Health and Social Care Alliance Scotland (the ALLIANCE)

COVID-19 Recovery Committee Inquiry: Excess deaths in Scotland since the start of the pandemic

5 January 2022

Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to the COVID-19 Recovery Committee's inquiry into excess deaths in Scotland since the start of the pandemic.[1] The ALLIANCE is a national intermediary with over 3,000 members including third sector health and social care organisations, disabled people, people living with long term conditions, and unpaid carers.

The direct and indirect impacts of COVID-19 – and responses taken to it – have been felt significantly by disabled people, people living with long term conditions and unpaid carers. It is essential that we fully address the inequalities that have been made worse by COVID-19, particularly for marginalised groups.

Throughout the pandemic, the ALLIANCE has engaged with members and partners on the impacts of COVID-19. Key pieces of work include our recently published response to the NHS Recovery Plan,[2] our People at the Centre report on remobilising health and social care services,[3] research on access to GP services across Scotland during the pandemic, and our ongoing COVID-19 policy engagement work.

Question 1. Has the public health emergency shifted from COVID-19 deaths to deaths from non-COVID-19 conditions?

The COVID-19 pandemic is an ongoing crisis. Since March 2020, the direct and indirect impacts of COVID-19 have been felt across society, including in the health and social care sectors. Progress has been made with the Scottish Government's vaccination programme, and the number of COVID-19 related deaths has reduced substantially from the peak in April 2020.[4] However, we continue to face significant direct pressures through infection with the virus, most recently through the new Omicron variant which is causing case numbers to rise exponentially.[5] At the same time, people are facing pressures from the indirect impacts of COVID-19, and excess deaths are 15% above average levels for this time of year.[6]

ALLIANCE members and partners have continually emphasised that the COVID-19 pandemic is not over.[7] It is important to recognise that people are continuing to be

directly and indirectly impacted by COVID-19, and new issues are emerging. As the Scottish Government sets plans for recovery and renewal, it is imperative that the ongoing impacts of the virus are addressed and considered, alongside the indirect and non-COVID related health impacts.

Question 2. Is there evidence that patients are now presenting in a more acute condition?

Changes to health and social care, and social distancing measures introduced to control the virus, have changed the way in which people interact with healthcare services. The ALLIANCE has heard of the barriers that people have faced in accessing healthcare services and support during COVID-19. The implications of these barriers means that health outcomes may have worsened, and many people may now be presenting in a more acute condition to healthcare services.

During our *People at the Centre* work, participants highlighted a lack of access to healthcare services. Steps taken to respond to COVID-19 has led to care being disrupted and delayed, having a significant impact on people with wider healthcare needs.[8] Similarly, preventative, and non-urgent care such as screening services have been delayed. While a small number of participants spoke about attending breast screening services and smear tests, others found that these services were unavailable.[9] One participant summarised the situation as follows:

> *"They felt like they are inaccessible unless you have COVID. I received messages from GPs advising not to visit the surgery at all, but never received a message saying it is now safe to do so."*[10]

This was echoed in a recent ALLIANCE survey which gathered over 200 responses on people's experiences of accessing General Practice during the pandemic, with findings due to be published in early 2022.[11] General Practitioners (GPs) are often people's first point of contact in the healthcare system and play an essential role in supporting people to manage longer term conditions. The initial survey findings highlight that 35% of people felt that their expectations were not met when calling upon their GP surgery. Additionally, some respondents felt uncomfortable discussing personal health issues with secretarial and reception staff who are often triaging cases to help GPs in their work and were viewed as "gatekeepers" to accessing support.[12]

People have also expressed concern about the effectiveness of virtual consultations where face to face access was reduced. While online platforms such as Near Me have been positive for many, they have not been suitable for everyone, and some participants described virtual and teleconsultations as an "inadequate replacement" to traditional face to face services:

> *"I am not confident that health professionals are assessing me properly if they are only speaking to me on the phone."*[13]

As highlighted in our response to the NHS Recovery Plan, these challenges have been heightened for marginalised groups, including people from ethnic communities, people with learning/intellectual disabilities, women, children and young people, and people living with sensory loss.[14] One participant explained the challenges faced by people from ethnic minorities:

> *"Inaccessibility increased for everyone, but it increased two or three-fold for ethnic minorities, because of other barriers, because of lack of information, because of lack of support. It kept increasing. Services moved online and the majority of people at grassroots level, South Asians we work with, especially women, older people and families on low income, they didn't know how to go online."*[15]

Members have also shared how shielding measures have had a significant impact on people.[16] Concerns have been raised about the consequences of shielding, including health issues going unnoticed or undetected, social isolation, and inadequate access to food. Similarly, some people have opted to choose self-imposed isolation to stay safe.

