Written evidence to Scottish COVID-19 Inquiry from the Health and Social Care Alliance Scotland (the ALLIANCE)

1. As Chief Officer of Development for the Health and Social Care Alliance Scotland (the ALLIANCE) I, Sara Redmond, am responsible for leading and continuing to shape the vision of the organisation. I am responsible for developing the strategic direction of the organisation and overseeing the ALLIANCE's portfolio of programmes. Central to this is ensuring a strong voice for disabled people, people living with long term conditions and unpaid carers and opportunity to influence change based on their lived experiences.

2. My work involves working closely with ALLIANCE members, developing innovative partnerships that show how change can be achieved, and promoting the role of the third sector as a key innovator and partner in realising Scotland's national health and wellbeing outcomes. The lessons from COVID-19 have been hard-learned, and we cannot lose sight of them. We must work hard to continue to keep people's experiences at the centre.

3. The ALLIANCE are the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

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

5. Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice, and service delivery. Together our voice is stronger, and we use it to make meaningful change at the local and national level.

6. The ALLIANCE has a strong and diverse membership of over 3,400 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation, and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national

policy and campaigns and putting people at the centre of designing support and services.

7. We aim to:
   - Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
   - Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production, and independent living.
   - Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.

8. ALLIANCE members have consistently called for an Inquiry to take place without delay to cover issues which have impacted the health and social care sectors in Scotland and for the individuals which our members represent. Since the beginning of the pandemic, the ALLIANCE has worked to ensure the rights and interests of our members are considered in COVID-19 law, policy and practice. As such, we have gathered valuable insight based on people's experiences of COVID-19 and responses taken to control the virus. Our evidence includes examples of innovation and good practice that emerged during the pandemic as well as areas where the system was not equipped to deal with the crisis.

9. Throughout the COVID-19 pandemic the ALLIANCE has engaged closely with the Scottish Parliament's COVID-19 Committee and the COVID-19 Recovery Committee, providing evidence on a range of issues including: the Coronavirus (Recovery and Reform) (Scotland) Bill,[1] excess deaths since the start of the pandemic,[2] vaccination certification,[3] and communication of public health information. We have also submitted evidence to the Scottish Government to ensure that policy changes and considerations take into account the rights and interests of our members, including in relation to Scotland's Long Covid Service, COVID-19 Recovery, and the impact of COVID-19 on the third sector.

10. In 2020 the ALLIANCE undertook the 'People at the Centre Engagement Programme'[4] short and longer term reform of the health and care support system, following the COVID-19 pandemic outbreak in Scotland. The programme captured the lived health and wellbeing experience of the COVID-19 pandemic. Over 1,000 people across each of

Scotland's 32 local authority areas engaged and the experiences captured were collated, analysed, and had prominent themes drawn out to inform a final report. [5]

11. We continue to hear and gather evidence on the lasting impact of COVID-19 from our members, including for those living with Long Covid. In 2022 we published commissioned research on accessing social support for Long Covid. [6] The research aimed to build understanding of the life circumstances of people with Long Covid in Scotland, as well as their experiences of accessing social support. We also commissioned research into the lived experience of COVID-19 of marginalised communities, as both a member of the Inclusion Health Partnership and the CLEAR (Community Lived Experience Action Research) partnership. [7] We have published research exploring disabled children's, young people's, and carers' experiences of accessing healthcare services and support during the pandemic.[8]

12. The ALLIANCE in partnership with Engender recently undertook and published research in September 2023 which looks at experiences of pregnancy and maternity services across Scotland during COVID-19.[9] The research captures over 200 responses covering the period March 2020 to November 2022.The research aimed to get a better understanding of access related to pregnancy, fertility, maternity, abortion, miscarriage and post-partum care during COVID-19. The report highlights key findings and makes a series of recommendations for Scottish Government and relevant health bodies. For instance one of the participants in the research commented:

    > "It is essential that Scotland learns from people's experiences during the pandemic to improve maternity services and public health messaging. To do otherwise would be to fail, and further compound the trauma, of thousands of parents over the last few years."

13. We have also reflected the interests of our members in discussions with the Scottish Government on shielding, vaccination, and Long Covid care and support, and have been involved in a range of stakeholder groups, including the Scottish Government's Long Covid Task and Finish Group and Public Health Scotland's Shielding Evaluation Advisory Group.

