

Witness Name:

Statement No.:

Exhibits:

Dated:

## **UK COVID-19 INQUIRY**

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### **WITNESS STATEMENT OF HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND (THE ALLIANCE)**

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We, Health and Social Care Alliance Scotland (the ALLIANCE), will say as follows: -

1. The information below is the Health and Social Care Alliance Scotland (the ALLIANCE) response to questions set out in the Module 3 Request for Evidence under rule 9 of the UK COVID-19 Inquiry Rules 2006 dated 2<sup>nd</sup> June 2023, reference M3/HSCAS/01.
2. 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.
3. 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.

## Health and Social Care Alliance Scotland Overview

4. The Health and Social Care Alliance Scotland (the ALLIANCE) is 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.
5. 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.
6. 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.
7. 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 work to ensure people are at the centre of designing support and services.
8. 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.

### **How the ALLIANCE gathers information**

9. 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.
10. 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: our consultation response to the Coronavirus (Recovery and Reform) (Scotland) Bill [HSCAS/1-INQ000224574] (February 2022) in which we broadly agreed with the proposals but also recommended that changes should be underpinned by equalities and human rights. We also provided a response to the COVID-19 inquiry on excess deaths since the start of the pandemic in our report 'COVID-19 Recovery Committee Inquiry: Excess deaths in Scotland since the start of the pandemic' (January 2022) [HSCAS/2-INQ000224575] where we emphasised that the COVID-19 pandemic is not over and outlined the continued impact of COVID-19 on disabled people, people living with long term conditions and unpaid carers. The ALLIANCE also provided a briefing 'COVID-19 Status Certificates ('Vaccine

Passports’ (September 2021) [HSCAS/3- INQ000224576] where we made some key recommendations, for example, the need for greater clarity around the scope, purposes, and length of vaccine passports, and for communication around the scheme to be inclusive and accessible. 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.

11. In 2020 the ALLIANCE undertook the ‘People at the Centre Engagement Programme’ which is outlined in the paper ‘Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the future.’ [HSCAS/4- INQ000224577] This paper (February 2021) sets out the health and wellbeing experiences of a broad range of people living in Scotland during the COVID-19 pandemic, as captured by the People at the Centre Engagement programme. This programme was designed to inform short and longer term reform of the health and care support system, following the COVID-19 pandemic outbreak in Scotland. Over 1,000 people across each of Scotland’s 32 local authority areas engaged and the experiences captured were collated, analysed, and the prominent themes were drawn out to inform a final report. [HSCAS/4- INQ000224577]
12. We continue to hear and gather evidence on the continuing impact of COVID-19 for our members, including for those living with Long Covid. In 2022 we published commissioned research on accessing social support for Long Covid. [HSCAS/5 - INQ000224578] The research ‘Accessing social support for Long Covid’ (May 2022) aimed to build understanding of the life circumstances of people with Long Covid in Scotland, as well as their experiences of accessing a range of social support including state entitlements. 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 partnership. [HSCAS/6 - INQ000224579] The report ‘Understanding the lived experience of COVID-19 for marginalised communities’ (March 2022) that emerged from this research was

based on in-depth interviews with those who are often marginalised and experience exclusion from society and systems of support.

13. Additionally, we have published research exploring disabled children's, young people's, and carers' experiences of accessing healthcare services and support during the pandemic. [HSCAS/7- INQ000224580] This research 'Disabled children's, young people's and carer's experiences of accessing healthcare services and support during the pandemic: a qualitative research report' (March to June 2022) was undertaken by Dr Liliana Arias-Urena, and drew on children's, young people's and parents' own accounts, exploring the impacts of the pandemic on access to health care, social care services, state entitlements and supports in Scotland.
14. 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.