The subsequent impact of these challenges has had – and continues to have – significant consequences for individual health and wellbeing. Many people feel like needs have not been met and have experienced considerable deterioration of both physical and mental health.[17]

Question 3. What accounts for the deaths from non-COVID-19 conditions?

Research by Public Health Scotland, which analysed excess deaths between 16 March to 21 June 2020, highlights that while the majority (82%) of excess deaths were linked directly to COVID-19, the remainder could be attributed to underlying causes, including; dementia and Alzheimer's, external and ill-defined causes, circulatory causes, other causes, cancer, and diabetes.[18] "External and ill-defined" causes included some drug related deaths, alcohol related deaths, and suicides.[19]

We know that health inequalities impact different population groups disproportionately. [20] Crucially, COVID-19 has highlighted and exacerbated pre-existing inequalities. Accordingly, the direct and indirect effects of COVID-19 mean that some population groups have been affected in different ways, including disabled people, people with long term conditions, older people, Black and minority ethnic people, and socio-economically disadvantaged people.

Both non-COVID-19 excess deaths and deaths involving COVID-19 are twice as high in the most deprived areas compared to the least deprived areas.[21] Inequality is widened when the data is disaggregated by specific population groups, including age, sex, disability, long term conditions, and ethnicity.[22] It is crucial that the social determinants of health – including the intersectionality of inequality – are fully addressed. As we move into the next phase of the pandemic, it is important that

measures are introduced or strengthened that can address this inequality and challenge the social determinants of health.

Question 4. Is there enough of a strategic focus on the indirect health impacts of the pandemic?

No. As highlighted in our answers to Questions 2 and 3, it is imperative that the indirect health impacts of the COVID-19 pandemic are adequately addressed.

Our briefing, *Putting people at the centre of an independent inquiry into COVID-19*, sets out some of the key indirect health impacts that our members have experienced during the COVID-19 pandemic.[23] These are detailed below:

- Confusing, inaccessible, limited, and interrupted communication was experienced at all levels: between services, for people who access services, and at the national public health messaging level.[24] This has created issues for people accessing healthcare services.

- Lockdown and restrictions have imposed new barriers for people with sensory impairments including loss of lip reading due to face masks, inability to access appointments accompanied by a support worker, and navigating public areas under social distancing guidelines.

- Members reported that some population groups were receiving unsolicited requests by some General Practices to sign Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms.[25] It is important that steps are taken to prevent a similar situation happening again in future.

- People with long term conditions faced difficulties accessing healthcare services. The decision making behind this must be addressed and the long term impact properly reviewed.

- The need for palliative and end of life care increased, and there was a substantial increase in the number of people dying at home. Most of these deaths at home were attributed to causes such as cancer, dementia and heart failure.[26] There is also concern that a lot of the pressure of end of life care and death at home fell on family members and unpaid carers, who may not have had adequate or appropriate support.

Question 5. What are the realistic options open to the government in addressing the indirect health impact of the virus in winter 2021/22?

To address the indirect health impact of the COVID-19 virus, the ALLIANCE makes recommendations in the following key areas:

Equalities and human rights

To address the health inequalities faced by certain population groups, it is imperative that the Scottish Government adopts an equalities, human rights, intersectional and person centred focus. Steps should be taken to ensure that measures taken to control the virus, as well as responses in the wider health and social care sector are explicitly aligned with human rights.

The rights of marginalised people who have been disproportionately affected by COVID-19 must be at the centre of government decision making, and the voice of lived experience must be involved meaningfully, and in a way that addresses intersectional experiences.

There are practical tools that can be used to embed an equalities and human rights based approach:

- The five-point PANEL Principles (Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality) can be used to ensure that people's human rights are at the heart of policy and practice.[27]

- Consideration could also be given to enacting the AAAQ Framework.[28] The framework is underpinned by key elements of the human right to the highest attainable standard of physical and mental health. This means that the provision of goods, services and facilitates that are necessary for the realisation of people's rights to health could be measured against indicators of whether they are "available", "accessible", "acceptable", and of "good quality".[29]

- The ALLIANCE recommends that robust and timely Equality and Human Rights Impact Assessments (EQHRIAs) are carried out for all proposed actions to address the indirect health impacts of COVID-19. EQHRIAs were developed by the Scottish Human Rights Commission and Equality and Human Rights Commission to combine Equality Impact Assessments and Human Rights Impact Assessments.[30]

  This is a practical tool that should be used both at the earliest stages to inform policy, and after the policy has been implemented to assess its impact. This will help to improve outcomes, reduce inequality, demonstrate transparency,

accessibility, accountability, and ensure compliance with human rights and equality legislation. Assessments should be evidence led, carried out at the earliest opportunity, and based on meaningful involvement of communities, including marginalised population groups.

