

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

1. The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary organisation for health and social care. We are a registered charity and membership organisation for individuals and organisations working or interested in the health and social care sector in Scotland. Members share our vision of a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect. 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. A full list of our members can be found on our website¹.

2. 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.

3. All of our work is action-oriented and outcome focused. Staff work on multiple and varied areas which include:
 - ALLIANCE Live



Connecting audiences to experts from across health and social care via a range of digital formats including in-depth podcasts providing a platform to the voice of lived experience, and video interviews and case studies that aim to enlighten and inform.

- Communications

Communications is at the heart of our work at the ALLIANCE. It allows us to connect with our members, stakeholders, and a wider audience, and is central to strengthening our collective voice. Our communications team work to create impactful, cohesive content, ensuring our messaging, media and digital outputs align with our values and strategic aims.

- Digital

We are exploring innovative technologies and ways of working to support people's wellbeing. A main focus of this work piece is A Local Information System for Scotland (ALISS) which is a coproduced, web-based systems for finding and sharing information about community assets. These assets include local and national services, groups and activities for health and wellbeing across Scotland.

- Health and Social Care Integration

Spanning across several our programmes including the Health and Social Care Academy, our Integration work encourages and supports Scotland's health and social care services to put people at the centre of policy and practice. Connected to this is the Community Links Worker initiative which enables people - including those attending 'Deep End' GPs (those who work in general practices serving the 100 most deprived populations in Scotland, based on the proportion of patients on the practice list with postcodes in the most deprived 15% of Scottish data zones) - to access tailored advice and support.

- Humans of Scotland



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A campaign which aims to raise awareness, challenge misconceptions and spark ideas and conversation by sharing and highlighting stories from disabled people, people living with long term conditions and unpaid carers on subjects like hidden disabilities, mental health, addiction recovery and Adverse Childhood Experiences (ACEs). We also hear from those who provide support and services, with a behind-the-scenes look at the world of health and social care.

- **Lived Experience**

We champion lived experience to ensure people inform national policies, campaigns, and service design. We do this through engagement via our programmes and our lived experience networks of which we go into further detail below.

- **Membership**

The ALLIANCE membership network brings together over 3,500 organisations and individuals working to improve the lives of people who use health and social care services in Scotland.

Beyond connecting within this dynamic network members are able to attend range of members networking events, training and development sessions; opportunities to platform their work to other members and work collaboratively with the ALLIANCE; receive regular bulletins; and the chance to input on policy and research findings. Members work collaboratively and with a shared vision, representing a diverse community that are committed to working together. We welcome membership from:

- Disabled people, people living with long term conditions and unpaid carers
- Health and social care providers
- Health and social care professionals
- Third sector organisations of all sizes
- Grassroots and user led organisations

- Corporate organisations who wish to show support to the ALLIANCE
- Partnership

To achieve our aims, we work in partnership and collaborate with organisations. This allows us to reach seldom heard groups and provide a platform to connect networks. Through a range of our programmes, we share learning and influence policy and practice at the national and European level. Current partnerships are with Scottish Ballet Health and Macmillan Cancer Support.
- Self Management

The ALLIANCE works to embed the self-management approach across Scotland delivering events to explore the topic, funding related projects and bringing together over 800 third sector staff, healthcare professionals and individuals through the Self Management Network Scotland to share self management learning and connect efforts to improve self management support.
- Scottish Sensory Hub

The Scottish Sensory Hub provides a platform for the voice of lived experience for anyone in Scotland with lived experience of Deafness, Deafblindness or Visual Impairment. The Sensory Hub acts as a bridge between the Scottish Government, public bodies, the third sector, and individuals, and enshrines a human rights-based approach for all. It focuses on three key areas to promote living a good life – communication, information, and mobility. The Scottish Sensory Hub looks to support partnerships which uphold the strategic aims of the Scottish Government’s See Hear strategy and engage with organisations and individuals across the sensory landscape.



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4. Cutting across these areas is our policy and research work. Our team engages with national policies to improve health and social care in Scotland and population health. To achieve this, we bring together the expertise of people with lived experiences, communities, third sector and professionals to inform our policy work. Our work covers a wide range of policy areas including primary care, Self-directed Support, human rights, the proposed National Care Service, mental health, social security, and the cost of living crisis. With every piece of work we do, we incorporate the voices of our members and people with lived experience through designed engagement processes, including through surveys and events, feeding into public consultations from the Scottish Government and other relevant bodies, responding to short-notice stakeholder engagement queries or consultations, and produce reports on topical issues relating to health and social care.

5. At the ALLIANCE, our definition of ‘social care services’ recognises that health and social care is not only about formal or statutory services delivered by public sector bodies, but also encompasses a wealth of third sector, community, informal and peer support.

6. According to the Scottish Government’s definition, adult social care comprises all forms of personal and practical support for adults who need extra support (which also applies to children and young people)².

7. It describes services and other types of help, including care homes and supporting unpaid carers to help them continue in their caring role. It is a vital public service infrastructure which helps to protect, respect and fulfil people’s human rights and means supporting people to:
 - live independently
 - be active citizens

- participate and contribute to our society
 - maintain their dignity and their human rights
 - supporting people to stay at home or in a homely setting, with maximum independence, for as long as possible.
8. The ALLIANCE, as a membership organisation, works with and supports both unpaid carer organisations and community-based organisations as well as other organisations and groups which would come under the umbrella of ‘third sector’. A non-exhaustive list can be found in this endnote reference³. A full list of the ALLIANCE’s organisational members can be found can on our website.⁴ The term “community care organisation” is not one that we are familiar with or use in our work.
9. Our unpaid carer member organisations support people by providing information, advice and support to unpaid carers in their local areas and at a national level, whilst working in partnership with other voluntary and statutory sector organisations. Examples of our members who do this vital work are Local Carers Centres, PAMIS and Contact Scotland⁵. In terms of policy related issues, we work closely with the National Carer Organisations Coalition which is comprised of ALLIANCE members such as Carers Trust Scotland, Minority Ethnic Carers of Older People Project (MECOPP) and Shared Care Scotland⁶.
10. We also have member organisations which are carer-led, providing help and advice, spaces to connect and learn from each other’s experiences and campaigning for change. For instance, Carers Scotland is a carer-led organisation to ensure that carers are at the heart of everything they do as a charity⁷.



