled people, unpaid carers, that there
4 was that opportunity to feed in the experiences and the
5 priorities of those individuals. It was on the back of
6 our membership of that group that we were then invited
7 to undertake that wide engagement programme, the People
8 at the Centre Engagement Programme.

9 Q. Now, I am going to go slightly off script here,
10 Ms Redmond, and it's my fault.

11 You have mentioned on a number of occasions, and you
12 continue to mention, throughout your statement the role
13 of unpaid carers and your role in assisting and advising
14 unpaid carers.

15 Can you put, in perhaps a relatively short
16 paragraph, what you feel was the role of unpaid carers
17 during the pandemic, and what impact there was on unpaid
18 carers? Because we are mindful as an inquiry that there
19 is a specific reference in our terms of reference to the
20 role of unpaid carers.

21 A. Yes. I would say that the impact has been profound for
22 unpaid carers. I mean, I guess just to express, these
23 are family members, these are loved ones of people that
24 they also provide care for. There was almost
25 a juxtaposition; in one respect, unpaid carers were and

16

1 felt very much excluded from arrangements, from
 2 decision-making, from decisions that were taken about
 3 people's care and support during that period of time, so
 4 they very much described experiences where their
 5 involvement was just sidelined; and yet, at the other
 6 side, they also were in a position where they were left
 7 very often to provide significant amounts of additional
 8 care to family members because of the disruption to
 9 other, you know, support and care packages that people
 10 had access to.

11 Many described that they were having to provide
 12 almost round-the-clock — 365 days, 24 hours — care and
 13 support to loved ones, and also at the same time,
 14 for example, people who are caring for disabled
 15 children, they were also having to provide education and
 16 schooling support. They were — despite the significant
 17 role they play, they were not able to accompany loved
 18 ones to healthcare appointments and to be there when
 19 information was being provided, when people were
 20 accessing healthcare and support.

21 We also heard experiences, as I am sure you will
 22 hear more about as well, from people who were an
 23 important part of a person's support when living in
 24 a care home environment, and all of a sudden being
 25 excluded from being able to be part of that care team

17

1 during the period.

2 Q. An expression that I have come across in the work that
 3 the Inquiry has been doing — I have seen it on
 4 a number of occasions in a number of different
 5 sources — is that unpaid carers were the "forgotten
 6 army" during the pandemic and, indeed, beyond the
 7 pandemic; would you agree with that?

8 A. Yes. I think it is a phrase that we hear about and have
 9 heard, you know, even before the pandemic, that there
 10 are more people providing unpaid care than there are
 11 paid carers within our social care system. They provide
 12 a huge amount of care and support and, in recognition of
 13 that, the Carers (Scotland) Act that was enacted in 2016
 14 was there to outline and try and provide a description
 15 of the rights that people had as unpaid carers: the
 16 right to breaks, the right to be involved at significant
 17 points in a person's health and care journey, on
 18 discharge from hospital and similarly, and to be
 19 involved in decision-making is a really critical part of
 20 the care and support that is important to people.

21 I would also say, from the other side of it, during
 22 our engagement we asked what was important to people
 23 looking at the remobilisation of health and social care,
 24 and one of the strongest themes that came across was
 25 that people want family members to be involved in their

18

1 care and support.

2 Q. Yes.

3 Right, forgive me, I did go slightly off script, but
 4 I think it is useful to get that context.

5 As I said earlier, you've engaged very effectively,
 6 if I may say, with the Inquiry. You have provided
 7 details of 110 relevant documents in response to
 8 a Rule 8 request that was sent to you, and, again, we
 9 express our thanks to you for doing that.

10 What you summarise at paragraph 19 of your statement
 11 are some of the points that are brought out, and
 12 I think, with respect, it would be useful if you just
 13 read that section so that it is public in this Inquiry.

14 A. Yes, absolutely.

15 So these include:

16 Responding to the Scottish Government, Social Work
 17 Scotland and the Scottish Commission for Learning
 18 Disability's call for comment on the options for
 19 remobilising social care day services, including those
 20 for adults with learning disabilities and people with
 21 dementia.

22 Responding to Scottish Government's stakeholder
 23 questions on shielding next steps.

24 A paper outlining the lived health and well-being
 25 experience of a broad range of people living in Scotland

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1 during the COVID-19 pandemic, as captured by the People
 2 at the Centre Engagement Programme to inform the
 3 Scottish Government's Mobilisation Recovery Group. It
 4 gives insights into how people viewed health and social
 5 care services when restrictions were still in place and
 6 shares their experiences and stories.

7 A joint letter to the First Minister from the
 8 Alliance and 32 other signatories calling on the
 9 Scottish Government to establish a third sector recovery
 10 and renewal fund for national third sector health and
 11 social care organisations.

12 Advice for health and social care staff in Scotland
 13 during the COVID-19 pandemic. Co-produced inclusive
 14 guidance on accessibility and inclusive communication
 15 for people living with sensory loss in relation to
 16 the COVID-19 outbreak.

17 Cross-sectoral guidance on issues including face
 18 coverings, social distancing and travel restrictions,
 19 co-produced in inclusive and accessible formats.

20 Emails and papers relating to the Alliance's
 21 membership of the Scottish Government's Long COVID Task
 22 and Finish Group which produced an implementation
 23 support note on managing the long-term effects of
 24 COVID-19.

25 Requests from the Scottish Government to share

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1 information relating to COVID-19 on the Alliance's
2 website and social media channels.
3 Providing comments on a Scottish Government booklet
4 with advice for people at highest risk.
5 Communication with Public Health Scotland regarding
6 the Alliance's involvement in setting up a panel of
7 lived experience of shielding or supporting a shielding
8 individual to inform Public Health Scotland's shielding
9 evaluation report.
10 Emails and papers relating to the Alliance's
11 membership of Public Health Scotland's Shielding
12 Advisory Group.
13 Emails and papers relating to the Alliance's
14 membership of the Scottish Government's Vaccine
15 Inclusive Steering Group.
16 Agenda for a roundtable discussion on long COVID
17 with the Cabinet Secretary for Health and Social Care.
18 Providing comments on the Scottish Government's
19 Coronavirus Scotland Strategic Framework and shielding.
20 Providing comments on a letter from the
21 Scottish Government to those on the shielding list
22 outlining protection levels and advice on what measures
23 people should take to stay safe.
24 Emails relating to the Alliance's membership of
25 Public Health Scotland's Shielding Evaluation Advisory

21

1 Group.
2 Discussion with the Scottish Government regarding
3 work on marketing materials to support Public Health
4 against COVID-19 and wider respiratory viruses over the
5 winter period.
6 Email regarding the Scottish Government's campaign,
7 Clear Your Head, and ALISS, which is a local information
8 system for Scotland which the Alliance hosts as
9 a supporting partner.
10 Emails regarding the inclusion of ALISS on the
11 Ready Scotland website.
12 Q. I think we can see from that you have been busy.
13 Obviously we have all these documents and, as
14 I said, these documents are being analysed, have been
15 analysed, and they will input into our consideration.
16 Please be assured of that.
17 You mention then the report, "Living with COVID-19",
18 and that followed a Parliamentary event. I think we can
19 probably read that and just take that as read.
20 I would just like to clarify what you say at
21 paragraph 22, where you say -- I think you talk about
22 the media coverage of the pandemic, and you say that it
23 was portrayed:
24 "... that it was 'only the vulnerable' who were
25 impacted; a damaging perception which fundamentally

22

1 overlooked the rights of individuals at risk, their
2 families, and carers."
3 Can you just expand on that a little, please.
4 A. Yes, certainly.
5 The way in which the risks associated with COVID-19
6 were presented in the media and in public narrative led
7 to almost a perception that, for the majority of people,
8 there was not much of a risk to be concerned about with
9 regards to COVID-19, and it was something which only the
10 vulnerable had a reason to be concerned about.
11 I think in addition to that what we heard was that
12 the way in which it was presented as something which,
13 you know, it was older people who were at risk of, also
14 meant that many people living with disabled children,
15 people who were higher risk because they were
16 immunocompromised and for other reasons, their
17 circumstances were overlooked and they weren't seen as
18 visible in terms of the risk that this presented for
19 them.
20 I think there was a huge amount of concern as well
21 that -- if it is okay to I guess expand upon this in
22 respect of --
23 Q. Yes, please.
24 A. -- many people living with long-term conditions and
25 disabled people feel almost systematically overlooked in