Holistic care and support

A holistic care and support planning approach should be adopted in primary care to ensure ongoing support for people accessing healthcare services and support. Scotland's House of Care model is a useful framework to ensure that people living with long term conditions are meaningfully involved in decisions about their care.[31] The House of Care model is an important tool that allows healthcare to embed collaborative care and support planning and fulfil its responsibilities to support the self management of people living with one or more long term conditions in General Practice. This approach supports and enables people to articulate their own needs and to decide on their own priorities, through a process of joint decision making, goal setting and action planning. It consists of:

- **Right hand wall:** Health and care professional team committed to shared decision making, partnership working and a "*What Matters to You*?" conversation
- **Left hand wall:** Engaged, informed, empowered individuals and carers ready to engage in a "*What Matters to You*?" conversation
- **Foundation:** "More than Medicine" informal and formal sources of support and care sustained by the responsive allocation of resources
- **Roof:** organisational processes, policies, systems and arrangements

Each of these are built around a "care and support planning conversation", which is at the heart of the house. This conversation enables a person with one or more long term conditions to engage with healthcare professionals in a person centred manner, and to utilise local resources. Crucially, the house needs all components to stand strong.

Third sector involvement

To mitigate the impact of COVID-19, urgent investment in health and social is needed. The third sector has played a key role in responding to COVID-19, and in supporting people to access care and support. The ALLIANCE's Community in Action project shared almost 70 reports on the third sector's response to COVID-19, highlighting the speed at which organisations adapted to support people in March 2020 and the months that followed.[32] Yet chronic underfunding and undervaluing of the sector can hinder the full enjoyment of quality, accessible services and support.

This can have a detrimental impact on disabled people, people living with long term conditions, unpaid carers, and the third sector workforce.

The third sector must be recognised as an equal partner in the delivery of healthcare services and support. The ALLIANCE recommends that the Scottish Government commits to working with the third sector as meaningful and valued partners in the design and delivery of care and support. This should be underpinned by long term, adequate and sustainable funding to reflect the vital work of the sector. This will allow the 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.[33]

Community Links Practitioners

Health and wellbeing should be prioritised by increasing investment in community-based services, and guaranteeing people access to timely, good quality support. Asset-based approaches are key to reducing inequalities and creating personalised services built around the rights and needs of communities.

The ALLIANCE's Links Worker Programme is an example of a model that improves health outcomes, and supports people to access care and support services that enable them to live well. The ALLIANCE employs 55 Community Links Practitioners (CLPs), who are based within 63 GP surgeries across Glasgow and West Dunbartonshire. The Links Worker Programme aims to mitigate the impact of the social determinants of health for people that live in areas of high socio-economic deprivation (the most deprived 15% of areas, as measured by the Scottish Index of Multiple Deprivation (SIMD))[34] – a population group disproportionately affected by COVID-19.[35] To prevent further entrenching inequality, the ALLIANCE recommends expansion of CLPs to all GP practices, with prioritisation to appointing CLPs in practices within Scotland's 100 most deprived areas.

Data gathering and analysis

There are a range of data gaps around the indirect impacts of COVID-19. Greater attention should be given to evidence outlining the indirect impacts of COVID-19. It is important that robust research on the impact of COVID-19 is undertaken, underpinned by disaggregated data collection and intersectional analysis. This research should be used to inform future support and services to ensure practical, inclusive measures are developed to support people, including disabled people, people living with long term conditions and unpaid carers.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay 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 better cross-sector understanding and partnership.