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11. In Scotland there are an estimated 30,000 young carers⁸. According to the Scottish Government, young carers are those who provide help or support to family members, friends, neighbours, or others because of either long term physical or mental ill health, disability or problems related to old age⁹. Due to their age and stage in life, young carers need tailored services which offer support, information provision, respite and personal development, training and self-management activities. Our members who are involved in this work include Edinburgh Young Carers Project and Realize Your Potential¹⁰.

12. Community-based, member-led and social care organisations provide social opportunities and support so that unpaid carers and the people they care for live the best lives possible and the lives they want in their homes and communities.

13. According to the SCVO State of the Sector Statistics, out of 11,758 Social Care organisations in Scotland, these include 228 dedicated Carers Organisations in Scotland and 1094 services for disabled people¹¹. In relation to health, 1988 services provide varying support for carers across mental health, care homes and other health services including local support groups. Social care and health organisations employ half of all paid staff in the third sector across care and support work, social work, childcare, nursing and mental health support. However, in both health and social care organisations there has been a decrease in income, especially for small charities. There is also a significant scarcity of social care provision outside of the central belt and the north east according to the SCVO state of sector statistics.

14. There are examples of ALLIANCE member organisations who are delivering much needed provision in areas out with the central belt some of which are referenced to in the paragraphs below. One such organisation providing support for both people with long term conditions and their carers is Long

Term Conditions Hebrides (LTCH)¹². LTCH aims to enhance self management techniques, encourage skills development, reduce isolation and provide volunteering opportunities.

15. Additionally, Community Integrated Care (CIC) work in the community delivering life-enhancing support to people with a diverse range of care needs, including learning disabilities, mental health concerns, autism, age related needs and dementia¹³. CIC deliver a host of specialist, community-based care services, supporting people in leading fulfilling and independent lives in their communities.

16. Key to all of the ALLIANCE's work, is engaging with individual and organisation members and people with lived experience. The principles of co-production - as defined by the New Economics Foundation - underpin the philosophy of the ALLIANCE and its programmes¹⁴. For example, good co-production involves:

- Recognising people as assets
- Building on people's existing capabilities
- Promoting mutuality and reciprocity
- Developing peer support networks
- Breaking down barriers between professionals and recipients
- Facilitating rather than delivering

17. The ALLIANCE organise and facilitate engagement by sharing learning and good practice, connecting with others through events and meetings. To ensure that we achieve our commitment of breaking down barriers to people participating and being involved in our programmes we offer a programme of capacity building support as well as design our engagement work to provide a range of ways for people to engage such as online, in person and hybrid ways



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of working and implement accessible adjustments to anyone who may need it as well as factor in costs to recognise and compensate people for their involvement¹⁵. Informed by our work over the years, we developed a set of insights on how to meaningfully engage people with lived experience in our work.

18. Our engagement insights report recommends addressing power imbalances, giving people time to engage, considering accessibility and inclusivity, learning from engagement activities, considering ethics and carefully recognising and compensating people for their contributions¹⁶. It warns against making assumptions, being unclear about why you are engaging, relying on the same engagement methods and forgetting feedback.
19. Engagement is a continuous process, and we must all ask ourselves how we can continue to challenge power, create relationships with seldom heard groups and promote meaningful and non-tokenistic engagement.
20. People can share their voices, expertise and experiences with the ALLIANCE in a range of ways including: complete surveys, join focus groups, attend and/or speak at events and get in touch with us via email, letter or online via social media.
21. Alongside this we have varied lived experience networks that bring together people from a range of backgrounds and communities wanting to be heard, participate and make change. These include but are not limited to:
 - Long Covid Lived Experience Network¹⁷
In partnership with Asthma+Lung UK and Chest, Heart and Stroke Scotland, we have established a network for people affected by Long

Covid. The network will help to inform the design, development and implementation of local and national services¹⁸. This group is directly feeding into the Clinical/Subject Matter Expert Group, the Service Planning Group and the Steering Group within the Scottish Government's Long-Term Effects of COVID-19 Strategic Framework¹⁹.

- Integrated Joint Board (IJB) Lived Experience Representative Network²⁰

Individuals are appointed to a role on an IJB to represent the perspectives and experiences of people accessing support and services in their local area. The network is led and shaped by its members but organised and facilitated by the ALLIANCE. The network is vital for ensuring that health and social care is influenced and shaped by people with lived experience. This network provides these lived experience representatives (also called service user representatives) the opportunity to connect share learning and ideas that will support them in their role. The network and the ALLIANCE regularly share member insights and ideas with key stakeholders able to enact meaningful change for the network.

- Digital Citizen Panel²¹

In partnership with the Scottish Government, we listen to people and organisations on using digital to manage their housing health and social care needs. We capture insights of the members to support the Scottish Government implement the Digital Health and Care Strategy. Our aim is to ensure that people with lived experience drive policy and practice.

- Diverse Experiences Advisory Panel (DEAP)²².

DEAP is run in partnership with the Mental Health Foundation. The aim of the panel is to bring together lived experiences of mental health to advise the Scottish Government and others on how public policy can reduce mental health inequalities and explore ways to support more people to experience good mental health. One way the panel have done this is by sharing their views to inform the Mental Health and Wellbeing Strategy²³.

22. As part of our engagement activity, the ALLIANCE held an online event during the 2022 Carers Parliament exploring the continued impact of COVID-19 on unpaid carers in Scotland²⁴. The event aimed to explore the challenges that people, families and unpaid carers who were at higher risk of COVID-19 were continuing to experience at the time of the session in November 2022. This was in response to feedback we had received from members that the experiences of people who were at higher risk of COVID-19, their families and unpaid carers were felt to be overlooked in the decisions which had been taken as restrictions were being eased. The key themes reported not only relate to miscommunication and confusion but also the consequences of each. These included carers having to move to full time caring roles without acknowledgment or warning, lack of clarity and confusion in information and communication, fear and isolation compounding negative impacts on mental health and wellbeing, impact on relationships, lack of recognition of trauma, impractical support and advice.

