Research Report for COVID-19 Public Inquiry: Corrected Draft, May 2022

Professor Colin McKay (note 1), Professor Elizabeth McKay (note 1), Professor Jill Stavert (note 1), Dr Jennifer Murray (note 1), Lucy Johnston (note 1), and Aimee Macdonald (note 1)

Note 1: Edinburgh Napier University, School of Health and Social Care.

Author Note

We have no known conflict of interest to disclose. Correspondence concerning this report should be addressed to Professor Colin McKay, Edinburgh Napier University, School of Health and Social Care, Sighthill Campus, 9 Sighthill Court, Edinburgh, EH11 4BN. Email: **C.McKay@napier.ac.uk**

Disclaimer:
This report was commissioned by the Scottish Covid-19 Inquiry as introductory scoping research. It was written to assist the inquiry with its planning process about the shape and direction of its investigation, and is published in the interests of transparency. The inquiry is grateful to the author[s] for their work. The inquiry is an independent body, and will be carrying out its own investigations to fulfil its terms of reference. The introductory research represents the views of those who wrote it, and nothing in it is binding on the inquiry. The introductory research is one of many sources which will be considered by the inquiry during the course of its investigation.

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1. Introduction to the Report

This report seeks to introduce the key areas of recommended investigation for the Scottish Covid-19 Inquiry in the context of the impact of responses to the pandemic on health and social care. In doing so it will identify key events, the presence or absence of legal frameworks, the main bodies or persons involved, relevant research papers and publications, and areas for further investigation. Our focus is on disability because of its significance to the provision of health and social care. We have not had time to examine any differential impact on all protected characteristics, including race and sex, but it is important that this should also occur. For the sake of clarity, our reference to 'disability' refers to physical and mental disability, the latter including mental illness, learning disability, autism, dementia, acquired brain injury and other related conditions.

Our research has been conducted using a human rights lens. We are all entitled to enjoy human rights on an equal basis in all situations and a state's commitment to fulfilling its international human rights obligations is particularly tested during times of emergency such as the Covid-19 pandemic. This applies to the full range of a person's civil, political, economic, social and cultural rights.

The rights to life and to be free from inhuman or degrading treatment cannot be limited under any circumstances. However, international human rights treaties allow states to deny the exercise of other rights during national emergencies provided this is lawful, proportionate and necessary only to the extent that the emergency requires this.

These rights requirements apply as much to the provision of health and social care as elsewhere. Our investigation therefore concentrates on rights identified in the European Convention on

Human Rights (ECHR) and the UN Convention on the Rights of Persons with Disabilities (CRPD). It should be noted that neither of these treaties allow for the presence of disability to justify the denial of rights. In particular, the CRPD, which is currently very influential in Scotland and we understand will be incorporated into its legal framework in due course, emphasises that persons with physical and mental disabilities are entitled to enjoy the full range of rights on an equal basis with others, that support must be provided where necessary to ensure this, and that disability must never justify the denial of human rights.

In this report we start by explaining key elements of a human rights-based approach to rights during an emergency, rights that were particularly engaged in health and social care and the human rights framework in Scotland. The report then continues to look at the specific issues of admission and discharge to registered care homes, the Care Inspectorate's oversight and role, investigations of care homes, prioritisation in the delivery of treatment (notably ethical and clinical guidance provided and the role of advance care planning and DNACPR), decision-making on the front line of health and social care and lived experience of the pandemic.

2. The Human Rights-Based Approach to Rights During an Emergency

Key Messages

Academic and grey literature is currently limited. The evidence to date suggests:

- The rights of persons with disabilities may have been disproportionately, and sometimes unlawfully, impacted in various instances across health and social care provision.
- Covid-19 exacerbated challenges health and social care provision was already experiencing pre-pandemic.
- Unintended consequences of measures adopted to protect life and health may have resulted in actual and experienced rights being limited by persons with disabilities.
- A lack of timely, or confusion over, guidance amongst those working in health and social care.
- A lack of data to enable effective and thorough investigation and understanding of the impact of measures to address the pandemic and accountability for this across health and social care provision.
- This requires further investigation.

Key Elements of Human Rights-Based Approach

Various emergency legislative modifications were made, and guidance was issued, to address potential staffing and other resourcing challenges resulting from the pandemic and to ease processes to allow, where necessary, for individuals' health and social care needs to be properly met. These reduced certain safeguards but there remained an obligation on health and social care services to adhere to international human rights standards.

Rights Engaged During Pandemic in Health and Social Care

Rights that were particularly engaged during the pandemic in health and social care settings were those to life (**footnote 1**), to liberty (**footnote 2**), respect for private and family life/autonomy/to exercise legal capacity (**footnote 3**), freedom from inhuman or degrading treatment (**footnote 4**), to personal physical and mental integrity (**footnote 5**), to a fair hearing/access to justice (**footnote 6**), to the highest attainable standard of physical and mental health (**footnote 7**) and community living (**footnote 8**). All these rights must be enjoyed without discrimination based on a particular characteristic including but not limited to physical or mental disability (**footnote 9**). By 'mental disability' we mean mental illness, personality, learning disability, autism, dementia, acquired brain injury and other related conditions (**footnote 10**). We have focused on the protected characteristic of disability in our analysis because of its significance to the provision of health and social care. Any differential impact on other protected characteristics, such as race and sex, should also be examined but we have not had time to analyse these.

Human Rights Framework in Scotland (**footnote 11**)

The European Convention on Human Rights (ECHR) is embedded in the UK (including Scottish) legal framework by the Human Rights Act 1998, requiring public authorities to give effect to its rights and allowing for such rights to be enforced through national courts and tribunals (**footnote 12**). The ECHR purchase is even greater in Scotland where non-compliant devolved legislation and policy is unlawful and thus unenforceable (**footnote 13**).