23

1 society anyway. There was -- you know, we heard from
2 people during our engagement that the restrictions
3 imposed upon everyone in society gave people an insight
4 into what it is like for some people already without
5 those restrictions, just because society is not
6 accessible for them. So there was almost a sense of
7 a levelling down, if you know what I mean, that people
8 were feeling like: well, this is -- more people have
9 an opportunity to see what it's like when you are
10 isolated because of how inaccessible society is.
11 So the portrayal in the media that this was
12 something that only those who are vulnerable need to be
13 concerned about represented a narrative which they --
14 many people already encounter in society, that their
15 rights to live the same quality of life as anyone else
16 in society is something which is undermined or
17 overlooked. So they felt that the narrative that,
18 "Don't worry, most of you are okay, carry on about your
19 business", actually really made it so that those who
20 were at higher risk had to be extra careful, extra
21 cautious, in the choices they made.
22 And I would add that that is how people still feel.
23 For those who feel really concerned and they feel very
24 much still at risk from the impact that COVID presents
25 to them, now they are having to make and navigate those

24

1 decisions really by themselves without a huge amount
2 of support available.

3 Q. That perhaps reflecting the perception that the worst is
4 over.

5 A. Yes.

6 Q. I think you reflect that in paragraph 23, where you
7 quote from one participant. I would be grateful if you
8 would just read that, please.

9 A. Yes. So this was during the event that members of our
10 team held at the Carers Parliament last year, where one
11 participant said:

12 "We still have to be very cautious, for example by
13 wiping down packaging and mail. We've been advised by
14 the GP to keep doing so. We feel that the rest of the
15 world has moved on and we haven't ... It feels like
16 people think COVID-19 never happened. You get your
17 vaccinations and boosters but you're just left to get on
18 with it."

19 Q. In the next three paragraphs, you go on to talk about ---
20 if I can give it a general heading --- communication, and
21 I think this is a particular point you want to get
22 across to the Inquiry and, indeed, it's one of
23 the points you make at the end of your statement ---

24 A. Yes.

25 Q. --- as a recommendation from you that the Inquiry should

25

1 be aware of.

2 In paragraph 24, you say:

3 "One in four respondents said that they had simply
4 have not received any information, and 22% felt
5 concerned that they were receiving unclear guidance
6 about the right procedures in terms of shielding,
7 self-isolating and using PPE."

8 A. Mm-hmm.

9 Q. The importance of getting out clear guidance is,
10 I think, essential to your message; is that right?

11 A. Mm-hmm.

12 Q. How do you see that being taken forward in the event of
13 there being a future pandemic? And I think this is
14 really what you say in paragraph 25. If you would just
15 read that.

16 A. Yes. So in the event of a future pandemic, the Alliance
17 recommends further listening and co-production to ensure
18 that people's experiences are embedded in the decisions
19 made and the way in which messages are disseminated.
20 The way in which messages are communicated must be
21 clear, consistent and compassionate, and recognise the
22 disproportionate impact of the COVID-19 pandemic and the
23 impact that it has had. Messaging must be informed by
24 human rights standards and principles, including
25 non-discrimination, and consider those who are likely to

26

1 be more affected by any future public health crisis and
2 the measures taken.

3 Q. Yes.

4 You take that slightly further in paragraph 26,
5 where you say that:

6 "... the Scottish Government must ensure [in the
7 event of a future pandemic] that there is clear,
8 accessible, and timely communication to everyone in
9 Scotland, including people with sensory loss and people
10 with learning/ intellectual disabilities and their
11 families, carers, and supporters from the outset. This
12 includes ensuring materials are consistently available
13 and accessible formats."

14 I think one of the things that you make the point
15 about is the need for that information to be in various
16 languages.

17 A. Yes. Yes.

18 Q. And to be available to those with sensory impairments.

19 A. Yes.

20 I think the other thing that we --- that is really
21 important is that there are feedback loops. So we need
22 to know that, when information is provided, it reaches
23 those that it is seeking to reach. One of the things
24 that we also found and I think was quite successful
25 during the work around the vaccinations was by working

27

1 with voluntary and community groups and organisations,
2 those where they have existing relationships, where
3 there is trust in place. One of the things that was fed
4 back around that is that, for some people, there isn't
5 necessarily the relationship and the trust with some of
6 our institutions, and with the amount of misinformation
7 that was also coming out, it was difficult for people to
8 discern what to trust. So those organisations and
9 groups where they have that trust and relationship is
10 a really effective way of information being cascaded.

11 There was also the opportunity to be quite outreach
12 focused and considering different mechanisms for getting
13 information out to different parts of society, and it
14 was --- I think that was one of the things that we were
15 really concerned about, was that people felt what they
16 were hearing nationally didn't chime with what they were
17 experiencing locally. They were finding it very
18 difficult to find the information to --- that allowed
19 them to understand what they could and couldn't do, how
20 to stay safe, and also that they were finding that, with
21 regards to the circumstances that they faced in life ---
22 so having a health issue arise, a worsening of
23 a symptom, some matter relating to their health or their
24 social care needs arise --- they weren't able --- they
25 weren't sure how to access those services and contacts

28

1 in the health and social care system, they weren't able
2 to find out what services were available, what weren't
3 available, where they were in terms of waiting for care
4 and treatment.

5 So there was kind of a huge range of factors around
6 the communication that people raised with us.

7 Q. I suppose one of the issues that you raise is that the
8 information that was being put out had to be information
9 that the recipient could trust.

10 A. Yes.

11 Q. Because of some of the other information that was
12 circulating at the time.

13 A. Yes.

14 Q. You go on to talk about digital technology, if I can use
15 it as a general heading. What is your view about that?

16 A. I think this was --- we were talking right at the start
17 about learning from innovation. Increasing the access
18 points through digital health and care tools and
19 technology was something which as an organisation we
20 were very aware the health and social care system had
21 been seeking to take forward for, you know, over
22 a decade, and yet the pandemic really was a catalyst for
23 accelerating the access points through digital.

24 Through the engagement that we had, many people
25 really welcomed that. They felt that the choice that

29

1 they had around how to access their GP, how to access
2 other aspects of the Health Service, particularly if
3 they were living in remote and rural areas, not having
4 to travel to appointments, that was really welcome.

5 On the other side of that, there were --- many people
6 described feeling as though they were concerned that the
7 blanket use of a digital --- first approach felt really
8 challenging for them. There were some examples where
9 people were receiving physiotherapy, for example,
10 through the virtual videoconferencing technology
11 platform, and they felt it didn't meet their needs, it
12 wasn't particularly tailored, they weren't following
13 what was being provided. There was a --- I remember
14 a family member of a disabled child saying that it was
15 pretty much they were just left to deliver the physio to
16 their child without the support that they usually would
17 be getting.

18 There were people who said that they were having
19 lumps or, you know, symptoms checked out via the
20 videoconferencing technology, and they were concerned
21 that that was --- they were concerned about trusting the
22 diagnosis at that point because they didn't feel that,
23 if someone hadn't actually been able to see, to feel, to
24 really assess whatever the symptom, whatever the
25 scenario was for them, they didn't trust that it was the

30

1 same standard of care that they would have had
2 face-to-face.

3 There was ---

4 Q. I'm sorry, I think you give a number of examples of that
5 from paragraph 30 through really to 35. Various
6 scenarios: people with sensory impairments, autistic
7 people ---

8 A. Yes.

9 Q. --- pregnant women.

10 A. Yes.

11 Q. And I think there is an interesting quote that you give
12 in paragraph 33. Perhaps you could just read that,
13 please.

14 A. Absolutely. So this was in response to pregnancy and
15 maternity services, with someone saying:

16 "Communication was extremely limited, poorly
17 conveyed, and frequently appeared to be poorly
18 understood by healthcare staff. I do not say that to
19 blame the individuals in question, but to highlight
20 inconsistencies with information sharing and staff
21 support."