23. Examples include:

- Many carers and families report experiencing a lack of check in support from local authorities and Health and Social Care Partnerships (HSCPs). Almost three years on, people continue to feel isolated.



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- Continuing to experience a lack of information from Social Work departments about the more flexible use of Self-directed Support (SDS) Option 1 (a direct payment which is a payment to the individual or third party to pay for their own support). One participant explained that they used their direct payment to employ a Personal Assistant, and were not comfortable with someone coming to their home during the height of the pandemic due to risk of infection. Yet, they faced challenges in using this payment option more flexibly in other formats and towards other types of support.
- Other participants highlighted a lack of contact from Social Work departments at the beginning of the pandemic, with little information about alternative options and no check in phone calls.
- 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. With measures taken to control the virus being reduced, participants shared that it felt like public perception and public health messaging had shifted to the COVID-19 pandemic being over. People at high risk of COVID-19 infection – and their carers – were continuing to shield. As a result, many carers and those they support feel left behind.
- 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.
- It was also recognised that while there is guidance for workplaces and homes, there is a lack of clear signposting on whether public spaces have addressed ventilation.

24. Participants have shared that:

“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”.

“Social work helped in the beginning of COVID-19 but we felt left in the unknown”.

“We felt that nobody wanted to know. Letters from government weren’t enough. We need help, rather than letters. I still feel petrified to go out in case I catch something”.

25. The ALLIANCE knows that people living with long term conditions, disabled people, unpaid carers, minority ethnic communities, those who live in Care Homes and many others have shared experiences that describe the disproportionate negative impact on their health, wellbeing and rights evidenced in the wider research²⁵. People have told us how the virus and the impacts of the resulting restrictions have disempowered many of them in their ability to access health services and negatively impacted their health and human rights²⁶.

26. We have heard from unpaid carers who experienced a deterioration in their physical health, as health services have prioritised the COVID-19 response, reducing access to the health management and health monitoring supports, which many people rely upon to live well²⁷.

27. Further, people who relied on community support groups, respite care and ongoing rehabilitation or prehabilitation support shared that, in extreme cases,

their inability to access care has not only resulted in their health deteriorating but has been fatal²⁸.

“Such a lack of consultation about the removal and/or reduction of services made carers feel invisible along with a lack of consideration of their ability or willingness to undertake additional caring responsibilities”²⁹.

28. However, when unpaid carers find it difficult accessing health care and support, it does not solely impact them but also the people they provide care and support for. For instance, at the Living with Covid-19 Carers Parliament event, participants outlined their concerns about carers becoming unwell, and the implications that this would have on their caring responsibilities and for the people they support, particularly where there is a lack of contingency planning and support from social care services³⁰.

29. Practically speaking, some have struggled to access appropriate Personal Protective Equipment (PPE), whilst others, to the detriment of the individuals they care for, have been excluded from healthcare appointments and decisions³¹. In comparison, many people have not been able to get in contact with service providers to access support or to make appointments at all³².

30. Through their research into The Impact of Coronavirus on People with Learning Disabilities and their Parents, Carers and Supporters, SCLD uncovered common concerns caused by the impact of the Coronavirus emergency³³. There was increased pressure on family/unpaid carers, because of reductions in support from care providers or fears of accepting support due to the risks of Coronavirus. Other common concerns were the reduction or removal of support, increased social isolation, in part due to digital exclusion, and the mental health impact.



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31. Many carers felt that there was a lack of clear guidance on specific issues, such as whether the person they were supporting should ‘shield’ and how often they were allowed to leave the house. These findings informed responses to the Equalities and Human Rights Committee, the Joint Committee on Human Rights, the Scottish Parliament COVID-19 Committee and Public Health Scotland³⁴.
32. For example:
- “The key is we’re not receiving it [information], we’re having to search out the clear factual information. No one we’ve approached; be it social work, health, or carers organisation has actually asked us or our sons whether we have the right information”³⁵.*
- “Perhaps activity packs, ideas and links to helpful resources via email or post would be helpful. Access to physical resources like trampolines, games, therapy toys etc.”³⁶.*
33. In terms of information provision, strong themes show that the accessibility needs of disabled people, people with learning disabilities, people with sensory impairments, or those whose first language is not English were long overlooked even pre-COVID-19. For example, some D/deaf individuals shared frustration around telephone-based triage and being unable to email their GP, while others shared the benefits of being able to do so, indicating the lack of standard communication guidelines³⁷.
34. Additionally, carers of disabled children and young people told us that general information about benefits, eligibility criteria, and the process of assessment available on the Scottish Government website was made only available as



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text. No alternative formats (e.g. Audio versions, videos, closed captions, BSL/English interpretation) or information in other languages were available³⁸.

35. Others have received unexpected correspondence regarding health and social care matters which they have had no other contact regarding. For example, an individual shared that without any notification their partner was discharged into a Care Home that was over one hour's drive away, which they were unable to reach due to a lack of access to transport³⁹.
36. Seeing the experiences and impact of the pandemic, the ALLIANCE's Community Links Practitioners (CLPs) shared with us that they have been approached by unpaid carers who have been struggling with providing the carer role during the challenge of lockdown⁴⁰.
37. Through the ALLIANCE's People at the Centre Engagement Programme (PATC), carers told us about their experiences of health and wellbeing in the pandemic⁴¹:

"It was personally difficult to be managing a work from home environment alongside personal caring responsibilities. For me, I was also supporting and organising care for my elderly mother who is affected by dementia. Most of her services stopped overnight because they were not critical. I suddenly became a carer and had to manage this alongside a busy and ever-changing workload. And while I received good support from social work services, it was intense".

"Easy access to joined up information! My husband has Parkinson's, a complex illness in itself and on top of that, I am faced with the complexities of finding the right support and benefits - it's a maze, at both national and local levels. I want to know I can connect quickly with the people and services we



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need and be met with compassion and understanding but this is not the reality”.