### **Liaison and communication with stakeholders**

15. 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 [HSCAS/8 - INQ000224581]. This page 'ALLIANCE launch 'Humans of Scotland'' (November 2018) sets out that the project aimed to give the people we work with and who access support and services a visual platform to express their opinions on issues that they are passionate about. Many of the stories published as part of the Humans of Scotland project are relevant to this statement, including Amanda's story of Long Covid. Amanda shared her experience of living

with Long Covid, and the way in which it impacted her own mental health and resulted in her feeling broken both mentally and physically. Another example is Kirsty's story of supporting people as an Occupational Therapist during COVID-19. Kirsty describes the change needed both professionally and personally to adapt during the pandemic restrictions.

16. During this time, our Community in Action series [HSCAS/9 - INQ000224582] also demonstrated how third sector organisations responded to the pandemic. This report 'Community in Action: Learning from the third sector's early response to the COVID-19 pandemic in Scotland' (April 2021) covers activity from March to September 2020, and analyses the 51 Community in Action articles published during this time. It sets out that there have been a number of conflicting knock-on effects which have emerged as a result of the pandemic, some positive and some negative. For example, the shift towards remote services have made support for some more inclusive and accessible, however face to face services are also necessary to ensure availability of services to all.
17. The ALLIANCE also liaised with Scottish Ministers and Directorates for projects, for example, through membership of the Mobilisation Recovery Group [HSCAS/10 - INQ000224583] – people at the Centre. This page 'Mobilisation Recovery Group' sets out that the Mobilisation Recovery Group is an advisory group established under Re-mobilise, Recover, Re-design, The Framework for NHS Scotland, and sets out the role of the group. 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. This engagement work was the 'People at the Centre Engagement Programme' referred to in paragraphs 11 and 18.
18. To achieve the engagement to inform the Mobilisation Recovery Group, 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'. [HSCAS/4 - INQ000224577]

19. The ALLIANCE was also represented in the cross-sectoral communications group set up by the Scottish Government. The group brought together communications individuals 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.

#### **Rule 8 notice**

20. The ALLIANCE 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.

21. These include:

- Responding to the Scottish Government, Social Work Scotland, and the Scottish Commission for Learning Disability (SCLD)'s calling for comment on the options for remobilising social care day services, including those for adults with learning disabilities and people with dementia. [HSCAS/11 - INQ000327737]
- Responding to Scottish Government stakeholder questions on 'Shielding – next steps'. [HSCAS/12 - INQ000327738]

- 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. [HSCAS/4 - INQ000224577]
- 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. [HSCAS/13 - INQ000327739]
- 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. [HSCAS/14 - INQ000327740]
- Cross-sectoral guidance on issues including face coverings, social distancing, and travel restrictions, co-produced in inclusive and accessible formats. [HSCAS/15 - INQ000327741]
- 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. [HSCAS/16 - INQ000327742; HSCAS/17 INQ000327743]
- Requests from the Scottish Government to share information relating to COVID-19 on the ALLIANCE's website and social media channels. [HSCAS/18 - INQ000327744; HSCAS/19 INQ000327745]
- Providing comments on a Scottish Government booklet with advice for people at highest risk. [HSCAS/20 - INQ000327746; HSCAS/21 INQ000327747]

- 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. [HSCAS/22- INQ000327748]
- Emails and papers relating to the ALLIANCE's membership of Public Health Scotland's Shielding Advisory Group. [HSCAS/23- INQ000327749]
- Emails and papers relating to the ALLIANCE's membership of the Scottish Government's Vaccine Inclusive Steering Group. [HSCAS/24- INQ000327750; HSCAS/25 - INQ000327751; HSCAS/26 - INQ000327752; HSCAS/27 - INQ000327753]
- Agenda for a roundtable discussion on Long Covid with the Cabinet Secretary for Health and Social Care. [HSCAS/28 - INQ000327754]
- Providing comments on the Scottish Government's Coronavirus (COVID-19): Scotland's Strategic Framework (Strategic Framework) and shielding. [HSCAS/29 - INQ000327755; HSCAS/30 - INQ000327756]
- 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. [HSCAS/31 - INQ000327757]
- Emails relating to the ALLIANCE's membership of Public Health Scotland's Shielding Evaluation Advisory Group. [HSCAS/32 - INQ000327758; HSCAS/33 - INQ000327759]