22 That refers to quite a lot of the examples that were
23 shared with us. I would say people were extremely
24 understanding of the pressures facing the Health Service
25 and the social care support and services, and yet their

31

1 experiences also needed to be understood and heard, and
2 some of the decisions that were taken led to some really
3 severe outcomes for people.

4 Q. Yes.

5 In relation to pregnancy and maternity care, we will
6 be hearing more about that, particularly tomorrow. But
7 I think it is interesting what is said in, again,
8 a quote from a source at paragraph 38. It's a simple
9 statement, but perhaps you could just read that. It's
10 at the end of --- I'm sorry, it's at paragraph 36, my
11 apologies.

12 A. Oh, yes.

13 Q. Perhaps you can just read that, and perhaps you can
14 explain how that statement is reflected in the rest of
15 your evidence.

16 A. Our People at the Centre Programme also heard from those
17 who had experienced pregnancy and maternity services
18 during COVID-19, who shared that the experience was
19 anxiety-provoking and isolating due to the reduction in
20 postpartum follow-up services and visitation allowances,
21 with a quote shared:

22 "Pregnant women were forgotten about and treated
23 like 2nd class citizens with their rights taken away."

24 Q. The other theme that you go on to in paragraph 37 is
25 isolation. You begin that by looking at it in the

32

1 context of women's pregnancy and maternity care, but
 2 I think isolation was across the board.
 3 A. Yes. Yes.
 4 Q. Perhaps you could just read from 37 onwards, please.
 5 A. Yes. So isolation was a key theme which emerged from
 6 our research, impacting all aspects of women's pregnancy
 7 and maternity care. Participants described undergoing
 8 distressing and traumatic experiences alone, including
 9 managed miscarriage, fertility procedures and abortion
 10 care. Additionally, lack of antenatal and post-natal
 11 support in the community contributed to poor mental
 12 health outcomes. The report calls for mitigations in
 13 a future public health crisis to prevent perinatal
 14 isolation and allow women to be accompanied when they
 15 are undergoing appointments, giving birth, experiencing
 16 miscarriage or baby loss. Learning from the experiences
 17 shared by members, it is clear there should be a blended
 18 approach to delivering services which is rooted in
 19 choice and flexibility, as well as human rights
 20 standards.
 21 Q. Yes. Can I just stop you there.
 22 You then continue on to refer to what you call the
 23 rapid migration to digital as services and activities
 24 moved online. You have touched on that.
 25 Can you go to paragraph 40, because obviously there

33

1 is a balance in relation to the use of digital services;
 2 obviously it can be a boon to some people and a wonder;
 3 to others, it can be confusing and off-putting.
 4 A. Yes.
 5 Q. I think that is reflected in what you say at
 6 paragraph 40. Could you just read that, please.
 7 A. Yes. So, regarding digital, this has been a welcome
 8 development for those who can access internet services
 9 easily and confidently. However, we know that access
 10 and use of internet services remains uneven.
 11 For example, only 43% of people aged over 75 and 71% of
 12 adults with some form of limiting long-term condition
 13 use the internet. Research has shown that disabled
 14 people are less likely to use the internet or to have
 15 internet access at home than non-disabled people.
 16 I think one of things that really came out during
 17 the engagement that we have undertaken and subsequently
 18 through our digital health and social care programme --
 19 and we were -- and we really kind of campaigned on this
 20 with Scottish Government as well around their digital
 21 health and social care strategy -- that rather than
 22 a digital-first approach, it needs to be digital choice.
 23 There will be occasions where people prefer
 24 a face-to-face interaction over digital. That might be
 25 to do with the circumstances of their health, it might

34

1 be to do with, you know, situations within their wider
 2 life. We heard from people who were saying during the
 3 pandemic they had no private space to -- for which
 4 a health appointment could be accessed digitally, there
 5 were no safe spaces for them to have those conversations
 6 with healthcare professionals; to others who were saying
 7 that they just didn't feel -- particularly around mental
 8 health -- you know, interestingly, I think there has
 9 been some real successes around the digital mental
 10 health programmes that Scottish Government are taking
 11 forward, but during our engagement, there was a really
 12 consistent theme from people that they felt that digital
 13 mental health care was not suitable for many; that they
 14 felt they really would have preferred face-to-face
 15 mental health support during that period.
 16 Q. In paragraph 41 you talk about the five human rights
 17 principles for digital health and social care. Could
 18 you just tell us what those are? You set them out in
 19 paragraph 42.
 20 A. Yes. So the Alliance, working with Scottish Care and
 21 VOX -- which is Voices of Experience, it's a member --
 22 an organisation that is led by people with experience of
 23 mental health problems -- we undertook some engagement
 24 around what principles exemplified a human rights-based
 25 approach with regard to digital health and social care.

35

1 So the five principles which emerged from the engagement
 2 that we undertook with people were that: people needed
 3 to be at the centre of developments; it was about
 4 digital where it is best suited; digital as a choice;
 5 it's about digital inclusion, not just widening access;
 6 and also around access and control of digital data.
 7 Q. Could I just ask you, the second of those points,
 8 digital when it is best suited, that could be obviously
 9 a difficult decision to make. Who would you see as
 10 making that decision? Who would be the arbiter, as it
 11 were, as to whether or not digital was best suited?
 12 A. I think, from our point of view, people have to be
 13 involved in decisions about their access to health and
 14 social care. That does not need to be, you know,
 15 without dialogue taking place. I think, as I was saying
 16 before, people are often extremely reasonable and
 17 understanding about different circumstances, but what we
 18 witnessed during the pandemic was that there was
 19 variation in access, but not because people were being
 20 involved in those decisions. These decisions were taken
 21 behind the scenes by government, by health boards, by
 22 services themselves.
 23 So I think for us to ensure that people's rights
 24 aren't breached, there has to be some involvement with
 25 people. We have to understand the circumstances that

36

1 might lead them to say that digital is not best suited
2 for them in that situation.

3 Q. I think you mentioned it in an earlier context, but
4 would that involve, as it were, shelving the idea that
5 there should be a blanket provision on this?

6 A. I think we saw too many blanket approaches during the
7 pandemic and, for us, that was — one of the major
8 concerns we had was that, when decisions were taken,
9 they were not taken understanding that there will be
10 different impacts of those decisions, and for the people
11 that we were representing and working on behalf of, many
12 of those individuals and groups were disproportionately
13 impacted by those, whether it was around access or the
14 acceptability of the information or the services that
15 were provided, and that led to some really severe
16 outcomes for people.

17 Q. You go on to talk about digital inequalities, and
18 I don't want to simplify this, because I think obviously
19 it's a very complex and nuanced issue. This is
20 paragraph 44 of your statement.

21 I suppose some of the inequalities involve,
22 for example, an ability to comprehend and use digital
23 technology, and then another inequality would be the
24 ability to afford it.

25 A. Mm—hmm.

37

1 Q. Are these two of the principal concerns you have?

2 A. Yes. So definitely the affordability of the hardware
3 was a concern and, in addition to that, the
4 affordability of the data, the connection, that people
5 needed in order to be able to get online. So you needed
6 to have the hardware, you needed to have the data and
7 the connections to be able to get online.

8 Issues around confidence, understanding, you know,
9 the skills in order to be able to know what is available
10 in terms of the tools, the services, and how to access
11 them.

12 The other aspect is around the design, the inclusive
13 design of services. So you referred previously to some
14 of the experiences people with sensory impairments
15 encountered where, you know, some of the — the only
16 methods for them to get access to health services did
17 not take into account their communication needs, whether
18 it was — you know, for some individuals accessing GP
19 services, they were having to go through telephone
20 lines, maybe they were hard of hearing or they were
21 deaf; for people accessing virtual consultations, if
22 they didn't work with their screen readers, again, that
23 is not — they can't navigate to get online. So
24 inclusive design is another important factor.

25 I would say it is an example where there was some

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1 good practice. The Connecting Scotland programme was
2 really well received, and the way in which it was
3 implemented worked well. Working with community groups
4 and organisations to utilise their networks of people
5 they were working with and supporting to help them
6 access devices, support and connectivity.