“It takes a lot for me to ask for help, and when I did it was so difficult to access. I am even getting upset thinking about this and the most annoying thing is no one has got back to me. I presume we are in a queue. I think it would help to have a letter or email even, which acknowledges I have been in touch and says we are dealing with you but it might take time. Otherwise you feel you are in a hopeless situation, you don’t matter, your file has been lost, you don’t exist, nobody cares - any number of very negative emotions, which aggravate your situation”.

“[My relative] doesn’t understand why we are not there and she desperately misses my dad. The Government has done little to make it easier for people with dementia and technology is not the answer for everyone”.

“It would have been helpful to have had some support, anything really”.

38. The ALLIANCE commissioned research into disabled children’s, young people’s, and carers’ experiences of accessing healthcare services and supports during the pandemic⁴². This research was shared with the Children and Young People’s subgroup of the Scottish Government’s National Care Service team, the Scottish Government’s Long Covid team and Social Work Scotland.
39. There was a consensus among participants that they did not receive a formal notice/letter informing them of healthcare services closures, or instructions on what they should do to have their appointments or regular treatments in place.

Not having ‘communication lines open’, made participants feel abandoned, with their complex healthcare needs unmet⁴³.

40. In addition to this, people felt that decisions about pandemic-related protocols, such as non-resuscitation notices or DNRs, were not properly contextualised and poorly thought out. There was a general feeling that applying blanket statements and policies was the norm during the pandemic, revealing that people’s particularities and own opinions were not considered by decision makers.

“[...] I remember getting the phone call from the... from the GP about making Bob 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... [...]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”.

41. Health services closures had negative impacts on children’s and young people’s symptoms and progression of their health conditions. Despite support from carers, without full access to the right support and control of symptoms for, for example, chronic pain, mobility difficulties, and mental health issues, there were negative impacts on their everyday lives.

42. Alongside this, social isolation and mobility restrictions related to lockdowns had negative impacts on children’s, young people’s, and carers’ mental health. Participants linked these to the limitations on everyday life that they experienced, caused by the poor control of children’s and young people’s conditions and concerns about their present and future lives.



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“Physio now is more like a patient led physio...so when you get a parent trying to show a child to do physio it’s just an absolute lie... because... no child does it and you don’t know how to teach them”.

43. When carers did find and access social care support, they mainly found out about it through informal conversations with friends, school teachers and neighbours rather than social workers (as stated in paragraph 38 this result was shared with Scottish Government groups and Social Work Scotland).

44. However, the process of actually applying for benefits and being assessed was described by carers as a ‘nightmare’. As well as the long turnaround times, carers found terminology and the language on forms complex and repetitive.

45. Carers voiced that they wished they had ‘someone in the system’ with whom they could share their concerns, struggles, and with whom to sense-check decisions about their children’s care, particularly during difficult times.

“[...]I didn’t know anything about social care... I thought it was more related to those people who take your children from you! It was a friend who is a GP who told me, you should apply for the disability allowance”.

46. In our Humans of Scotland stories, we heard from unpaid carers in Scotland during Covid-19 and some of the impacts it had⁴⁴:

“Eventually, I know, everything will return to normal or as near to normal as possible! I am sure we will make it through but some days we do start to doubt ourselves and I am sure we are not alone...”



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“It’s all about round the clock care, increased exponentially with this lockdown. Services are closed and there is no respite. That means the burden of care I felt, which was already at the sharp end before, has become a knife edge. Loneliness is a huge factor. In some ways this lockdown gives people just a small insight as to what it’s like for Carers’ – a loss of freedom, job insecurity, financial worries, fear for the future, health both mentally and physically impacted and shock that our dreams for our future have disappeared. I hope the Government will now look at the unequivocal evidence as to just how much unpaid Carers’ hold together the threads of society’s holes in social care”.

“With the arrival of COVID-19, we suspended mum’s care package last March and I moved into my brother’s home to help care for mum. Basically, we’ve shielded ourselves since. The experience has transformed my brother and I into introverted, unsociable recluses...”.

“I’m the project manager, I’ve got wages to do, rotas, stock to order and medicine to keep on top of. It’s not the actual caring that’s hard, it’s everything that goes around it. The biggest challenge for me is I’ve not got a lot of freedom in my own life to go and do the things that I’ve dreamed about. I did have a bit of a breakdown, everything was overload”.

47. At the outset of the pandemic, many unpaid carers and families experienced a lack of check in support from local authorities and HSCPs. Several years on, people continued to feel isolated⁴⁵.

48. A lack of clarity of information led to one participant’s heightened levels of anxiety:



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“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”.

49. Participants at the Living with Covid-19 Carers Parliament event outlined their concerns about carers becoming unwell, and the implications that this would have on their caring responsibilities and for the people they support, particularly where there is a lack of contingency planning and support from social care services⁴⁶. Some participants who had contracted COVID-19 described their experience:

“It was terrifying as I have a respiratory disease. I couldn’t access anti-virals and the GP was unsure if I would get them if I got worse. I felt kind of left. I self-isolated in my own home, but was terrified that other family would catch it. My [partner] had to care for me and I felt guilty because I’m the carer”.

“I got COVID-19. I panicked because I thought I’d passed it onto my family”.

50. Throughout and following the pandemic we have shared advice and information to our members, our followers on social media, readers of our website and to our ALLIANCE Live audience, all of which include health and social care staff. We also shared updates and news from our members and partner organisations.

51. Generally speaking, the ALLIANCE’s focus was on sharing information, research, resources and guidance created by the Scottish Government, NHS Scotland and Public Health Scotland on updates to safety guidelines.⁴⁷ These would usually also be accompanied by accessible versions and summaries. As mentioned in our previous written evidence, 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.