Contact

Gillian McElroy, Policy and Information Officer
gillian.mcelroy@alliance-scotland.org.uk

Rob Gowans, Policy and Public Affairs Manager
rob.gowans@alliance-scotland.org.uk

0141 404 0231
www.alliance-scotland.org.uk
@ALLIANCE Scot

References

[1] Scottish Parliament, *COVID-19 Recovery Committee: Inquiry into excess deaths in Scotland since the start of the pandemic.* Available at: https://www.parliament.scot/chamber-and-committees/committees/current-and-previous-committees/session-6-covid19-recovery-committee/business-items/excess-deaths-in-scotland-since-the-start-of-the-pandemic-inquiry

[2] The ALLIANCE, *Putting People at the Centre of NHS Scotland Recovery* (14 December 2021). Available at: https://www.alliance-scotland.org.uk/wp-content/uploads/2021/12/Putting-People-at-the-Centre-of-NHS-Scotland-Recovery.pdf
[3] The ALLIANCE, *Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future*. Available at: https://www.alliance-scotland.org.uk/people-and-networks/wp-content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Final-Report.pdf; The ALLIANCE, *Health, Wellbeing and Primary Care during the COVID-19 Pandemic*. Available at: Microsoft Word - Appendix A - ALLIANCE report (nhs.scot)
[4] Scottish Government, *Coronavirus (COVID-19) state of the epidemic – 3 December 2021* (3 December 2021). Available at: https://www.gov.scot/publications/coronavirus-covid-19-state-epidemic-03-december-2021/documents/
[5] Scottish Government, *Coronavirus (COVID-19): Omicron in Scotland – evidence paper* (10 December 2021). Available at: https://www.gov.scot/publications/omicron-scotland-evidence-paper/
[6] Scottish Government, *COVID-19 in Scotland – Detailed analysis* (15 December 2021). Available at: https://data.gov.scot/coronavirus-covid-19/detail.html
[7] See, for example: The ALLIANCE, *Putting people at the centre of an independent inquiry into COVID-19* (18 October 2021). Available at: https://www.alliance-scotland.org.uk/blog/news/putting-people-at-the-centre-of-an-independent-inquiry-into-covid-19/
[8] The ALLIANCE, *Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future*. Available at: https://www.alliance-scotland.org.uk/people-and-networks/wp-content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Final-Report.pdf
[9] The ALLIANCE, *Health, Wellbeing and Primary Care during the COVID-19 Pandemic*. Available at: Microsoft Word - Appendix A - ALLIANCE report (nhs.scot)
[10] The ALLIANCE, *Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future*. Available at: https://www.alliance-scotland.org.uk/people-and-networks/wp-content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Final-Report.pdf
[11] The ALLIANCE, *Putting People at the Centre of NHS Scotland Recovery* (p.14) (14 December 2021). Available at: https://www.alliance-scotland.org.uk/wp-content/uploads/2021/12/Putting-People-at-the-Centre-of-NHS-Scotland-Recovery.pdf
[12] The ALLIANCE, *Health, Wellbeing and Primary Care during the COVID-19 Pandemic* (p.14). Available at: Microsoft Word - Appendix A - ALLIANCE report (nhs.scot)
[13] The ALLIANCE, *Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future*. Available at: https://www.alliance-scotland.org.uk/people-and-networks/wp-content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Final-Report.pdf
[14] The ALLIANCE, *Putting People at the Centre of NHS Scotland Recovery* (14 December 2021). Available at: https://www.alliance-scotland.org.uk/wp-content/uploads/2021/12/Putting-People-at-the-Centre-of-NHS-Scotland-Recovery.pdf
[15] The ALLIANCE, *Putting People at the Centre of NHS Scotland Recovery* (p.5) (14 December 2021). Available at: https://www.alliance-scotland.org.uk/wp-content/uploads/2021/12/Putting-People-at-the-Centre-of-NHS-Scotland-Recovery.pdf
[16] The ALLIANCE, *Health, Wellbeing and the COVID-19 Pandemic Final Report*. Available at: https://www.alliance-scotland.org.uk/blog/resources/health-wellbeing-and-the-covid-19-pandemic-final-report/; The ALLIANCE, *Putting people at the centre of an independent inquiry into COVID-19* (18 October 2021). Available at: https://www.alliance-scotland.org.uk/blog/news/putting-people-at-the-centre-of-an-independent-inquiry-into-covid-19/
[17] The ALLIANCE, *Health, Wellbeing and the COVID-19 Pandemic Final Report*. Available at: https://www.alliance-scotland.org.uk/blog/resources/health-wellbeing-and-the-covid-19-pandemic-final-report/
[18] Public Health Scotland, *Underlying causes of excess deaths in Scotland during the COVID-19 pandemic, by area deprivation* (26 August 2020). Available at: https://publichealthscotland.scot/media/7186/non-covid-19_excess_deaths_by_cause-report.pdf
[19] *Ibid.*
[20]Scottish Government, *The Impacts of COVID-19 on Equality in Scotland*. Available at: https://www.gov.scot/binaries/content/documents/govscot/publications/research-and-analysis/2020/09/the-impacts-of-covid-19-on-equality-in-scotland/documents/full-report/full-report/govscot%3Adocument/Covid%2Band%2BInequalities%2BFinal%2BReport%2BFor%2BPublication%2B-%2BPDF.pdf
[21] National Records of Scotland, *Deaths involving coronavirus (COVID-19)* in Scotland. Week 49 (6 December to 12 December 2021). Available at:

https://www.nrscotland.gov.uk/files//statistics/covid19/covid-deaths-21-report-week-49.pdf; Public Health Scotland, *Underlying causes of excess deaths in Scotland during the COVID-19 pandemic, by area deprivation* (26 August 2020). Available at: https://publichealthscotland.scot/media/7186/non-covid-19_excess_deaths_by_cause-report.pdf

[22] National Records of Scotland, *Deaths involving coronavirus (COVID-19)* in Scotland. Week 49 (6 December to 12 December 2021). Available at: https://www.nrscotland.gov.uk/files//statistics/covid19/covid-deaths-21-report-week-49.pdf

[23] The ALLIANCE, *Putting people at the centre of an independent inquiry into COVID-19* (18 October 2021). Available at: https://www.alliance-scotland.org.uk/blog/news/putting-people-at-the-centre-of-an-independent-inquiry-into-covid-19/

[24] The ALLIANCE, *Health, Wellbeing and the COVID-19 Pandemic Final Report*. Available at: https://www.alliance-scotland.org.uk/blog/resources/health-wellbeing-and-the-covid-19-pandemic-final-report/

[25] Age Scotland, *Older people need answers on inappropriate use of DNACPR*. Available at: https://www.ageuk.org.uk/scotland/our-impact/policy-and-research/political-briefings/coronavirus-lockdown-anniversary/older-people-need-answers-on-inappropriate-use-of-dnacpr/; National Autistic Society, *Coronavirus – Access to health services* (5 June 2020). Available at: https://www.autism.org.uk/what-we-do/news/coronavirus-access-to-health-services

[26] Scottish Partnership for Palliative Care, *Every Story's Ending* (September 2021). Available at: https://www.palliativecarescotland.org.uk/content/publications/Every-Storys-Ending.pdf

[27] Scottish Human Rights Commission, *A human rights based approach: an introduction*. Available at: https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf.

[28] Public Health Scotland, *The right to health*. Available at: http://www.healthscotland.scot/health-inequalities/the-right-to-health/overview-of-the-right-to-health.

[29] Public Health Scotland, *The right to health*. Available at: http://www.healthscotland.scot/health-inequalities/the-right-to-health/overview-of-the-right-to-health; OCHR, *The Right to Health – Fact Sheet No. 31* (p.4). Available at: https://www.ohchr.org/documents/publications/factsheet31.pdf

[30] Scottish Human Rights Commission, *Equality and Human Rights Impact Assessment*. Available at: https://eqhria.scottishhumanrights.com/eqhriahome.html.

[31] The ALLIANCE, *Scotland's House of Care*. Available at: https://www.alliance-scotland.org.uk/health-and-social-care-integration/house-of-care/#expanded

[32] The ALLIANCE, *Community in Action*. Available at: https://www.alliance-scotland.org.uk/blog/case_studies/#area_of_work=community-in-action

[33] *Ibid.*

[34] The ALLIANCE, *Links Worker Programme*. Available at: https://www.alliance-scotland.org.uk/in-the-community/national-link-programme/.

[35] Scottish Government, *The Impacts of COVID-19 on Equality in Scotland* (Sept. 2020), available at: https://www.gov.scot/binaries/content/documents/govscot/publications/research-and-analysis/2020/09/the-impacts-of-covid-19-on-equality-in-scotland/documents/full-report/full-report/govscot%3Adocument/Covid%2Band%2BInequalities%2BFinal%2BReport%2BFor%2BPublication%2B-%2BPDF.pdf; The Lancet, *Editorial: understanding long COVID: a modern medical challenge* (August 2021). Available at: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)01900-0/fulltext#articleInformation; Ali Howard, University of Glasgow News, *Poverty linked to higher risk of COVID-19 death, study suggests*. Available at: https://www.gla.ac.uk/news/archiveofnews/2020/december/headline_767449_en.html.

End of document.