7 But one of the things that we are — so we continue
8 to deliver some work around helping people identify what
9 digital tools and services there are available to them.
10 There is a huge amount of work we still need to do to
11 develop people's understanding of what is available,
12 their confidence in using it. We really need — if we
13 are going to make sure that digital choice is a choice
14 people can make, we need to make sure that we are
15 supporting them and we are building that capability, as
16 well as with the workforce. You know, there is often
17 quite a bit of nervousness amongst the workforce as well
18 about how to engage with people through digital means as
19 well.

20 So I would say there is still quite a lot of work to
21 do there.

22 Q. In paragraph 46 you I think summarise your position, and
23 I think we have already perhaps looked at this. If
24 I can just pick up just a couple of points there.
25 You say digital is supported by you, but not as the

39

1 default position. I think you also go on to say that
2 there should not be a one—size—fits—all solution to
3 this. Is that essentially encapsulating how you are
4 approaching this issue?

5 A. Yes. Yes, absolutely.

6 Q. Okay.

7 Paragraph 47, you talk about DNR, and this is again
8 a subject that the Inquiry is specifically tasked at
9 looking at. I think you go on to talk about it later in
10 your statement, but perhaps we could just get the
11 context of what you are saying.

12 Perhaps just read through paragraph 47 for us,
13 please.

14 A. Yes. At the outset of pandemic, the Alliance received
15 concerning reports from our members highlighting that
16 some population groups in Scotland were receiving
17 unsolicited requests by some GP practices to sign "Do
18 Not Attempt Cardiopulmonary Resuscitation" forms, or
19 DNACPR forms. Our members Age Scotland and National
20 Autistic Society Scotland are among those who have
21 raised the issue. While DNACPR forms have an important
22 role in anticipatory care planning, decision—making
23 should be based on an open discussion with individuals
24 and their families, and firmly cemented in human rights
25 standards. Blanket approaches should never be taken.

40

1 The inappropriate use of DNACPR forms during the
 2 pandemic has caused distress for many people and their
 3 families. The longer-term impact of the increased
 4 number of DNACPR forms completed, their improper use and
 5 the impact on individuals and families must be addressed
 6 by the Inquiry, as well as recommendations on how to
 7 prevent a situation like this happening again in future.
 8 Q. To take up some of the points you make there — and
 9 I know we will look at it later in your statement in
 10 perhaps a little more detail, but I think it is useful
 11 in that context — one of things that we have heard and
 12 will continue to hear, I think, in this Inquiry is the
 13 need for DNR notices and forms to be accompanied by
 14 proper and compassionate discussion about them. Is that
 15 something you favour?
 16 A. Absolutely. I think we recognise, as an organisation
 17 who — we have been working around this and similar
 18 issues for many a year now, and people understand that
 19 anticipatory care planning and planning for end-of-life
 20 care is something which is a real matter people will
 21 engage with and need to engage with. The way in which
 22 it was handled during the pandemic with calls — I mean,
 23 there was one mum who shared an experience where she
 24 received this unsolicited request and it was about her
 25 child, and she was told that this form was going to be

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1 applied to her son and there would also be no hospital
 2 transport in the event that he needed support to save
 3 his life. It was delivered to her, you know, pretty
 4 much as a cold-call, extremely distressing and
 5 traumatising for her, and has left her really
 6 questioning the support that is available for her and
 7 her son, now and in the future.
 8 We call — I believe we will cover this in more
 9 detail, but consistently what we hear from people is
 10 that they are looking for a greater sense of
 11 person-centredness in the care and support that they
 12 receive navigating the healthcare system, particularly
 13 when their circumstances will require them to have
 14 repeat or frequent engagements with the healthcare
 15 system. So it's not that people want to, you know,
 16 overlook these issues or that they are putting their
 17 heads in the sand or anything, but they want to have
 18 a meaningful conversation with a healthcare professional
 19 about these issues ahead of time, not at a point in
 20 crisis and not in a way which is about protecting the
 21 service, not protecting their life and their rights.
 22 Q. I suppose, using the example you gave, there is
 23 a necessity to discuss those matters —
 24 A. Mm—hmm.
 25 Q. — but there is a way how you should do that.

42

1 A. Yes.
 2 Q. And that probably was not the way to do it.
 3 A. Yes, absolutely.
 4 I would add — I mean, there is guidance around
 5 anticipatory care planning. There has been a programme
 6 of work which Healthcare Improvement Scotland has been
 7 taking forward — gosh, a number of years ago we were
 8 involved, so I would say several years, maybe dating
 9 back even to 2016 or around that time, to try and
 10 increase the use of anticipatory care planning across
 11 Scotland.
 12 So this was something which, again, need not have
 13 been an issue during the pandemic if it had been
 14 implemented in the way in which the guidance said; that
 15 this is about having early conversations with people,
 16 not just about their end-of-life care wishes, but about
 17 how — what is important to them as they progress
 18 through life as their health maybe deteriorates. It is
 19 not just about as things get towards the end, but really
 20 about planning for the future.
 21 MR GALE: My Lord, perhaps we could take a break briefly at
 22 that point. Thank you.
 23 THE CHAIR: We will come back at about 11.25.
 24 (11.08 am)
 25 (A short break)

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1 (11.36 am)
 2 THE CHAIR: Thank you.
 3 Yes, Mr Gale.
 4 MR GALE: Thank you, my Lord.
 5 Ms Redmond, we had been talking about DNR notices
 6 before the break, and can I take you on to paragraph 48
 7 of your statement and following, because here you return
 8 to the question of long COVID. Again, to a certain
 9 extent these are some of the points that we have already
 10 touched on when we looked at it earlier today.
 11 Just one or two points I would like to take from you
 12 in relation to long COVID.
 13 First of all, I take it from what you are saying to
 14 the Inquiry that this is a condition about which you —
 15 and your members reflect to you that is quite
 16 appreciable within the population?
 17 A. Mm—hmm.
 18 Q. I think you have given a figure in paragraph 48 that the
 19 ONS estimates that 2.1 million people in the UK are
 20 living with the condition, and I assume that this is
 21 just a simple reflection of the population of Scotland.
 22 If that is the sort of figure in the UK wide, then we
 23 would be talking about 187,000 people in Scotland.
 24 A. Yes.
 25 Q. Do you think that is a realistic figure?

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1 A. I think the trouble is that we don't know for definite,
2 and I think, you know, it is something which does need
3 to be — you know, the issue of data I think is possibly
4 something that we might talk about a bit as well, but
5 I think the issue of recording and capturing data in
6 a way that helps us to understand the prevalence of
7 different conditions that people are living with. But
8 I think if we are looking at that figure across the UK,
9 then that would be — it would be accurate for us to
10 assume that there is an equivalent proportion of that
11 population living in Scotland with this condition.

12 Q. You have given us a number of quotes from respondents to
13 your organisations, and some of these, I think, perhaps
14 sum up the point that you are wanting to get across
15 about long COVID. In paragraph 49, a respondent said
16 that:
17 "[Long COVID] is life changing. Sometimes it feels
18 like we are invisible."

19 I am asking you obviously to comment on somebody
20 else's comment, but do you understand that?

21 A. Yes, I think one of the things that struck me from
22 listening to people's experiences of living with
23 long COVID was that they were overwhelmed at the fact
24 that their experiences initially were not believed.
25 They received feedback that: well, they couldn't still

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1 be living with symptoms; they had had COVID months ago,
2 how could they still be describing these symptoms?
3 There was no place to go to get support, to get
4 information. They were having to do all this research
5 by themselves. And that is why we have seen the numbers
6 of people who are connecting with peer support group,
7 online groups, etc., so that they can share their
8 experiences of the research and the support that they
9 have found.

10 I would also say it is not an experience which is
11 unique to long COVID. I think working with the Alliance
12 for the years that I have, that feeling of being
13 invisible is described by people living with other
14 conditions as well, particularly conditions which are
15 perhaps harder to diagnose, there might not be one
16 recognised test or procedure to diagnose a condition,
17 such as people living with ME, chronic fatigue syndrome,
18 people living with endometriosis, other conditions
19 that — you know, those experiences, and I think that is
20 coupled with what we were talking about by, you know,
21 dominant messages in the media and publicly, that there
22 was a perception — not by everyone in the kind of
23 public narrative, but a feeling as though this was
24 a made up condition, this was not a real condition, and
25 I think that has just compounded those experiences for

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1 people feeling as though their lived experience of this
2 has just been completely overlooked.