52. In addition to written advice, our ALLIANCE Live team produced podcasts relating to different COVID-19 issues with several guests including Scottish Personal Assistants Employers Network (SPAEN), Energy Action Scotland, Carers Scotland, Royal Pharmaceutical Society and GMC Scotland⁴⁸.
53. For health and social care staff specifically, on our website we published Cross- Sector Sensory Guidance which was co-produced by people with lived experience⁴⁹. Additionally, we conducted and published an interview with MHScot on ways to promote good mental health in the workplace⁵⁰.
54. To highlight lived experiences of staff, we shared their stories, alongside the experiences of 'Deep End' GPs including the advice and support provided by Community Links Practitioners⁵¹. Alongside this work we also signposted people to external resources⁵².
55. According to ALLIANCE member the Scottish Commission for People with Learning Disabilities (SCLD), many unpaid carers in particular felt there was a lack of clear guidance on specific issues, and in particular accessible information and guidance, such as whether the person they were supporting should 'shield' (as further described in paragraph 31) and how often they were allowed to leave the house⁵³. There were also difficulties explaining the situation to who they were caring for. People also expressed feelings of

anxiety and uncertainty about how long measures would last, and whether their usual support would return once measures were lifted.

“Guidelines about out walking not clear for someone with a disability”.

“My daughter can’t understand why she has no visitors so a lot of behaviour issues”.

56. In addition, to this 1 in 4 (25%) respondents said that they had simply not received any information⁵⁴. Some (11%) suggested that contact from social work would have been useful. Further detail on what the ALLIANCE did in relation to information is provided in paragraph 51 and 52.

“The key is we’re not receiving it, we’re having to search out the clear factual information. No one we’ve approached; be it social work, health, or carers organisation has actually asked us or our sons whether we have the right information in the right format”.

57. The exacerbation of existing barriers was also seen for people shielding and their need for additional support. Often, they were the most marginalised and excluded people in society, and the pandemic meant that the support mechanisms they did receive were disrupted⁵⁵.

58. When lockdown was announced and shielding letters disseminated, many recipients reported feeling overwhelmed by the instructions. There were some instances when the person was unsure what shielding involved, especially if they had not received a Chief Medical Officer (CMO) shielding letter and then subsequently received a shielding letter directly from a GP practice after a consultation⁵⁶.



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59. There was also confusion regarding who was identified to shield and who wasn't. Some people shared that they believe they should have received a shielding letter but did not. These individuals therefore chose self-imposed isolation to stay safe but were unable to access any available shielding supports.

60. As further described in paragraph 23, 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. 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. 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.

61. In the research conducted by SCLD, it was found that 22% of respondents were concerned that they were receiving unclear guidance about the right procedures in terms of shielding, self-isolating and using PPE during the Coronavirus emergency⁵⁷.

“It is not been clear enough how we are supposed to use PPE and whether we are supposed to be social distancing (this is not possible where we live). In the original list of vulnerable conditions ‘learning disability’ was listed and this seemed very vague and we would like more clarification on this”.

“Information as to whether my son should be classed as extremely vulnerable due to other conditions have been unclear and vague”.

“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”.

62. While progress in the rapid implementation of digital delivery of services was a welcome development for those who can access internet services easily and confidently, we know that access and use of internet services remains uneven. For example, only 43% of people aged over 75, and 71% of adults with some form of limiting long term condition, use the internet⁵⁸. Research has shown that disabled people are less likely to use the internet or to have internet access at home than non-disabled people.

63. Our Community Link Practitioners reported that people they met were unable to access the internet due to little or no access, affordability or inability to work the technology⁵⁹.

“I can open emails and read them but I don’t use internet because I fear I will do something wrong so getting any help has been difficult and I still don’t know what help is available”.

64. GPs at the Deep End told us:

“Often our patients struggle with the technology, don’t have enough data or reliable access to the internet, struggle to articulate their health concerns over the phone, or don’t have access to a private space.”

65. Furthermore, not all NHS, Scottish Government or Local Authority’s online health and social care resources and guidance provide Easy Read or accessible versions, or are compatible with screen readers, causing further

issues for people with learning difficulties, and for blind and partially sighted people.

66. Consideration should have been made for people who are unable or prefer not to access digital technology, who lack the necessary digital skills and/or who may require support from paid/unpaid carers to take part in a virtual appointment; mechanisms should be put in place which appropriately identify and support these individuals.
67. For some, often those with mental health issues, it was important to see a healthcare professional face to face; it has also been established that not all people can confidently take part in a virtual consultation or lack the private space in a homely setting in which to take part.
68. There was also 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.
69. People have also raised the affordability of digital connectivity and the concerns around reliable broadband in rural areas as a potential barrier.
70. 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 and where they did not feel online was the right medium for some forms of treatment such as support for their mental health or physiotherapy as examples.

71. In relation to mental health support services, the majority of participants in our Health, Wellbeing and the COVID-19 pandemic engagement shared that they found the digital delivery of mental health services to be inappropriate and an ineffective model of delivering support:

“Nothing has worked well. My daughter had no support for 6 months. She was in services and had weekly appointments until COVID. She is now at crisis”.

“I didn’t find talking on the telephone, to someone I’ve never met, either helpful or comforting”.

72. In relation to other services, participants told us:

“Assumptions have been made about carers ‘ability and willingness to care’ which goes against the Carers Act. The lack of consultation about the removal and/or reduction of services during lockdown period made carers feel invisible along with a lack of consideration of their ability or willingness to undertake additional caring responsibilities”.

“Tried to get involved in online course but found my technical abilities were lacking and this led to frustration”.

73. Across services, there were new tools and initiatives that were developed and implemented. For instance, triage processes were completed online, and support and advice were available digitally⁶⁰.

74. However, there were areas of both practical and digital good practice in specific HSCPs and programmes that we would like to highlight:



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- Edinburgh HSCP made a high volume of calls using its Assistive Technology Enabled Care 24 service (ATEC24)⁶¹. This enabled teams to check on individuals' wellbeing, provide companionship and offer advice and support on managing the emotional and practical challenges of the COVID-19 restrictions. Edinburgh HSCP reported that this service was positively received by those accessing support.
- One local authority/HSCP 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.
- Under the Scottish Government's Connecting Scotland Programme, digital devices were offered to care homes as part of the Connecting Care Home Residents initiative⁶². 76% of all Scottish Care homes took up the offer, with 1,961 iPad devices being delivered. The initiative made a difference to the general wellbeing of care home residents, while reducing the number of visitors and the risk of transmitting the COVID-19 virus.