14. The ALLIANCE worked relatively closely with the Scottish Government, Public Health Scotland, and NHS National Services Scotland during this relevant period. This included sharing public health communications with ALLIANCE members, assistance with recruitment of participants for COVID research, providing comment and feedback on

draft public health information, and producing briefings and responses summarising issues and views raised by members. We shared people's direct experience of COVID-19 through our Humans of Scotland stories.[10] During this time, our Community in Action series [11] also demonstrated how third sector organisations responded to the pandemic.

15. The ALLIANCE also liaised with Scottish Ministers and Directorates, for example, our former Chief Executive was a member of the Mobilisation Recovery Group[12]. The Cabinet Secretary invited the ALLIANCE as a member of the Mobilisation Recovery Group to lead engagement work with people in Scotland. The aim of this was to ensure that there is a wide person centred focus from the outset of remobilisation efforts and, to ensure that the voice lived experience is heard.

16. To achieve this, the ALLIANCE designed the People at the Centre Engagement Programme to inform short and long term reform of the health and care support system, following the COVID-19 pandemic outbreak in Scotland. The Programme captured the lived health and wellbeing experience of the COVID-19 pandemic through a range of engagement activities between September and December 2020. More than 1,000 people were engaged with the programme, whose experiences were captured in the programme's final report 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'. [13]

17. The ALLIANCE was also represented in the cross-sectoral communications group set up by the Scottish Government. The group brought together communications personnel from different health boards, Health and Social Care Partnerships and the third sector. The focus of the group was to coordinate messaging at the height of the pandemic, sharing knowledge between group members which could then be used to inform messaging to our members and the public.

18. Additionally, we provided details of 110 relevant documents in response to the Rule 8 request made by the Scottish COVID-19 Inquiry in January 2023. This includes email correspondence, research reports, written and oral evidence to Scottish Parliamentary Committees, policy briefings, and statements.

19. These include:
    - Responding to the Scottish Government, Social Work Scotland, and the Scottish Commission for Learning Disability (SCLD)'s call for comment on the options for remobilising social care day services, including those for adults with learning disabilities and people with dementia.

- Responding to Scottish Government stakeholder questions on ‘Shielding – next steps.’
- A paper outlining the lived health and wellbeing experience of a broad range of people living in Scotland during the COVID-19 pandemic, as captured by the People at the Centre Engagement Programme (PATC) to inform the Scottish Government’s Mobilisation Recovery Group. It gives insights into how people viewed health and social care services when restrictions were still in place and shares their experiences and stories.
- A joint letter to the First Minister from the ALLIANCE and 32 other signatories calling on the Scottish Government to establish a Third Sector Recovery and Renewal Fund for national third sector health and social care organisations.
- Advice for health and social care staff in Scotland during the COVID-19 pandemic. Co-produced inclusive guidance on accessibility and inclusive communication for people living with sensory loss in relation to the COVID-19 outbreak.
- Cross-sectoral guidance on issues including face coverings, social distancing, and travel restrictions, co-produced in inclusive and accessible formats.
- Emails and papers relating to the ALLIANCE’s membership of the Scottish Government’s Long Covid Task and Finish Group which produced an Implementation Support Note on managing the long term effects of COVID-19.
- Requests from the Scottish Government to share information relating to COVID-19 on the ALLIANCE’s website and social media channels.
- Providing comments on a Scottish Government booklet with advice for people at highest risk.
- Communication with Public Health Scotland regarding the ALLIANCE's involvement in setting up a panel of lived experience of shielding or supporting a shielding individual to inform PHS' shielding evaluation report.
- Emails and papers relating to the ALLIANCE’s membership of Public Health Scotland’s Shielding Advisory Group.
- Emails and papers relating to the ALLIANCE’s membership of the Scottish Government’s Vaccine Inclusive Steering Group.
- Agenda for a roundtable discussion on Long Covid with the Cabinet Secretary for Health and Social Care.
- Providing comments on the Scottish Government’s Coronavirus (COVID-19): Scotland's Strategic Framework (Strategic Framework) and shielding.