3 Q. I suppose in that context what is said in paragraph 50,
4 the quote there, is:
5 "Along with the fatigue the other biggest thing is
6 attitudes."

7 A. Yes.

8 Q. "The more education there is — education is so important
9 — and with that maybe it would be a bit more
10 recognised."
11 I suppose also certain comments that had been
12 made — Boris Johnson's "bollocks" — probably didn't
13 help.

14 A. No, no, absolutely.

15 Q. At 51, there is, as you put it, an anthology of opinions
16 about — perhaps you could just read that quote, please.

17 A. Yes, absolutely:
18 "It is disappointing [...] that despite the
19 information we now have on Long COVID people are still
20 struggling to have their voices heard. I've lost count
21 of the number of people who have told me they were
22 dismissed by their GP and other healthcare
23 professionals, being told they were suffering from
24 anxiety, and they should get out and exercise more.
25 People in employment are also struggling with their

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1 employers, with many being forced to go back to work
2 when they're not ready or facing disciplinary action.
3 Dealings with the Department for Work and Pensions have
4 also added to the pressure people are already facing,
5 particularly with PIP [Personal Independence Payment]
6 applications, with people giving up on claiming benefits
7 they are entitled to because the claims processes are
8 far too exhausting for them."

9 Q. Can I just bring this section on long COVID to
10 a conclusion at paragraph 54 of your statement. I think
11 you are looking at the support which is available to
12 individuals with long COVID, and you conclude by saying
13 that:
14 "... it is clear that these experiences are
15 inconsistent and varied across Scotland, with
16 participants acknowledging their own positive
17 experiences as 'unusual'."

18 That is the import that you have taken from this.

19 A. Yes, and I wouldn't say that that — I definitely think
20 progress is being made and continues to be made, but
21 I don't think we have a comprehensive package of support
22 for people across Scotland. I think there is still
23 a lot of variability.

24 Q. Okay.
25 Paragraph 55 and following, you touch on shielding

48

1 and shielding measures. You say that your members
 2 shared how shielding measures had a significant impact
 3 on certain population groups who are often the most
 4 marginalised and excluded people in society. You say
 5 these included disabled people with long-term
 6 conditions, unpaid carers, minority ethnic people and
 7 older people. That was the information you were getting
 8 back from your members.
 9 A. Yes.
 10 Q. Also you mention the concerns that were raised about the
 11 consequences of shielding. These are probably the ones
 12 that we have come across quite often —
 13 A. Yes.
 14 Q. — in our discussions: social isolation, inadequate
 15 access to food, health issues going unnoticed or
 16 undetected. Again, that is something that was being
 17 reported back to you.
 18 A. Yes.
 19 Q. You go on to talk about confusing and contradictory
 20 guidance. Can you give us some context for that
 21 comment, please.
 22 A. I think initially what people found confusing was
 23 whether or not they were on the shielding list to begin
 24 with. I think there was a situation where, down to what
 25 data — you know, coming back to what data actually was

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1 held nationally on people across society through the
 2 Health Service. There were some people who were
 3 identified as on the shielding list and received
 4 a letter accordingly; there were others who were able to
 5 be added on because of their — they were liaising with
 6 local GPs, other healthcare professionals. We also,
 7 through our links worker service, were aware that,
 8 through relationships that links workers had with
 9 different members of their practice population, they
 10 were able to advocate for the inclusion of members on to
 11 this list.
 12 So there were some people who thought they should
 13 have been and weren't added on. They might also be in
 14 contact with someone else whose circumstances were quite
 15 similar, but they themselves were in a different
 16 situation to someone else. And, of course, being
 17 identified on this list meant that they had access to
 18 documentation which they could use to share with their
 19 employer, with others, to identify that they were
 20 shielding. It gave them — you know, they were able to
 21 access local support as well to counter some of those
 22 issues around isolation and access to essentials.
 23 I think as well the way in which the process was
 24 managed as the pandemic progressed and the shielding
 25 list transitioned into a higher risk list and some of

50

1 the communications then that subsequently came out to
 2 people felt confusing to them, particularly what they
 3 should be doing, could be doing, shouldn't be doing, and
 4 the point we are making here was that this was
 5 exacerbated by the fact that the way in which
 6 restrictions were eased and continued to be implemented
 7 differed whether you were living in Scotland, which part
 8 of Scotland you were living in, when restrictions were
 9 locally applied, and if you were living in different
 10 parts of the UK.
 11 So trying to navigate that, the complexity of it,
 12 was perhaps inevitable, but being able to make the right
 13 decisions based on your circumstances was critical for
 14 people, so they needed to have access to that
 15 information to be able to know what they should be
 16 doing, could be doing.
 17 Q. You say at paragraph 57 that:
 18 "Many people feel that they are 'being left to fend
 19 for themselves' ..."
 20 Is that a reflection really of what you have been
 21 saying; that if somebody has been shielding, felt that
 22 they were — that there was a necessity for them to be
 23 shielding and then restrictions are eased, there might
 24 be an understandable reluctance to go back to what might
 25 appear to be a normality?

51

1 A. Yes, yes, absolutely. And I think as well that this
 2 relates as well to whether or not those people are able
 3 to access boosters, whether they are able to access the
 4 kinds of treatments that can help prevent — for people
 5 who couldn't — who wouldn't benefit from vaccination,
 6 if they are able to access a treatment that would be
 7 supportive of them. I think there is a whole range of
 8 aspects to this which is making it very difficult for
 9 people to continue living their life when there are
 10 still risks to their health from COVID.
 11 Q. Yes.
 12 Right, could we move on to unpaid carers, please, at
 13 paragraph 58 and following. Again, we touched on this
 14 a little. I think you make reference to the Alliance as
 15 being part of the Carers Parliament in November of last
 16 year, and looking at the ongoing impact of COVID for
 17 unpaid carers.
 18 Could you read on from paragraph 59, please.
 19 A. Inclusive of 59?
 20 Q. Inclusive of, yes.
 21 A. So participants shared experiences of miscommunication,
 22 lack of clarity in information provision and confusion
 23 about risks. For example, information about who should
 24 be on the shielding list was contradictory or lacking.
 25 One person's condition meant that while they were not

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1 formally on the shielding list, they were advised by
2 specialist healthcare professionals to shield.
3 With measures taken to control the virus being
4 reduced, participants shared that it now feels like
5 public perception and public health messaging has
6 shifted to the COVID-19 pandemic being over. Fewer
7 people are wearing masks, yet people at high risk of
8 COVID-19 infection and their carers are continuing to
9 shield. As a result, many carers and those they support
10 feel left behind. Carers also described anxiety around
11 their own health conditions, maintaining their caring
12 responsibilities, fear of contracting COVID-19, but also
13 managing feelings of anxiety and isolation. As
14 summarised by one participant:

15 "It feels unsafe to leave the house because the risk
16 of infection is still very real ... Social work helped
17 in the beginning of COVID-19 but we felt left in the
18 unknown."

19 Q. Yes, thank you.

20 To a certain extent, what follows in paragraph 61
21 and following does follow on to a certain extent from
22 unpaid carers, and again, can I trouble you just to read
23 61 inclusive and following.

24 A. Absolutely. This was a really strong theme from the
25 engagement we have had with members.

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1 So we heard from our members that there was reduced
2 and disrupted access to healthcare services across the
3 board, where the prioritisation of COVID-19 has had
4 an impact on people with non-COVID-19 needs. Whilst
5 people have shared their understanding about the
6 unprecedented demand that COVID-19 placed on health
7 services, the impact of the lack of access has been
8 considerable and has led to a deterioration of people's
9 physical and mental health.

10 Individuals told the Alliance they had experienced
11 a number of disruptions when trying to access healthcare
12 services. For example, health clinics had been paused,
13 outpatient appointments and elective surgeries
14 cancelled, face-to-face appointments reduced or
15 cancelled and waiting times increased.