75. One now widely used digital service that was developed was the Near Me Service⁶³. Near Me is a video consulting service that enables people to attend appointments from home or wherever is convenient. The service is already widely used across NHS Scotland for health and care appointments with around 20,000 consultations being held every week. This service experienced in both positive and negative ways as described further in paragraphs 76 and 77 below.

76. Local authorities/HSCPs referred to the use of Near Me, which was used to undertake care reviews, and which Mental Health Officers used to carry out assessments⁶⁴. The service is now being rolled out across a wide range of public services.

77. However, we were told by a research participant via our Health, Wellbeing and the COVID-19 study that⁶⁵:

“Near Me has also been problematic for people who have deafness, particularly when they are asked to keep repeating things. In one case a man had to depend on his wife as he was deaf- she had to repeat everything. This meant the call took twice as long: unhelpful as the call was about memory. It is also difficult to respond because of pauses and sound distortions”.

78. Local authorities and HSCP’s accomplished a great deal during and after the pandemic. A commonality across local authority/HSCP responses was the importance of adopting a “pragmatic” approach to responding to the crisis, with a focus on delivering services to those accessing care, their families, and unpaid carers⁶⁶.

79. Trends in responses demonstrated changes to social care assessments and packages, varying application of emergency legislation, a rapid migration to

digital delivery of social care, flexibility in working and partnership and collective working.

80. As we know, emergency legislation was brought in to allow for both safety and flexibility in the delivery of health and social care. Out of 26 local authorities, six - across five Health and Social Care Partnerships (HSCPs) - reported that they were using the powers: Clackmannanshire, Dundee, East Lothian, East Renfrewshire, Stirling and South Lanarkshire⁶⁷. Scrutiny and decision making around whether to use the emergency powers was undertaken by Senior Management teams, and reports were made both to Corporate Leadership/Management Teams and the Chief Social Work Officers' Group. Some local authorities/HSCPs also referred to the introduction of "decision making forums", which senior management teams attended.

81. However, it is important to note that disabled people, people living with long term conditions, unpaid carers and other marginalised groups were not part of these forums. For example, one local authority/HSCP who had made use of the section 16 powers explained that co-produced assessments were not "tenable" at the beginning of the pandemic due to workforce issues and redeployment of staff. This raises some concern about how partial assessments were undertaken in practice, and the extent to which people were involved in decisions affecting them.

82. We also heard that in some areas non-emergency respite care and residential day care was stopped, and alternative was sometimes provided. Further, in some areas local authorities suspended their complaints services, meaning that service users did not have access for resolution, which led to the ALLIANCE, Scottish Human Rights Commission (SHRC) and the SDS Collective intervening and highlighting it to the Scottish Public Services Ombudsman (SPSO)⁶⁸. For example, Glasgow City Council stated that "we

would encourage you to refrain from submitting a complaint to our office” if it pertains to specific topics – including “delays in service delivery which are the result of organisations having to cope with COVID-19 and which are non-essential”. However, after our intervention, East Dunbartonshire, Midlothian, and North Lanarkshire subsequently updated the complaints sections of their websites and online portals to make it clear that people are still able to submit complaints (although with expected delays due to the impact of the pandemic on service provision), following earlier statements that they were suspending complaints processes during the pandemic. Local authorities/HSCPs explained that contact was maintained with those who used the services, and outreach programmes were operated. Some services also set up virtual day support using video technology.

83. During COVID-19, local and national third sector health and social care organisations have played a crucial role in bringing people necessities, crisis, health and wellbeing support, as well as informing policy to ensure people’s rights are upheld⁶⁹.

84. ALLIANCE members and partners have been agile and flexible in their responses to the new demands brought about by COVID-19, as demonstrated by the broad range of activity in our ‘Community in Action’ initiative on our website⁷⁰. Some of the many examples include:

- Perth and Kinross Association of Voluntary Service (PKAVS) increased its telephone capacity to continue to support carers in the local area, making more than 1,000 contacts per week⁷¹.
- SCLD developed a ‘knowledge sharing hub’ to make essential information readily available and accessible for people living with learning/intellectual disabilities, who face particular challenges in accessing COVID-19 information⁷².



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- In addition to converting its work to online platforms in the space of just a week, Multiple Sclerosis Centre Mid Argyll delivered food and essential supplies to people who are unable to leave their home⁷³.
- RNIB Scotland's 'Technology for Life' service supported blind and partially sighted people to access technology they haven't used before, in order to keep in touch with friends, keep entertained and access information about COVID-19⁷⁴.
- Moray Wellbeing Hub adapted all of its services to be accessible remotely, including delivery of Principles of Mental Health First Aid sessions⁷⁵.
- Mel-Milaap moved from providing day care facilities to older people to providing hot meals three times per week across Glasgow⁷⁶.
- Macmillan Cancer Support's Volunteering Hub shifted from face to face to telephone and online support, reducing risks for many of their volunteers who are older people and/or shielding⁷⁷.

85. Scotland's third sector has been facing a difficult funding situation for several years now. As a whole, the sector has experienced a range of freezes, reductions and withdrawals of funding. This long-running problem has been exacerbated by the COVID-19 pandemic. The Scottish Council for Voluntary Organisations (SCVO), the umbrella body for Scotland's third sector, has described the sector as being "overlooked", including in the Scottish Government 2022 Resource Spending Review that was intended to chart a course for public spending for several years⁷⁸.

86. Third sector health and social care organisations are particularly crucial to preventing many people being left behind or forgotten. However, while adapting to respond to a huge increase in demand for their services, many organisations reported significant financial pressure, due to restrictions on

their ability to fundraise⁷⁹. For some this was not a new phenomenon caused by the pandemic; it has been a developing situation over many years.

87. According to research conducted by SCVO, funders responded well and showed flexibility around outcomes, deadlines, and reporting⁸⁰. Similarly, they worked closely with grant-holders to identify issues and needs⁸¹. However, funds and new applications were postponed, and some smaller charities reported barriers to accessing government funding which included lack of staff capacity, lack of information and clarity, difficulty in forward planning, and not meeting criteria⁸². It was highlighted that transitional funding would help charities impacted by closures and loss of revenue .