- Providing comments on a letter from the Scottish Government to those on the shielding list outlining protection levels and advice on what measures people should take to stay safe.
- Emails relating to the ALLIANCE’s membership of Public Health Scotland’s Shielding Evaluation Advisory Group.
- Discussion with the Scottish Government regarding work on marketing materials to support public health against COVID-19 (and wider respiratory viruses) over the winter period.
- Email regarding the Scottish Government's campaign, 'Clear Your Head' and ALISS (A Local Information System for Scotland, which the ALLIANCE hosts) as a supporting partner.
- Email regarding the inclusion of ALISS on the Ready Scotland website.

20. The ALLIANCE published a report[14] following the ‘Living with COVID-19' Carers Parliament 2022 event, which took place in November 2022. The event aimed to explore the challenges that people, families and unpaid carers who are at higher risk of COVID-19 are continuing to experience. This event gave some important insight into the role of public health information and communication. Participants shared experiences of miscommunication, lack of clarity in information provision, and confusion about risks. Participants stated that information about who should be on the shielding list was contradictory or lacking. One person’s condition meant that while they were not formally on the shielding list, they were advised by specialist healthcare professionals to shield.

21. Those who attended this event also explained that a lack of clarity led to heightened feelings of anxiety. As summarised by one carer:

> “There was a lack of information about what I could and couldn’t do. Anxiety had a greater impact on me than COVID-19 did, on top of trying to look after myself and care for others at the same time.”

22. Additionally, it was highlighted that the way in which COVID-19 was reported in the media led to a public portrayal that it was ‘only the vulnerable’ who were impacted; a damaging perception which fundamentally overlooked the rights of individuals at risk, their families, and carers.

23. With measures taken to control the virus being reduced at this time (November 2022), participants in the Carer’s Parliament event shared that it felt at this time like public perception and public health messaging had shifted to the COVID-19 pandemic being

over. Fewer people were wearing masks, yet people were still at high risk of COVID-19 infection – and their carers – were continuing to shield. As a result, many carers and those they support were feeling left behind. The situation was summarised by one participant as follows:

> "We still have to be very cautious, for example by wiping down packaging and mail. We've been advised by the GP to keep doing so. We feel that the rest of the world has moved on and we haven't … If feels like people think COVID-19 never happened. You get your vaccinations and boosters but you're just left to get on with it."
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> "Information has been inconsistent. It feels like only safe place is a health setting because that's the only place where masks are still worn. The perception is that people are shielding are no longer at risk."

24. ALLIANCE members The Scottish Commission for People with Learning Disabilities (SCLD) conducted a survey and published a report[15] on its findings in June 2020, looking at the impact of Coronavirus on people with learning disabilities and their parents, carers, and supporters. When the parents, carers, and supporters of people with learning disabilities were asked if they thought they were receiving enough information about supporting a person with a learning disability while measures are in place to tackle COVID-19, 48% answered no. One in four respondents said that they had simply not received any information, and 22% felt concerned that they were receiving unclear guidance about the right procedures in terms of shielding, self-isolating and using PPE.

25. In the event of a future pandemic, the ALLIANCE recommends further listening and co-production to ensure that people's experiences are embedded in the decisions being made and the way in which messages are disseminated. The way in which messages are communicated must be clear, consistent, and compassionate, and recognise the disproportionate impact of the COVID-19 pandemic and the impact that it has had. Messaging must be informed by human rights standards and principles, including non-discrimination, and consider those who are likely to be more affected by any future public health crisis and the measures taken.

26. We also recommend, in agreement with the SCLD report, that for any future pandemic the Scottish Government must ensure that there is clear, accessible, and timely communication to everyone in Scotland, including people with sensory loss and people

with learning/intellectual disabilities and their families, carers, and supporters from the outset. This includes ensuring materials are consistently available in accessible formats.

27. The ALLIANCE's People at the Centre Programme captured the lived health and wellbeing experience of a broad range of people living in Scotland during the COVID-19 pandemic.[16] It found that confusing, limited, and interrupted communication was experienced at all levels: between services, for people who access services, and at the national public health messaging level.[17] This was echoed during the engagement undertaken for this programme and continues to be an issue experienced today for people to determine how to act in their local area.

28. The People at the Centre Programme learned that the change towards virtual consultations was well received by many for whom it has brought benefits and greater convenience. [18]However, for some the inability to have face to face appointments was detrimental. The ALLIANCE found that greater consideration needs to be made for people who are unable or prefer not to access digital technology, those who lack the necessary digital skills or those who may require support from paid/unpaid carers to take part in a virtual appointment.[19] Mechanisms need to be put in place to appropriately identify and support these individuals.