16 Q. I think you then give a quote.

17 A. Yes. So this is an example of a quote that was
18 reflective of many of the responses and conversations we
19 had with people:

20 "They felt like they are inaccessible ..."

21 So this is about healthcare services:

22 "They felt like they are inaccessible unless you
23 have COVID. I received messages from GPs advising not
24 to visit the surgery at all, but never received
25 a message saying it was now safe to do so."

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1 So people really described to us not knowing what
2 was available, how they should be accessing it, what was
3 an essential service. I think some gave examples where
4 essential services such as supermarkets and other
5 services, which were of course deemed as essential, but
6 for many people those other healthcare services were
7 equally essential for them to maintain their health at
8 a level and those weren't — it wasn't either
9 communicated to them whether they were accessible or
10 they just weren't.

11 Q. You mention then in paragraph 63 audiology services.

12 Tell us a little about that.

13 A. Yes, so this is an example, and this was a separate
14 piece of engagement that was carried out, and I think
15 one of the things I would say is that — I have referred
16 to it around, you know, where people typically discuss
17 and describe sometimes their frustration at the lack of
18 person-centredness, the continuity of care, the
19 co-ordination of care, to what extent they are actually
20 involved in decisions about their care and treatment.
21 This was not unique to the pandemic, but we carried out
22 some engagement to inform an independent review of
23 national audiology services across Scotland.

24 So, during this, people told us about long waits
25 that they had received — that they'd experienced during

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1 the pandemic, and this was one example of a quote that
2 someone had shared with us. They had:

3 "Had to wait 12 months with profound hearing loss
4 and no hearing aids over COVID, [which] meant I couldn't
5 understand lectures or go to work."

6 Q. I think there is also a reference to professionals
7 discussion the backlog of cases.

8 A. Yes.

9 Q. Paragraph 65 I think is a general observation and,
10 again, I think it would be useful if you read that.

11 A. Yes. So in our briefing, "Learning from changes to
12 social care during the COVID-19 pandemic", we wrote to
13 32 local authorities and received many responses which
14 aided in our learning around good practice and learning
15 that emerged from the pandemic, as well as areas that
16 could be revised. Local authorities and health and
17 social care partnerships spoke about working
18 collectively with external partners and social care
19 providers at a local level to deliver services. One
20 example of this was an online weekly provider forum to
21 ensure the efficacy of PPE supply and delivery to social
22 care providers, to deal with any queries, to monitor
23 emerging areas of concern and ensure that there was
24 continuity of support.

25 Q. Is that something that is ongoing?

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1 A. This was one of the things that came out strongly during
2 the pandemic. One of the real success stories was, at
3 a local level, the collaboration and partnership working
4 which did take place to respond, almost in contrast to
5 perhaps what had existed before.
6 I am not sure whether this example still operates,
7 but we have heard a lot of feedback from members working
8 in the third sector that — and also from health and
9 social care partnerships, a concern and a lament that
10 that collaboration, that spirit of partnership working,
11 has receded, and actually I think because of the
12 financial crisis, it's —
13 Q. Been replaced.
14 A. — almost been replaced by the opposite.
15 Q. Yes.
16 Okay. Probably the subject of money has to be
17 addressed and, to a certain extent, you do that as you
18 go on in your statement and talk about funding.
19 A. Mm—hmm.
20 Q. You say in paragraph 66 that:
21 "Third sector organisations adapted and responded
22 flexibly to the COVID—19 pandemic to ensure that people
23 in their communities were supported and not left
24 isolated. However, some local authorities and HSCPs
25 also referred to the negative impact that COVID—19 has

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1 had on commissioning arrangements with third sector
2 organisations."
3 Can you explain what that is.
4 A. The commissioning arrangements?
5 Q. Yes.
6 A. So commissioning refers to a whole — a cycle of
7 planning and investment processes whereby the needs of
8 a particular population will be looked at, there will be
9 a look at: what does the market look like in terms of
10 providers to respond to some of those needs, what kinds
11 of interventions need to take place to encourage more
12 provision of services, and can also then involve
13 procurement. So it's a whole kind of cycle of
14 activities that is often — often involves ultimately
15 an arrangement where a tendering process is undertaken.
16 So a local authority or a health and social care
17 partnership will identify they need a provider of
18 a particular range of services, they will set out
19 a brief, and then they will invite proposals from
20 different providers to respond to that.
21 Q. What was the negative impact that you are talking about?
22 A. So I think what many areas experienced was just the
23 challenge with capacity. There were some problems in
24 just being able to go through commissioning processes
25 because they were having — staff were being relocated.

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1 There were financial pressures as well on areas because
2 they were having to provide for different responses than
3 what they had been used to be doing. There was also
4 an impact where organisations were not seen as
5 essential, so they were furloughing staff because there
6 wasn't — this was not seen as a kind of part of the
7 essential services that were available. And also the
8 impact on many third sector organisations financially
9 was also really challenging. Some of their provision
10 will have been supplemented through fundraising, through
11 charity shop sales, through volunteering. That was
12 really, really difficult to manage during the pandemic.
13 Q. I think you reflect that in the bottom of paragraph 66.
14 A. Yes. So vital services were not being delivered in some
15 areas. There were impacts on social care packages and
16 then on people's well-being.
17 Q. Paragraph 67, you say:
18 "The third sector continues to be undervalued and
19 under resourced."
20 I think I probably understand — adding another
21 "under" into it — under—resourced. Undervalued; can
22 you indicate why you say that and can you indicate also
23 who you feel undervalues the third sector?
24 A. Yes, I mean, I think one of the things — and it wasn't
25 just, you know — as a third sector intermediary, we

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1 would of course be celebrating and pointing to the good
2 work happening in the third sector during the pandemic,
3 but we weren't alone. Scottish Government, Healthcare
4 Improvement Scotland, also provided reports and research
5 which documented the very agile, flexible and at—pace
6 response that the sector provided to support people,
7 often in really significant ways as well. And that —
8 I think the other thing we saw during the pandemic was
9 that funding was provided without the kinds of strings
10 attached that you typically see through either grant
11 funding or through, you know, contracts and service
12 level agreements, whereby organisations were trusted to
13 respond to the needs they were encountering locally.
14 Organisations really appreciated that. They adapted
15 quickly to provide for the kinds of basic needs they
16 were encountering.
17 When we refer to that being almost the exception in
18 terms of the value placed on the sector, what we see and
19 have seen for many a year is that the contribution that
20 the third sector makes in terms of community health
21 provision and as a provider of a lot of social care
22 support and services, we tend to not be included as
23 a matter of course in decision—making bodies, in, you
24 know, governance and oversight boards and bodies, as
25 an equal partner. The kinds of agreements — you know,

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1 we've recently heard of one area, one local authority
 2 area, that is going out to re-tender for a service at
 3 a lower value than it currently provides that service
 4 for, despite the fact that costs of delivering services
 5 for all of us have gone up.
 6 We are not referenced typically --- there was health
 7 and social care workforce strategy by Scottish
 8 Government. The third sector workforce does not feature
 9 within that. Where it tends to be recognised as
 10 a contributor to our health and social care system, by
 11 and large that tends to be within the social care
 12 sphere. But there's a huge number of organisations that
 13 deliver a whole range of support for people's health and
 14 well-being, ranging from peer support groups and
 15 provision to really specialist support. There's
 16 organisations that provide rehabilitation and
 17 habilitation support for people with sensory
 18 impairments; there's really specialist support for
 19 people living with neurological conditions, befriending
 20 support. The response that was provided during the
 21 pandemic relied on that ecosystem within the third
 22 sector, and I would be really concerned that the way in
 23 which the sector is treated and the resourcing that goes
 24 into it, the lack of long-term funding, the lack of
 25 planning, and real understanding about --- there is waste

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1 in the sector caused by the way in which the sector is
 2 treated. That provision might not exist if we don't
 3 make sure that we are looking after it.
 4 Q. You make a recommendation in paragraph 68, which I think
 5 you then expand on in 69, that funding --- I assume this
 6 is general funding for the third sector --- should be
 7 provided for longer time periods, and funders and
 8 commissioners should support a flexible approach.
 9 Then you refer to the fair funding principle set out
 10 for the Scottish Council for voluntary organisations:
 11 " ... that funding should be multi-year, flexible,
 12 sustainable, and accessible."
 13 And you say that:
 14 "If the third sector is properly funded in a way
 15 that is set out under these principles, then it will be
 16 better prepared for a future pandemic."
 17 And that is your view?
 18 A. Yes, yes, very much so.
 19 Q. Really I suppose as a generality, if one goes down to
 20 paragraph 72 in your statement, you mention there that
 21 there have been and were positive changes in the course
 22 of the pandemic, but that they are now being reversed
 23 without proper consultation.
 24 Can you give an example of that, if possible, and
 25 can you just comment on that as a process.