- 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. [HSCAS/34 - INQ000327760]
- 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. [HSCAS/35 - INQ000327761]
- Email regarding the inclusion of ALISS on the Ready Scotland website. [HSCAS/36 - INQ000327762]

## Public health information and communication

22. The ALLIANCE published a report [HSCAS/37 - INQ000224584] following the 'Living with COVID-19' Carers Parliament 2022 event, which took place in November 2022. This event report was put together by the ALLIANCE to summarise the following findings. 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.
23. Those who attended this event also explained that a lack of clarity led to heightened feelings of anxiety. As summarised by one carer:
24. "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."
25. 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.
26. 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:

27. “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 ... It feels like people think COVID-19 never happened. You get your vaccinations and boosters but you’re just left to get on with it.”
28. Another participant shared that: “information has been inconsistent. It feels like the 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.”
29. ALLIANCE members The Scottish Commission for People with Learning Disabilities (SCLD) conducted a survey and published a report [HSCAS/38 - INQ000224585] on its findings in June 2020, looking at ‘The Impact Of Coronavirus On People With Learning Disabilities And Their Parents, Carers, And Supporters.’ (June 2020) This research undertaken by the SCLD involved two surveys, one for people with learning disabilities and one for 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.

**How the content and dissemination of public health messaging could be improved in the event of a future pandemic.**

30. 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.

31. We also recommend, in agreement with the SCLD report, that for any future pandemic the Scottish and UK Governments 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.

### **Communication with patients**

32. 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. [HSCAS/ 4- INQ000224577] 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.[HSCAS/4 - INQ000224577] 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.
33. 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. [HSCAS/4 - INQ000224577] 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. [HSCAS/4 - INQ000224577] Mechanisms need to be put in place to appropriately identify and support these individuals.
34. 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.

35. Additionally, we heard that information needs to be accessible. [HSCAS/4 - INQ000224577] 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.
36. 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.
37. 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 lip reading 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.
38. 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 isolation due to the reduction in post-partum follow up services and visitation allowances.

39. “Pregnant women were forgotten about and treated like 2<sup>nd</sup> class citizens with their rights taken away.” [HSCAS/4 - INQ000224577]
40. 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. [HSCAS/4 - INQ000224577]

### **Digital delivery of social care**

41. 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. In social care, this enabled staff to work flexibly in different locations (including from home) and for frontline delivery to continue to be delivered. [HSCAS/39 - INQ000224586] The briefing ‘Learning from changes to social care during the COVID-19 pandemic’ (November 2021) sets out that as Scotland recovers from the impact of the COVID-19 pandemic, we must learn from the serious issues and challenges that the social care sector faced. The briefing makes several recommendations for example, a review of COVID-19 working practices in social care setting should be undertaken to ensure the areas which worked well continue to benefit people accessing support, and health and social care staff.
42. Local authorities and Health and Social Care Partnerships (HSCPs) referred to the use of Near Me, [HSCAS/40 - INQ000224587], this page ‘What is Near Me?’ explains what Near Me is and what the benefits may be for users, which was used to undertake care reviews, [HSCAS/41 - INQ000224588], and which Mental Health Officers used to carry out assessments. This report ‘Scotland’s Digital Health and Care Response to COVID-19’ (October 2021) was prepared by the Digital Health and Care Directorate of the Scottish Government in July 2023, and it provides an update on the scale-up and adoption of digital health and care solutions in Scotland in response to the COVID-19 pandemic. 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.