29. Additionally, findings from the joint research with Engender highlight that the shift from in person to telephone/video appointments impacted the standard of care. This lack of in person interaction led to anxiety and difficulties accessing support from healthcare workers. Remote appointments meant there were fewer physical checks or support for breastfeeding. Participants also spoke about lack of antenatal support, negative attitudes from staff and the impact of staff capacity on care and treatment.[20] The ALLIANCE also learned that there was a lack of confidence in digital services being able to provide the same level of care and support. It was strongly felt that whilst digital services may be appropriate and effective to use in a variety of circumstances, face to face contact is a basic right which should continue to be available. A significant proportion of people felt that in the context of their health and wellbeing experience, virtual and teleconsultations had been an inadequate replacement to face to face care. For some people, the loss of physical examinations resulted in increased anxiety as to whether they had received the correct diagnosis and treatment.

30. Additionally, we heard that information needs to be accessible. [21] A strong theme that emerged from our People at the Centre Programme was a feeling that the needs of

disabled people, people with sensory impairments, or those whose first language is not English have been long overlooked even pre-COVID-19.

31. Members raised specific issues with confusing, inaccessible, and contradictory communication for autistic adults. For example, a reliance on telephone communication in GP practices is often inaccessible for autistic people, and written communication was often too ambiguous, and lacked clarity on key information. A lack of tailored, person centred approaches throughout health and social care interactions meant that the processes were often overwhelming and stressful for individuals and their families.

32. There are also specific communication barriers for people with sensory loss. For example, D/deaf and deafblind individuals and community groups have shared frustration around telephone-based communication at their GP surgeries, and the use of Near Me video consulting. The ALLIANCE has also heard about difficulties for people who lip read due to face masks, booking appointments online or accessing face to face appointments without a support worker, navigating shops if visually impaired. However, there have been positive changes and examples of good practice for people with sensory loss. For example, British Sign Language (BSL) interpretation became readily available for the First Minister's COVID-19 briefings – a welcome change.

33. Research focused specifically on experiences of pregnancy and maternity services revealed that fast changing guidance led to confusion and inconsistent messaging. Respondents highlighted gaps between policy and practice, with delays in implementation on the ground.

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

34. Additionally, information surrounding vaccination was described as lacking, confusing and contradictory. Many women undertook their own research using personal and professional networks.

35. Approaches to information provision must be tailored and person centred. Our research recommends that tailored information and advice for pregnant women is clear, timely, inclusive and accessible.

36. Our People at the Centre Programme also heard from those who had experienced pregnancy and maternity services during COVID-19, who shared that the experience

was anxiety provoking and isolating due to the reduction in post-partum follow up services and visitation allowances.

> “Pregnant women were forgotten about and treated like 2nd class citizens with their rights taken away.” [22]

37. Isolation was a key theme which emerged from our research impacting all aspects of women’s pregnancy and maternity care. Participants described undergoing distressing and traumatic experiences alone including managed miscarriage, fertility procedures and abortion care. Additionally, lack of antenatal and postnatal support in the community contributed to poor mental health outcomes. The report calls for mitigations in a future public health crisis to prevent perinatal isolation and allow women to be accompanied when they are undergoing appointments, giving birth, experiencing miscarriage or baby loss. Learning from the experiences shared by members it is clear there should be a blended approach to delivering services, which is rooted in choice and flexibility, [23] as well as the human rights standards.

38. As previously mentioned, at the outset of the pandemic, there was a rapid migration to digital as services and activities moved online, and new tools and initiatives were quickly developed and delivered across all sectors to continue to provide essential services to people accessing social care.[24] In social care, this enabled staff to work flexibly in different locations (including from home) and for frontline delivery to continue to be delivered.

39. Local authorities and Health and Social Care Partnerships (HSCPs) referred to the use of Near Me,[25] which was used to undertake care reviews,[26] and which Mental Health Officers used to carry out assessments. Some triage processes were completed online, and support and advice were available digitally. In some areas, local authorities, HSCPs and partner organisations used social media platforms to disseminate health information, provide information on exercise, health and wellbeing, stress, and anxiety, as well as suicide prevention and awareness.