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1 A. Yes. So examples that were given, both by
 2 representatives from health and social care partnerships
 3 as well as people working in the third sector, was that
 4 there was a spirit of collaboration which was enabled
 5 because we were all united with a common goal, and
 6 organisations --- I remember one organisation saying,
 7 "The health and social care partnership is actually
 8 coming to me to say: how can we work together on making
 9 sure that we are reaching people across society, can
 10 we work together on these matters?" So that was
 11 extremely welcome from all sides.
 12 As restrictions began to ease and we began to plan
 13 more for recovery, there was a concern at the time that
 14 we might not be able to learn those lessons quickly
 15 enough and implement them so that they become more
 16 business as usual. So there was direction set
 17 nationally which allowed for perhaps some of the
 18 procedures that would typically be in place to be
 19 loosened so that it was more about responding to those
 20 kind of emergency needs.
 21 That concern, I think, is definitely being evidenced
 22 by work that is happening locally. I was referring to
 23 one --- an organisation who was concerned about the
 24 arrangement for the recommissioning of a service for
 25 a particular service provision around social care, and

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1 they were really concerned that they were being expected
 2 to tender for that service at a lower cost which would
 3 not allow them to reflect the additional costs that have
 4 just been incurred because energy is higher, rents are
 5 higher, but also actually pay their staff, you know, an
 6 increase, because their costs will have also increased.
 7 Personally as an organisation we are seeing that as
 8 well. One of the services we deliver in Glasgow, you
 9 know, an example of a very person-centred support, the
 10 community links worker service, and because of the
 11 funding pressures on national government and locally,
 12 that service provision is being cut.
 13 It's not just about the cuts; it is also about how
 14 those decisions are taken. So we were not consulted, we
 15 were not involved in the decisions around that. The
 16 staff weren't involved in those. The people accessing
 17 those services were not consulted. That goes against
 18 guidance. It goes against what you would witness if it
 19 was a public sector employer. There are different
 20 standards, depending on whether you work for the public
 21 sector or the third sector, independent sector, in
 22 health and social care.
 23 Q. All right.
 24 You will appreciate, Ms Redmond, that probably some
 25 of these things are beyond the remit of this Inquiry ---

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1 A. Yes.
 2 Q. — and probably beyond — certainly beyond my wit, but
 3 we do know that the Scottish Government, in its opening
 4 statement to this Inquiry, said that it would be
 5 listening to everything that is said, and obviously what
 6 you have said I am sure will be heard by the government
 7 in that context.
 8 Paragraph 74, you deal really about staffing.
 9 Perhaps you can just summarise what you are saying
 10 there.
 11 A. So the pandemic led to significant changes in staff
 12 structures and the way in which services were delivered,
 13 and our research found that local authorities and health
 14 and social care partnerships adopted different ways of
 15 working. There were some areas where teams were working
 16 exclusively from home during the height of the pandemic;
 17 others were operating a more hybrid approach, with
 18 rotational staff bubbles. There were examples of
 19 well-being hubs set up, including utilising local public
 20 library spaces, which would allow staff working in maybe
 21 care-at-home services, where they are going out and
 22 visiting people's homes, to be able to come to a hub,
 23 a place where they could meet others delivering similar
 24 services and have a break, have somewhere to come to and
 25 just reflect on the difficulties that they were

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1 experiencing delivering those services.
 2 So there were definitely some really positive
 3 examples where the flexible working — there were also
 4 examples where there was delegated decision-making down
 5 to social workers at a more front-line level so they
 6 could make a decision about a person's — an assessment
 7 of their care needs and actually make sure that that
 8 provision was put in place at a much quicker — much
 9 more quickly and proactively than would be usual when
 10 a decision has to be taken to a kind of decision-making
 11 board to approve that.
 12 Q. I think what you say at paragraph 77 is that you
 13 recommend that there should be a review of COVID-19
 14 working practices undertaken to ensure the areas which
 15 worked well can continue to benefit people accessing
 16 support and health and social care. Do you know if that
 17 is going on?
 18 A. Not to my knowledge.
 19 Q. Okay. Thank you.
 20 Right, we are coming to the end of your statement,
 21 Ms Redmond, and what you conclude with is a series of
 22 bullet points in which the Alliance, through you, make
 23 certain recommendations.
 24 A word that we are going to come across, both with
 25 you and with the women's rights organisation, is

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1 "intersectional". Can you just explain that to me.
 2 A. Yes. So by that we mean having an understanding that
 3 people's identities are not siloed; that there will be
 4 an intersecting of identities and characteristics that
 5 will mean that a person's experience in society will be
 6 impacted not just by one label, but by those
 7 intersections between a number of their identities or
 8 characteristics.
 9 Q. Thank you.
 10 A. Mr Gale, would I also just be able, before we look at
 11 the recommendations, just to cover some of the
 12 experiences around social care?
 13 Q. Yes, certainly, if you wish. Yes, if you would like to.
 14 A. Sorry to — would that be okay?
 15 Q. Yes, please do.
 16 A. Reflecting on what we were talking about around flexible
 17 working and some of the spirit of collaboration
 18 around — with local authorities and health and social
 19 care partnerships, another aspect which people shared
 20 with us quite substantially was their experiences of
 21 their social care packages and accessing provision
 22 around social care during the pandemic.
 23 We heard from people that, without much notice or
 24 any notice, their social care packages would be stopped;
 25 that that was communicated without an explanation,

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1 really, or without any alternatives about what else
 2 would be put in place, and again put quite a lot of
 3 pressure then on family members and people providing
 4 unpaid care.
 5 There were — there was guidance which allowed local
 6 authorities and the health and social care partnerships
 7 to lessen the requirements around an assessment or the
 8 extent of the assessment that had to take place. The
 9 guidance was that that was to expedite the process and
 10 make sure that people were able to access the care they
 11 needed without lengthy delays; yet in practice,
 12 sometimes what that led to was people — those
 13 assessments not being communicated to people in a way
 14 that provided them with the information about what they
 15 were going to be able to access, and also seemed to then
 16 lead to a tightening of the eligibility criteria so that
 17 it was — they had to meet a higher threshold in order
 18 to access social care.
 19 There were also some examples that some local
 20 authorities had suspended their complaints processes,
 21 which again is a really important process that allows
 22 people's rights to be protected if there were concerns
 23 that they had about the provision that they were
 24 receiving, and that was raised by ourselves and the
 25 Scottish Human Rights Consortium, that this was not

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1 acceptable.
 2 There were some examples -- so I would -- and
 3 I spoke to some of those beforehand, where there were
 4 some positives around greater flexibility for social
 5 workers making decisions. There were also some
 6 opportunities where people were able to use their
 7 personal budgets more flexibly to help them meet some of
 8 the aspects of their daily living needs and
 9 circumstances, maybe to employ a family member as
 10 a personal assistant, which again allowed them to have
 11 some choice and control during that time.
 12 I think it was -- one of the things we kind of
 13 advocated for strongly was that experiences around
 14 social care were given due consideration during the
 15 Inquiry process, substantially because the way in which
 16 decisions were made were really difficult to track and
 17 to monitor for organisations and for people accessing
 18 social care, and for many people, social care is about
 19 enabling them to live an independent life and be able to
 20 participate. It's a hugely critical provision of
 21 support and services for people, so those experiences
 22 are really important that we hear about as well.
 23 Q. Just taking one point that you have mentioned there, and
 24 I think you mentioned this again earlier: if I can put
 25 it this way -- and I'm rather loath to ask this, because