88. In order to avoid uncertainty and insecurity with third sector funding resulting in, for example, staff recruitment and retention, organisations need longer term commitment and funding. Short-term funding takes time away from providing services that people rely on or worse, service delivery is cut, leaving them without the support they need or being presented with a new service entirely, one they didn't ask for or is not suited to their needs.

89. Further, in research conducted by Scottish Care, the competitive model currently in place for social care commissioning which in homecare, has driven prices down and in care homes, has resulted in a failed Cost of Care Model where local authorities end up spending twice as much for in-house services. Both result in waste by creating an unstable market and disrupting continuity of care and support⁸³.

90. Grounding commissioning practice and guidance in care realities and shifting away from purely cost-based decision making also requires overcoming current failings regarding the appropriate evaluation of people's needs and arranging supports accordingly. The current system sets out to deliver what people want, but only provides funds based on what is deemed affordable,

without effective routes to challenge inadequate funding or adjust service delivery in an equitable way.

91. Nevertheless, there is no ethical commissioning without ethical working practices. Scottish Care calls for improved terms and conditions for independent care staff through a dynamic and transparent system that caters to everchanging local demand for a care workforce to strengthen services being commissioned⁸⁴.
92. Some local authorities/HSCPs also referred to the negative impact that COVID-19 has had on commissioning arrangements with third sector organisations⁸⁵. 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. This meant that vital services were not being delivered in some areas, with an ensuing impact on social care packages. The third sector continues to be undervalued and under resourced (as referred to in paragraphs 85-87).
93. Indeed, research highlighted that even before COVID-19, the Scottish Fiscal Framework was proving “insufficiently flexible”⁸⁶. There was and continues to be a pressing need for human rights to guide financial policy and decision-making to address the disproportionate impact on people with protected characteristics and those living in the most deprived communities.
94. More than half of Scottish third sector organisations lost fundraising income due to the pandemic, with the cancellation of face-to-face fundraising events, the closure of charity shops and other venues, and reduced public donations⁸⁷. The extent of this lost revenue is significant.



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95. For example, Crohn's & Colitis UK's income halved, Cancer Support Scotland reported a loss of 40% income between March and July 2020, and Chest, Heart and Stroke Scotland lost £500,000 a month in fundraising income⁸⁸. Multiple datasets reveal the ongoing financial pressure faced by the third sector. SCVO research found that around half of charities think they will run out of funds in six months, and a third of organisations have less than three months' worth of reserves⁸⁹.

96. In many cases, organisations experienced significantly increased demand for their services due to the COVID-19 pandemic and now the cost of living crisis. For example, Crohn's and Colitis UK reported a 400% increase in demand for their helpline services and a 600% rise in demand for their website. This was due to rising concern amongst people access services in relation to their? health, work and caring; the health and social care workforce leaving the sector, being redeployed or furloughed; people requiring advice, and support and information; cancellation and delays to appointments; in person services being closed and difficulties accessing basic necessities.

97. Whereas, Chest Heart & Stroke Scotland reported an 80% increase in demand for its Community Support services, and there are now an estimated 1.1 million unpaid carers in Scotland due to the pandemic⁹⁰. According to Carers Trust Scotland, for many unpaid carers, the needs of the person(s) they care for have intensified during the pandemic⁹¹.

- Some unpaid carers felt that the restrictions had contributed to a deterioration in the condition of the person(s) they cared for which in turn had intensified their own caring role.
- Due to lockdowns, travel restrictions and shielding requirements, unpaid carers have found that they are now with the person(s) they care for more often. Some unpaid carers live with the person(s) they

care for, and others changed their living arrangements to be able to provide care during the pandemic.

- The restrictions on travel and socialising have also made it more difficult for unpaid carers to receive support from family and friends. In some cases the person(s) who would have shared the caring role is vulnerable to the virus, resulting in more responsibilities for the primary carer.
- Unpaid carers or the person(s) being cared for wanted to stop support from paid carers to limit the risk of the virus. These understandable precautionary measures placed additional responsibilities on unpaid carers.
- Many statutory services, local organisations and other services providing paid carers or day care services for the person(s) being cared for, paused their services. This increased the demands on unpaid carers who had to step in to fill the gap in provision, and is likely to continue, particularly for organisations working with people who have seen their situation and/or health conditions worsen.

98. A flexible financial approach was integral to Glasgow's Govan Youth Information Project (GYIP) being able to respond to the needs of local children during the pandemic⁹². Glasgow City Council, having provided funding for an Easter project, allowed GYIP to utilise that funding for its COVID-19 response, mainly distributing meals in the community.

99. Down's Syndrome Scotland had to furlough half of their staff team while demand for support increased three-fold. In the four months to the end of July 2020, they had 1,126 family contacts (compared with 1,065 during the whole of 2019)⁹³. Chief Executive, Eddie McConnell, said: "How sustainable is the current level of working going forward? Charities should be put at the centre

of the renewal process, and that doesn't just mean finance being made available, it means recognising the worth and value of the sector too.”

100. When the ALLIANCE refers to a ‘crisis management approach’ we wanted to highlight the way the Scottish Government responded to the crisis by allowing local authorities, HSCPs and the third sector to deliver services and support with lower levels of bureaucracy, and a more liberal, flexible approach to financial structures such as previously ring fenced funding, and flexible and collaborative working⁹⁴.

101. Particular examples that supported more liberal trust in LAs and HSCPs include:

- The Winter Social Protection Fund, which aimed to mitigate social harms posed by COVID-19, winter cost of living increases and Brexit, enabled direct payments to be issued to low-income families and included “flexible funding” for local authorities, meaning that people and families were empowered through financial allocations directly to their bank account⁹⁵. Local authorities/HSCPs reported that this was a positive initiative, which received positive feedback from recipients.
- Many local authorities adapted to enable close relatives and families to be employed as Personal Assistants (PAs) via SDS Option 1 (direct payments)⁹⁶. The use of direct payments to employ family members and relatives where necessary supported those shielding or in family bubbles and has been a beneficial option for people accessing support, as well as unpaid carers.
- One local authority/HSCP referred to an increased number of carer budgets, and a higher number of bespoke purchases around enabling technology to support people to keep in touch with family.