40. This has been a welcome development for those who can access internet services easily and confidently, however, we know that access and use of internet services remains uneven. [27] For example, only 43% of people aged over 75, and 71% of adults with some form of limiting long term condition, use the internet.[28] Research has shown that disabled people are less likely to use the internet or to have internet access at home than non-disabled people.[29]

41. Furthermore, not all online health and social care resources provide Easy Read versions, or are compatible with screen readers, causing further issues for people with learning difficulties, and for blind and partially sighted people. It is important that lessons are learned from the digital initiatives used in the sector and the digital inclusion practices which were accelerated during the pandemic, such as Connecting Scotland. The ALLIANCE, Scottish Care and VOX have been engaging with stakeholders and individuals across Scotland to develop a set of five Human Rights Principles for Digital Health and Social Care.[30]

42. These are:

    1. People at the centre
    2. Digital where it is best suited
    3. Digital as a choice
    4. Digital inclusion, not just widening access
    5. Access and control of digital data

43. We believe that these co-produced principles should be adopted to ensure that the provision of new service and digital initiatives do not impact negatively on the rights of people accessing digital health and social care.

44. The ALLIANCE recommends that the examples of good practice and digital initiatives during the pandemic should be developed to influence future delivery and reform of public services. This must involve addressing digital inequalities to reduce the risk of widening inequalities. By embedding choice and human rights approaches into digital health and care services – and focusing on outcomes, rather than delivery method – we can guarantee that people have equal access to digital and non-digital choices without compromising the quality of care they experience, even if faced with another pandemic.

45. The ALLIANCE recommends that to improve communication with patients in the event of a future pandemic, there must be investment in clear, accessible information about the support that is available and how people can access it. This is true not only of improving communication in the event of a future pandemic, but also in the remobilisation and dealing with the backlog of care during COVID-19 recovery.[31] This communication must also recognise the disproportionate impact of the COVID-19 pandemic and the impact that it has had - and continues to have – on different population groups. [32]

46. Overall, when thinking about digital services and information, the ALLIANCE support the use of digital, but not as default. It is important that digital services are offered as a supplementary channel to access services, and that other routes such as face to face remain available. It is clear that ‘one does not all fit all’ and services should offer a blended ‘Digital Choice’ approach; people want to feel empowered and have a choice in how they wish to access health. Additionally, codesigning digital services with users might be a route to ensure that online services are adapted to the target population. [33]

47. At the outset of the pandemic, the ALLIANCE received concerning reports from our members[34] highlighting that some population groups in Scotland were receiving unsolicited requests by some GP practices to sign Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms. Our members Age Scotland and National Autistic Society Scotland (NASS) are among those who have raised the issue.[35][36] While DNACPR forms have an important role in Anticipatory Care Planning, decision making should be based on an open discussion with individuals and their families and firmly cemented in human rights standards, and ‘blanket approaches’ should never be taken. The inappropriate use of DNACPR forms during the pandemic has caused distress for many people and their families. The longer-term impact of the increased number of DNACPR forms completed, their improper use, and the impact on individuals and families must be addressed by the inquiry, as well as recommendations on how to prevent a situation like this happening again in future.

48. Long Covid has had a significant impact on people across Scotland, with many people experiencing living with a long-term condition for the first time.[37] The latest data from the Office of National Statistics estimate 2.1 million people in the UK are living with the condition, which equates to over 187,000 people in Scotland.[38] However, members have raised concerns that the condition often goes uncounted and misdiagnosed and numbers may therefore be higher. It is important that an independent inquiry acknowledges the long-term physical, psychological and emotional impacts of the condition.

49. Research by the ALLIANCE has highlighted that many people experiencing Long Covid have described feelings of fear about their situation and future and felt as though they have been left to research the condition, possible treatment and support options by themselves. [39] We have heard consistently across our work on Long Covid that there is limited public awareness of the life circumstances of people living with Long Covid in Scotland. Long Covid is outwardly invisible and can therefore lead to problems with credibility for those who live with it. As a result, people have reported facing challenges with being listened to, being believed, and having their symptoms recognised. A

respondent to a Long Covid Lived Experience Survey summarised their experience as follows:

> “[Long Covid] is life changing. Sometimes it feels like we are invisible.”[40]

50. This was echoed in a research report published by the ALLIANCE and Chest Heart & Stroke Scotland, in which participants were keen to see the lack of public awareness of Long Covid remedied:

> “Along with the fatigue the other biggest thing is attitudes. The more education there is – education is so important – and with that maybe it would be a bit more recognised.” [41]

51. People living with Long Covid reported experiencing these challenges in a range of settings, including with healthcare professionals, in the workplace, with state entitlement agencies, and within wider society. The situation was summarised by one contributor to an anthology of opinions about people’s experiences of Long Covid:

> “It is disappointing […] that despite the information we now have on Long Covid people are still struggling to have their voices heard. I’ve lost count of the number of people who have told me they were dismissed by their GP and other healthcare professionals, being told that they were suffering from anxiety, and they should get out and exercise more. People in employment are also struggling with their employers, with many being forced to go back to work when they’re not ready or facing disciplinary action. Dealings with the Department for Work and Pensions have also added to the pressure people are already facing, particularly with PIP [Personal Independence Payment] applications, with people giving up on claiming benefits they are entitled to because the claims processes are far too exhausting for them.”[42]

52. Findings have also highlighted that a lack of recognition and awareness of the symptoms of Long Covid can have a significant impact on individual health and wellbeing with people reporting feelings of depression and isolation. [43]

53. More broadly, participants of the Long Covid Lived Experience Survey called for a greater awareness in the general public on the potential longer-term impacts of COVID-19 infection, and the importance of pacing recovery to prevent symptoms deteriorating:

> “[It is important to] make it clear to people in the early stages of COVID-19 infection that, if they are suffering fatigue, not to try and push through or go back to work too early. I'm almost certain this is what has set me back. This has to be an official

> position so that people don't feel pressured to return to work too soon and employers should be supported to allow this for their employees.” [44]

54. It should be noted that there are positive examples of progress being made to support those living with Long Covid, including some health boards in Scotland establishing their own care pathways for people living with Long Covid,[45] people being well supported from their employers,[46] and people having access to third sector organisations and peer support networks.[47] However, it is clear that these experiences are inconsistent and varied across Scotland, with participants acknowledging their own positive experiences as ‘unusual’.[48]

55. ALLIANCE members shared how shielding measures had a significant impact on certain population groups, who were often the most marginalised and excluded people in society. This included disabled people, people with long term conditions, unpaid carers, minority ethnic people, and older people. Various concerns were raised about the consequences of shielding, including social isolation, inadequate access to food, and health issues going unnoticed or undetected. The problems and concerns around shielding were also compounded by confusing and contradicting guidance, in part due to different restrictions in different areas of the UK, but also due to messaging that was inaccessible.

56. Additionally, information systems were inconsistent in terms of identifying who was required to shield and who was not. For example, in research carried out by the ALLIANCE, some people told us that they believed they should have received a shielding letter but did not, instead opting to choose self-imposed isolation to stay safe. However, this meant that they were unable to access any available shielding support.[49] Similarly, members reported that people who were advised to shield were not prioritised in the vaccination tiers.

57. It was also noted that this is an ongoing issue.[50] While government guidance has changed, many people are still shielding despite the removal of official advice to do so and are likely to continue to do so for some time. This includes people who have not yet been able to be vaccinated (for example, people who have had – or are undergoing – chemotherapy or who have had organ transplants), and as such are still at high risk of serious adverse health consequences if they contract COVID-19. Many people feel that they are “being left to fend for themselves”[51] as restrictions ease. The inquiry must consider what impact decisions around shielding have had on people, how they continue

to be impacted, and the long-term impacts on people. Participants also asked what support is available for those who are still shielding.

58. An online event hosted by the ALLIANCE as part of the Carers Parliament in November 2022 referred to earlier revealed the ongoing impact of COVID-19 for unpaid carers in Scotland, almost three years on from the start of the pandemic.[52]

59. Participants shared experiences of miscommunication, lack of clarity in information provision, and confusion about risks. For example, information about who should be on the shielding list was contradictory or lacking. One person's condition meant that while they were not formally on the shielding list, they were advised by specialist healthcare professionals to shield.