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1 it is probably not a question that can be answered in
 2 the generality but has to be done in the specifics --
 3 but so far as the input that your organisation has had,
 4 I suppose the greater autonomy that was given to certain
 5 social workers, was that welcomed?
 6 A. Yes, and I think, you know, as you say, I don't feel
 7 I have the authority to be able to say in all
 8 circumstances, but I think it was definitely welcome.
 9 I think some local authority areas are continuing to
 10 develop their approach to allowing greater autonomy for
 11 front-line workers, and there are some really positive
 12 examples of it elsewhere in the UK as well.
 13 One of the concerns and the frustrations that people
 14 often share with us when accessing social care is that
 15 the decision-making process, despite really bold and
 16 robust legislation which talks about choice control, you
 17 know, and the participation of people accessing social
 18 care in decisions about their social care provision,
 19 after an assessment is carried out, the decision is
 20 taken away and it's made in a closed room by others. So
 21 I definitely think, by and large, that was something
 22 which was welcome.
 23 Q. Okay, thank you.
 24 Can we go back to your recommendations at 78.
 25 I would like you just to read these through, if you

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1 would, Ms Redmond, and at the end of it, we'll perhaps
 2 discuss one or two of them.
 3 A. Certainly.
 4 So the Alliance also makes the following
 5 recommendations for future pandemic readiness:
 6 Adopt an inclusive and intersectional rights-based
 7 approach to policy and decision-making. It is
 8 imperative that people's rights are protected, respected
 9 and fulfilled as the Scottish Government continues to
 10 respond to the COVID-19 pandemic and future pandemics.
 11 Decision-making should be underpinned by an inclusive,
 12 intersectional, rights-based approach which prioritises
 13 the rights of those most at risk.
 14 We recommend to listen meaningfully to disabled
 15 people, people living with long-term conditions and
 16 unpaid carers to inform and co-produce policy decisions.
 17 The Scottish Government must listen meaningfully to
 18 people's experiences of COVID-19, including what they
 19 are continuing to experience. This should be
 20 accompanied by appropriate action, co-produced with
 21 people with lived experience.
 22 Also to ensure clear, consistent and compassionate
 23 communication, recognising that public health
 24 information is integral to a person's right to health.
 25 Communication must be clear, consistent and recognise

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1 the disproportionate impact of the COVID-19 pandemic and
 2 the impact that it has had and continues to have on
 3 different population groups, including people living
 4 with long-term conditions, disabled people and unpaid
 5 carers. It is important that the risks of COVID-19
 6 infection or future viral pandemics are made clear to
 7 the general public.
 8 We recommend to produce a ventilation strategy for
 9 public spaces to enable people at high risk and carers
 10 to access public spaces. A robust ventilation strategy
 11 is needed for public areas, and a clear and accessible
 12 ventilation strategy would support people to know that
 13 they are safe to access public spaces with reduced fear,
 14 and anxiety.
 15 We recommend to increase eligibility for and access
 16 to antiviral treatment. Investment, funding and
 17 research is needed to increase eligibility for antiviral
 18 treatment, particularly for those with low immunity.
 19 To adopt a trauma-informed approach to COVID-19 and
 20 future pandemic decision-making. Future decision-making
 21 must recognise the magnitude of loss, bereavement and
 22 trauma that people have experienced since the beginning
 23 of the pandemic. Decision-making needs to be
 24 considerate of the human rights standards, such as
 25 non-retrogression. This means that retrogressive

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1 measures should be prohibited, except if all of the
 2 strict rules governing these choices have been met.
 3 This would ensure that policies adopted that decrease
 4 anyone's enjoyment of their right must be temporary,
 5 necessary and proportionate, not discriminatory and
 6 mitigate inequalities, ensure the protection of minimum
 7 core content of rights and have considered all other
 8 options, including financial alternatives. This
 9 provides a robust framework for protecting rights within
 10 decision-making in any future pandemic.

11 We recommend systemic change for social care.
 12 Participants highlighted the need for longer-term
 13 solutions to respond to systemic issues in the social
 14 care sector, such as the removal of social care charges.
 15 It is important that such changes take place without
 16 delay, rather than waiting until the implementation of
 17 the National Care Service in Scotland.

18 Q. Having said that I would come back to one or two of
 19 those, I am not entirely sure that I need to — unless
 20 you particularly want to — because you have set them
 21 out very fully.

22 If there is — and I say this to all witnesses —
 23 something you would like to emphasise particularly,
 24 please do so. This is an opportunity for you to do
 25 that.

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1 I would also repeat what I have said to other
 2 witnesses: after you have left this room and there is
 3 something that occurs to you, please get in touch with
 4 the Inquiry, and that information will be added to the
 5 body of your evidence. So please don't think that this
 6 is necessarily the end of the process, so far as your
 7 input.

8 But if there is anything you would like to highlight
 9 or expand on, please do so.
 10 A. I think with regards to the first point about embedding
 11 human rights standards and principles into
 12 decision-making, I know that the World Health
 13 Organisation emphasised people's participation within
 14 a pandemic's preparedness and decision-making, and
 15 whilst I think we and our members can understand that
 16 decisions, particularly at the outset, had to be made at
 17 pace, there were too many occasions where blanket
 18 approaches were applied and there were not opportunities
 19 taken to involve people to understand the implications
 20 on their health and well-being, and human rights
 21 standards don't tell you what to do in a particular
 22 situation, but they can provide you with parameters and
 23 really welcome standards to allow the tensions between
 24 rights and risks to be surfaced and to be thought
 25 through.

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1 So we are not making that recommendation as if it
 2 would be — you know, it would provide all the answers,
 3 but it provides a really important framework, and
 4 people's rights, even — and perhaps especially — in
 5 pandemics, need to be protected and respected.

6 I think one of the other things when we are saying
 7 about people whose rights are most at risk, those people
 8 most disproportionately impacted, that was not unknown,
 9 it was not — not a surprise, but it wasn't to be
 10 unexpected. When we look at the evidence about those
 11 experiencing the greatest impact of health inequalities
 12 in Scotland, these are the same groups in society who
 13 were most disproportionately impacted by the pandemic
 14 and the response taken to it. If we are to be better
 15 prepared in the future, that means addressing some of
 16 the ongoing population health crises that face us around
 17 people's access to the building blocks of health, it's
 18 vital that we address some of those risks that people
 19 continue to face.

20 I would also add that — I have referred to it at
 21 previous times during this statement about the desire
 22 many people that we represent have for greater
 23 person-centred care and planning when they are
 24 navigating the health and social care system, and
 25 particularly around healthcare. There is not enough

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1 examples of person-centred planning, continuity of care,
 2 the importance of recording that and understanding —
 3 tracking the data around people who access our
 4 healthcare. It should not have taken the efforts it
 5 took to identify those people who needed additional
 6 support when restrictions were being imposed.

7 Lastly, I would just reiterate the points I was
 8 making before about — the third sector I strongly feel
 9 is really valued. From people that we spoke to, they
 10 often described the access they were still able to have
 11 to support through the third sector as some of the
 12 positive experiences that they described when they were
 13 talking about their health and well-being during the
 14 pandemic. It is a vital contributor to our health and
 15 social care system, and it's not treated as such in the
 16 funding decisions that are made and in the strategic
 17 decisions which are being made nationally and locally,
 18 and I feel that our response to public health
 19 emergencies is enhanced by a strong third sector, and
 20 I think that is something that we really need to be
 21 considerate of when we are thinking about the lessons we
 22 need to learn.

23 MR GALE: Ms Redmond, those are all the matters that I want
 24 to discuss with you. Thank you very much, from my
 25 perspective, for obviously the care that you put into

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1 your statement, and the care that you have given to your
 2 evidence today. We are very grateful to you.
 3 THE WITNESS: Thank you, Mr Gale.
 4 THE CHAIR: Yes, thank you, Ms Redmond.
 5 Very good. I think that is all we have for today.
 6 MR GALE: It is, my Lord, yes.
 7 THE CHAIR: Thank you very much. Tomorrow morning at
 8 10 o'clock.
 9 (12.31 pm)
 10 (The Inquiry adjourned until 10.00 am on Thursday,
 11 2 November 2023)
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