43. 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. [HSCAS/42 - INQ000224589] This page 'Digital inclusion, exclusion and participation' (April 2020) sets out an evidence summary relating to academic literature and research relating to digital inclusion, exclusion, and participation. For example, only 43% of people aged over 75, and 71% of adults with some form of limiting long term condition, use the internet. [HSCAS/43 - INQ000224590] This report 'Scotland's People Annual Report 2019' (September 2020) sets out results from the Scottish Household Survey, which is a Scotland-wide face-to-face survey of a random sample of people in private residences. Research has shown that disabled people are less likely to use the internet or to have internet access at home than non-disabled people.[HSCAS/42 - INQ000224589] 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.
44. 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. [HSCAS/44 - INQ000224591] This paper 'Human Rights Principles for Digital Health and Social Care' (April 2021) put together by the ALLIANCE, Scottish Care and VOX (Voices of eXperience) worked together to explore a set of five principles for a human rights-based approach to health and social care. These Human Rights Principles are:

- People at the centre

- Digital where it is best suited
- Digital as a choice
- Digital inclusion, not just widening access
- Access and control of digital data

45. 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.

46. 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 social care services – and focusing on outcomes, rather than delivery method – we can guarantee that people have equitable access to digital and non-digital choices without compromising the quality of care they experience.

### **Improving communication for patients in the event of a future pandemic**

47. 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. [HSCAS/4 - INQ000224577] 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. [HSCAS/37 - INQ000224584]

48. 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. [HSCAS/4 - INQ000224577]

### **Do not attempt cardiopulmonary resuscitation (“DNACPR”) instructions**

49. At the outset of the pandemic, the ALLIANCE received concerning reports from our members [HSCAS/45 - INQ000224592] 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 briefing 'Putting people at the centre of an independent inquiry into COVID-19' (October 2021) was informed by consultation with our members during an ALLIANCE engagement session and set out a number of issues that should be included within the aims of an independent inquiry into COVID-19, including Communication, Digital exclusion and Long Covid. Our members Age Scotland and National Autistic Society Scotland (NASS) are among those who have raised the issue. [HSCAS/46 - INQ000224593, HSCAS/47 INQ000224594] Age Scotland set out on their website 'Older People need answers on inappropriate use of DNACPR' that members came to them during the pandemic angry and worried after being called by their GP and asked to consent to a DNACPR form. One participant in our 'Disabled children's, young people's and carer's experiences of accessing healthcare services and support during the pandemic: a qualitative research report' research described this experience: [HSCAS/7 - INQ000224580]

50. “[...] I remember getting the phone call from the... from the GP about making **I&S** not eligible for resuscitation [...] I was very distressed by that, I was really distressed by that phone call, because it was just like a cold call by a doctor [...] I never met this doctor... I was really concerned about that because it seemed to be quite blanket... not for... not for transport to hospital and not for resuscitation[...]

51. "I said, well, you know, I said: that protocol has to depend on many nuances and I'm not into heroics and ridiculousness... Keeping someone alive, just for the sake of it, but there are many reasons why he might end up in ICU compared to somebody else [...]"
52. "I was clear to him ... any decision had to be contextual and I was very strict with that[...]"
53. "[...]that call was probably, I mean that was the only point of contact we had with people [from the healthcare system during the pandemic], and it was incredibly traumatic and really poorly thought out"
54. 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.

## Long Covid

55. 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. [HSCAS/45 - INQ000224592] 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. [HSCAS/48 - INQ000224595] This page 'Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK' sets out the estimates of ongoing symptoms following coronavirus (COVID-19) infection in the UK as of the 5<sup>th</sup> January 2023. 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.

56. 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. [HSCAS/ 4- INQ000224577] 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:

57. “[Long Covid] is life changing. Sometimes it feels like we are invisible.” [HSCAS/49 - INQ000224596] This quote is found from the Long Covid Lived Experience Network survey - insights report (January 2023). The report was published in partnership with Asthma + Lung UK and Chest, Heart & Stroke Scotland who, with the ALLIANCE, established a network for people affected by Long Covid to gain views from a wide range of people to inform service delivery.