Statement of truth



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

Signed

Date

¹ The ALLIANCE, "Our Members", available at: https://www.alliance-scotland.org.uk/blog/our_members/

² Jepson, A., "Adult Social Care and Support in Scotland" (2020), available at: [Adult social care and support in Scotland \(parliament.scot\)](https://www.parliament.scot/Adult-social-care-and-support-in-Scotland).

³ The following list is not exhaustive as many of our members work indirectly with carers or unpaid carers are not their main target support group: Aberlour Child Care Trust, Action for M.E., Age Scotland, Alzheimer Scotland, Annexe Communities, ASRA, BHF Scotland, Borders Care Voice, Carers Forum Stirling Area T/A Stirling Carers Centre, Carers Link East Dunbartonshire, Carers of West Lothian, Carers Scotland, Carers Trust, Caring Community Circle, Capability Scotland, Coalition of Carers in Scotland, Community Health and Social Care Shetland, Community Integrated Care, East Ayrshire Carers Centre, Edinburgh Young Carers Project, Fibromyalgia Friends Scotland, Glasgow Care Foundation, Glasgow North East Carers Centre, Highland Community Care Forum, Inverclyde Carers Centre, Long Term Conditions Hebrides (LTCH), Maggie's Cancer Caring Centres, MECOPP, Milan Senior Welfare Organisation, Realize Your Potential C.I.C, Scottish Care, Vocal Carers Centre.

⁴ The ALLIANCE, "Our Members", available at: https://www.alliance-scotland.org.uk/blog/our_members/

⁵ Stirling Carers Centre, "Welcome Page", available at: <https://www.stirlingcarers.co.uk/>. Vocal Carers Centre, "Homepage", available at: <https://www.vocal.org.uk/>; PAMIS, "Promoting a More Inclusive Society", available at: <https://pamis.org.uk/>; Contact Scotland, "Homepage", available at: <https://contact.org.uk/>.

⁶ National Carer Organisations, "National Carer Organisations in Scotland", available at: <https://carers.org/policy-and-strategic-influencing-in-scotland/national-carer-organisations-in-scotland>; Carers Trust, "Our Work in Scotland", available at: <https://carers.org/our-work-in-scotland/our-work-in-scotland>; MECOPP, "Homepage", available at: <https://www.mecopp.org.uk/>; Shared Care Scotland, "Homepage", available at: <https://www.sharedcarescotland.org.uk/>.

⁷ Carers UK, "Homepage", available at: <https://www.carersuk.org/>.

⁸ Scottish Government, "Scotland's carers update release: April 2022" (2022), available at: <https://www.gov.scot/publications/scotlands-carers-update-release-2/#:~:text=The%20latest%20figures%20show%20an%20estimated%20total%20of,carers%20living%20in%20Scotland%2C%20including%2030%2C000%20young%20carers.>

⁹ Scottish Government, *Young Carers: Review of research and data* (2017), available at: <https://www.gov.scot/publications/young-carers-review-research-data/>.

¹⁰ Edinburgh Young Carers Project, "Homepage", available at: <https://www.youngcarers.org.uk/>; Realize Your Potential, "Homepage", available at <https://www.facebook.com/RealizeYourPotentialQuest/>.

¹¹ SCVO, "State of the Sector 2022" (2023), available at: <https://scvo.scot/policy/sector-stats>.



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- ¹² Long Term Conditions Hebrides (LTCH), "Homepage, available at: <https://www.ltch.org.uk/>.
- ¹³ Community Integrated Care (CIC), "Homepage", available at: [Home - Community Integrated Care](#).
- ¹⁴ The ALLIANCE, "Co-production", available at: <https://www.alliance-scotland.org.uk/self-management/getting-involved/co-production/>.
- ¹⁵ The ALLIANCE, *Engagement Insights* (2021), available at: <https://www.alliance-scotland.org.uk/blog/news/engagement-insights-report-highlights-the-crucial-aspects-of-meaningful-engagement/>.
- ¹⁶ The ALLIANCE, *Engagement Insights* (2021), available at: <https://www.alliance-scotland.org.uk/blog/news/engagement-insights-report-highlights-the-crucial-aspects-of-meaningful-engagement/>.
- ¹⁷ The ALLIANCE, "Long Covid Lived Experience Network", available at: <https://www.alliance-scotland.org.uk/lived-experience/networks/long-covid-lived-experience-network/>.
- ¹⁸ The ALLIANCE, *Insight Report from the 2022 Long Covid Lived Experience Survey* (2022), available at: [Long Covid Lived Experience Survey- Insight Report. - Health and Social Care Alliance Scotland \(alliance-scotland.org.uk\)](#).
- ¹⁹ Scottish Government, *Coronavirus (COVID-19): Scotland's Long Covid service* (2021), available at: <https://www.gov.scot/publications/scotlands-long-covid-service/>.
- ²⁰ The ALLIANCE, "IJB Lived Experience Representative Network", available at: <https://www.alliance-scotland.org.uk/lived-experience/networks/ijb-lived-experience-representative-network/>.
- ²¹ The ALLIANCE, "Digital Citizen Panel", available at: <https://www.alliance-scotland.org.uk/digital/digital-health-and-care/digital-citizen-panel/>.
- ²² The ALLIANCE, "Diverse Experiences Advisory Panel (DEAP)", available at: <https://www.alliance-scotland.org.uk/lived-experience/networks/diverse-experiences-advisory-panel-deap/>.
- ²³ Scottish Government, *Mental Health and Wellbeing Strategy* (2023), available at: <https://www.gov.scot/publications/mental-health-wellbeing-strategy/>.
- ²⁴ The ALLIANCE, *Living with COVID-19: Carers Parliament Event Report* 92023), available at: <https://www.alliance-scotland.org.uk/blog/resources/living-with-covid-19-carers-parliament-event-report/>.
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- ²⁶ The ALLIANCE, *Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future* (2022), available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Final-Report.pdf>.
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