60. With measures taken to control the virus being reduced, participants shared that it now feels like public perception and public health messaging has shifted to the COVID-19 pandemic being over. Fewer people are wearing masks, yet people at high risk of COVID-19 infection – and their carers – are continuing to shield. As a result, many carers and those they support feel left behind. Carers also described anxiety around their own health conditions, maintaining their caring responsibilities, fear of contracting COVID-19, but also managing feelings of anxiety and isolation, as summarised by one participant:

> "It feels unsafe to leave the house because the risk of infection is still very real … Social work helped in the beginning of COVID-19 but we felt left in the unknown."[53]

61. We heard from our members that there was reduced and disrupted access to healthcare services across the board, where the prioritisation of COVID-19 has had an impact on people with non-COVID-19 needs.[54] Whilst people have shared their understanding about the unprecedented demand that COVID-19 placed on health services, the impact of the lack of access has been considerable and has led to a deterioration of people's physical and mental health.

62. Individuals told the ALLIANCE that they had experiences a number of disruptions when trying to access healthcare services.[55] For example, health clinics had been paused, outpatient appointments and elective surgeries cancelled, face to face appointments reduced or cancelled, and waiting times increased.

> “They felt like they are inaccessible unless you have COVID. I received messaged from GPs advising not to visit the surgery at all, but never received a message saying it was now safe to do so.”[56]

63. As part of engagement with people who had accessed audiology services, carried out by the ALLIANCE to inform the Scottish Government’s National Audiology Review, many people told us about their long wait before they received initial and subsequent appointments and the impact this had on their quality of life.

> "Had to wait 12 months with profound hearing loss and no hearing aids over COVID, meant I couldn't understand lectures or go to work."

64. Professionals also discussed the “backlog” of cases and the impact of other changes made during or after COVID pandemic restrictions.

> “During COVID they posted out spare parts and batteries to people but complained of the cost so no longer send out spares.”[57]

65. In our briefing ‘Learning from changes to social care during the COVID-19 pandemic’[58] we wrote to 32 local authorities, and received many responses, which aided in our learning around good practice and learning that emerged from the pandemic, as well as areas that could be revised. Local authorities and Health and Social Care Partnerships spoke about working collectively with external partners and social care providers at a local level to deliver services. One example of this was an online weekly provider forum to ensure efficacy of PPE supply and delivery to social care providers, deal with any queries, monitor any emerging areas of concern, and ensure continuity of support.

66. Local authorities and Health and Social Care Partnerships (HSCPs) also highlighted the importance of the third sector in supporting service delivery and responding to many of the immediate needs which arose due to the emergency measures imposed. Third sector organisations adapted and responded flexibly to the COVID-19 pandemic to ensure that people in their communities were supported and not left isolated. However, some local authorities and HSCPs also referred to the negative impact that COVID-19 has had on commissioning arrangements with third sector organisations. The impact of COVID-19 on the third sector has been stark: many third sector health and social care organisations closed at the outset of the pandemic, faced loss of fundraised income and volunteers, and employment cuts.[59] This meant that vital services were not being delivered in some areas, with an ensuing impact on social care packages and on people’s wellbeing.

67. The third sector continues to be undervalued and under resourced. The COVID-19 pandemic has shone light on the vital work of third sector health and social care organisations, and support for the sector should reflect that. Third sector funding should be protected and increased to ensure that no one is left struggling because vital support they relied on had to be reduced or withdrawn.

68. The ALLIANCE recommends that funding should be provided for longer time periods and funders and commissioners should support a flexible approach. This will allow the third sector to plan for the longer term, ensure that essential services continue to reach people and adapt to their requirements, keep staff in secure employment with good pay, terms, and conditions, and prevent the loss of valuable knowledge and expertise.[60]

69. The ALLIANCE agree with the fair funding principles set out by the Scottish Council for Voluntary Organisations (SCVO),[61] that funding should by multi-year, flexible, sustainable, and accessible. If the third sector is properly funded in a way that is set out under these principles, then it will be better prepared for a future pandemic.

70. The crisis management approach taken by the Scottish Government enabled more liberal trust in local authorities and Health and Social Care Partnerships (HSCPs) to deliver services and support. Previously ring-fenced money became available to use, and local authorities and HSCPs were enabled to work flexibly and collaboratively with local partners. As one response indicated, “people are coming to me, and it’s enabling us to do coordinated things with partners without the red tape. And we’re actually able to put money in people’s pockets for the first time.”[62]

71. Lower levels of bureaucracy around financial structures, and a more liberal, flexible approach has created greater empowerment, choice and control for individuals, families, and unpaid carers. It is important that lessons are learned from this approach to inform future service delivery.