58. 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:

59. “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.” [HSCAS/5 - INQ000224578]

60. 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:

61. "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." [HSCAS/50 INQ000224597] This quote can be found in our publication, 'Living with Long Covid: an anthology' (September 2022) which includes Opinion pieces from those with lived experience of Long Covid, those researching supports and treatment options, and people working within the third sector to support people with Long Covid.
62. 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. [HSCAS/5 - INQ000224578]
63. 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:
64. "[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.” [HSCAS/4 9- INQ000224596]

65. 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, [HSCAS/50 - INQ000224597] people being well supported from their employers, [HSCAS/5 - INQ000224578] and people having access to third sector organisations and peer support networks. [HSCAS/5 - INQ000224578] However, it is clear that these experiences are inconsistent and varied across Scotland, with participants acknowledging their own positive experiences as ‘unusual’. [HSCAS/5 - INQ000224578]

### **Shielding and the impact on those placed on the Shielding List/Highest Risk List**

66. ALLIANCE members shared [HSCAS/ 4- INQ000224577] 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.
67. Examples of this confusing and contradicting messaging provided in the report ‘Health, Wellbeing and the COVID-19 Pandemic’ [HSCAS/4 - INQ000224577] include a lack of communication to explain changes to care more widely, leaving many feeling unsure and confused about what happens next and when they may resume treatment and regain access to necessary services. Additionally, poor information sharing between redesigned services resulted in further barriers to people accessing appropriate referrals. One respondent reported being repeatedly referred to a physiotherapist whom they had already received

treatment from for long COVID rehabilitation, and who could not provide support for this other aspect of their condition.

68. 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. [HSCAS/4 - INQ000224577] Similarly, members reported that people who were advised to shield were not prioritised in the vaccination tiers.

69. It was also noted that this is an ongoing issue. [HSCAS/37 - INQ000224584] 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” [HSCAS/45 - INQ000224592] 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.

70. An online event hosted by the ALLIANCE as part of the Carers Parliament in November 2022 revealed the ongoing impact of COVID-19 for unpaid carers in Scotland, almost three years on from the start of the pandemic. [HSCAS/37 - INQ000224584]

71. 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.

72. 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:

73. “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.”  
[HSCAS/37 - INQ000224584]

#### **Other concerns or issues:**

##### **Non-COVID-19 Patients**

74. 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. [HSCAS/4 - INQ000224577] This paper set out that reduced and disrupted access included health clinics being paused, outpatient appointments and elective surgeries were cancelled, face to face appointments were reduced or cancelled and waiting times increased. We also heard that individuals faced difficulties when trying to make appointments or access healthcare services directly, experienced long waiting times on the telephone, were triaged away from healthcare services and told to ‘wait and see what happens’. 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.

75. “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.” [HSCAS/4 - INQ000224577]

### Valuing the third sector

76. In our briefing ‘Learning from changes to social care during the COVID-19 pandemic’ [HSCAS/39 - INQ000224586] 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.

77. 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. [HSCAS/51 - INQ000224598] This briefing paper for the Scottish Parliament debate ‘Valuing the Third Sector’ on the 27th November 2020 sets out that the impact of COVID-19 on the third sector health and social care organisations in Scotland which is stark, far-reaching and in some cases poses a threat to survival. 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.

78. 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.
79. 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. [HSCAS/51 - INQ000224598]
80. The ALLIANCE agree with the fair funding principles set out by the Scottish Council for Voluntary Organisations (SCVO) [HSCAS/52 - INQ000224599], that funding should be multi-year, flexible, sustainable, and accessible. This webpage 'Fair funding: it's time to abandon the spin' (2 November 2022) repeats this call for fair funding for the third sector that is 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.

### Financial Flexibility

81. 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. For example, 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." [HSCAS/39 - INQ000224586]

82. 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.
83. 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 come to an end, such as greater financial flexibility and worker autonomy. 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.
84. 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.

### **Flexible Working**

85. The pandemic led to significant changes in staff structures and the way in which services were delivered. [HSCAS/39 - INQ000224586] 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.”
86. 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.

87. 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.

88. 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.

### **Recommendations for future pandemic readiness:**

- Adopt an inclusive, 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, 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. 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.
- 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**

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false

statement in a document verified by a statement of truth without an honest belief of its truth.

**Signed:**

**Personal Data**

**Dated:** 3 November 2023