72. However, some local authorities and HSCPs have explained that many of the positive changes experienced during COVID-19 are interim arrangements and are beginning to, or have, come to an end. There is concern that some of these positive changes are now being reversed without consultation. We believe it is important that positive changes to social care, and the third sector health and social care sector, and support are maintained to improve service delivery and practically support people moving forward.

73. The ALLIANCE recommends that a review of financial decision making should be undertaken, including how public finances were used, the decision-making processes for

resource allocation, and the impact that decisions have had on people accessing support. Given the ongoing staffing issues within social care, people should be able to employ family members as Personal Assistants more consistently and easily.

74. The pandemic led to significant changes in staff structures and the way in which services were delivered. [63]Our research found that local authorities and Health and Social Care Partnerships (HSCPs) adopted different ways of working: some areas were working exclusively from home during the height of the pandemic, while others were operating a hybrid approach with rotational staff "bubbles."

75. One local authority/Health and Social Care Partnership referred to the operation of Cluster Assessment and Care Management Teams who worked remotely from home and were provided with laptops, mobile phones, Personal Protective Equipment (PPE) and lateral flow device testing kits. Staff used remote video conferencing software to maintain regular contact with colleagues, meet people accessing support, their families, and unpaid carers, as well as other professionals. Similarly, some local authorities/HSCPs reconfigured locality offices, which were used as spaces for staff to work between visits and to take welfare breaks, and "Wellbeing Hubs" were established and promoted to ensure that staff had access to appropriate information and resources which offered support, information, and reassurance.

76. Successful examples of flexible working during the COVID-19 pandemic have contributed to creating positive outcomes for people accessing support. It is important that the examples of best practice continue and are improved upon in a way that works both for people accessing support, and for health and social care staff.

77. The ALLIANCE recommends that a review of COVID-19 working practices is undertaken to ensure the areas which worked well can continue to benefit people accessing support, and health and social care staff.

78. The ALLIANCE also makes the following recommendations for future pandemic readiness:

    - Adopt an inclusive, and intersectional, rights based approach to policy and decision making. It is imperative that people's rights are protected, respected, and fulfilled as the Scottish Government continues to respond to the COVID-19 pandemic, and future pandemics. Decision making should be underpinned by an inclusive, intersectional, rights based approach which prioritises the rights of those most at risk.

- Listen meaningfully to disabled people, people living with long term conditions and unpaid carers to inform and co-produce policy decisions. The Scottish Government must listen meaningfully to people's experiences of COVID-19, including what they are continuing to experience. This should be accompanied by appropriate action, co-produced with people with lived experience.
- Ensure clear, consistent, and compassionate communication, recognising that public health information is integral to a person's right to health. Communication must be clear, consistent, and recognise the disproportionate impact of the COVID-19 pandemic and the impact that it has had – and continues to have – on different population groups, including disabled people, people living with long term conditions and unpaid carers. It is important that the risks of COVID-19 infection, or future viral pandemic, are made clear to the general public.
- Produce a ventilation strategy for public spaces. To enable people at high risk and carers to access public spaces, a robust ventilation strategy is needed for public areas. A clear and accessible ventilation strategy would support people to know that they are safe to access public spaces with reduced fear and anxiety.
- Increase eligibility for and access to antiviral treatment. Investment, funding, and research is needed to increase eligibility for antiviral treatment, particularly for those with low immunity.
- Adopt a trauma informed approach to COVID-19 and future pandemic decision making. Future decision making must recognise the magnitude of loss, bereavement, and trauma that people have experienced since the beginning of the pandemic. Decision making needs to be considerate of the human rights standards, such as non-retrogression. This means that retrogressive measures should be prohibited, except if all of the struct rules governing these choices have been met. This would ensure that policies adopted that decrease anyone's enjoyment of their right must be: temporary, necessary and proportionate, not discriminatory and mitigate inequalities, ensure the protection of minimum core content of rights and have considered all other options, including financial alternatives. This provides a robust framework for protecting rights within decision making in any future pandemic.
- Systemic change for social care. Participants highlighted the need for longer term solutions to respond to systemic issues in the social care sector, such as the removal of social care charges. It is important that such changes take place without delay, rather than waiting until the implementation of the National Care Service in Scotland.

Statement of truth

79. The contents of this statement are true and accurate to the knowledge and belief of the ALLIANCE.

Signed …

Date ……13 October 2023

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