Other international human rights treaties which the UK has ratified also inform the implementation of Scottish health and social care law, policy and practice. Importantly, the influence of these treaties extends beyond civil and political rights, such as those mainly identified in the ECHR, to include their social, economic and cultural rights; allowing for the rights of individuals to be considered in their wider health and social care and societal context. Such treaties notably include the Convention on the Rights of Persons with Disabilities (CRPD), and also the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and its Optional Protocol, the International Covenant on Economic Social and Cultural Rights, and the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment.

The rights identified in these treaties are currently not enforceable within Scotland but, pending the Scottish Government's stated proposal that it will introduce legislation to achieve such enforceability, they are nevertheless influential. For example, proposed Scottish law and policy must not place the UK in breach of its international obligation, which includes the duty to comply with human rights treaties under international law, and can be prevented by the UK Government (**footnote 14**). In addition, ECHR jurisprudence, which must be followed in Scotland, should follow United Nations human rights treaties as a higher source of international law.

Rights Restrictions During Emergencies

Where ordinary legislation continues to apply during an emergency it must not be interpreted or implemented as if emergency measures are in place. Moreover, even where the option to use emergency measures is available, they should only be used proportionately and only to address the impact of the stated emergency. Any restrictions of rights must be

authorised by law, necessary and proportionate, such proportionality crucially including non-discrimination. Indeed, UK and Scottish governments recognised this when introducing the Coronavirus and Coronavirus (Scotland) Bills each confirming that the Covid-19 measures would only be invoked if absolutely necessary (**footnote 15**) and both resultant Acts contain sunset and review clauses (**footnote 16**).

Article 2 ECHR and Article 11 CRPD are clear that the state has an obligation to protect life and to take all necessary measures to ensure the protection and safety of persons, including those with disabilities, in emergency situations. They acknowledge that states may introduce measures in legislation, policy and practice to address emergencies which reduce human rights safeguards. They are clear that the rights to life (which includes the state obligation to both protect life and to adequately investigate deaths of persons who fall within the care of the state) or to be free from torture and inhuman or degrading treatment are always absolute and untouchable even in emergencies (**footnote 17**). Other rights, however, such as the right to liberty, respect for private and family life/autonomy/to exercise legal capacity, to a fair hearing/access to justice, to the highest attainable standard of physical and mental health and community living may be proportionally limited.

As mentioned, non-discrimination is an essential component of proportionality. Article 15(2) ECHR requires that emergency measures are '…not inconsistent with its other obligations under international law.' This importantly includes the CRPD which both reinforces and expands the ECHR non-discrimination message and emphasises that the existence of a disability or related impairment must never justify a lower level of rights enjoyment (**footnote 18**). States must ensure that the effect of restrictions, even if applied to everyone, do not disproportionately adversely impact on persons with disabilities (**footnote 19**).

In order to overcome such inequalities, the CRPD requires the proactive support of persons with disabilities to achieve this through, for example, supported decision-making, reasonable accommodation and universal design (**footnote 20**) and also active consideration of how inequalities may be overcome.

The Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility have stated that these principles apply both during and outside of emergencies (**footnote 21**). No rights must therefore be limited to such an extent that an individual with mental disability or capacity issues is given fewer legal and procedural safeguards or a lower standard, of support, care and treatment than others. Additionally, whilst, of course, the right to life is particularly important – including the state's positive obligation to protect life and to take appropriate operational measures in order to achieve this - this needs to be carefully and proportionately balanced with respect for other rights. Protecting the right to life cannot of itself justify overriding the need to provide a legal basis for limiting the rights to liberty and respect for private and family life (autonomy).

The fulfilment of Article 12(3) CRPD, which places a duty on states to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (supported decision-making), is vital if all persons with mental disabilities are to make their voice heard in health and welfare decisions on an equal basis with others. Such support may, of course, take many different forms but may include advance planning. It may also be found in peer, family or professional support, independent advocacy clearly and appropriately communicated information and, of course, in welfare powers of attorney and other forms of advance planning (**footnote 22**).

3. Admission and Discharge to Registered Care Settings

Key Messages

- Large numbers of people were transferred from hospital to care homes in the early stages of pandemic – until 21 April 2020 without being tested for COVID.
- This was done more quickly and on a different scale to previous practice in discharging patients once they no longer required hospital treatment.
- The extent to which this contributed to COVID spreading in care homes is unclear, but has not been ruled out.
- The extent to which patients and families had any effective say in this process is unclear.
- There is evidence of homes feeling pressured into accepting patients.
- There is evidence that some patients who lacked legal capacity were transferred without the proper legal processes.
- There were justifiable fears early on of the NHS being overwhelmed.
- There should be an examination of the reasons for the transfers and whether they reflected a prioritisation of the NHS over care homes, or a lack of understanding of the care home sector, and how far the needs and rights of patients were taken into account.

Paragraph g) of the Terms of Reference includes consideration of 'in care and nursing homes: the transfer of residents to or from homes.' The stakeholder consultation stated that 'a priority for many respondents was for the Inquiry to investigate the rationale for the decision to discharge untested patients from hospital into the community, and specifically into care homes …

and the response of the Scottish Government and care home owners as the harm from this decision became evident'.

Issues raised by public and stakeholder responses during the consultation prioritised

- Establishing the timing of the availability of data and intelligence from various sources used by SG to inform the decision to discharge untested patients
- When and from what sources (including reports from other countries' experiences) the SG knew of the scale and specifics of the impact on care home providers and the harm to residents
- Given the speed and increased numbers of people discharged in February and March 2020 to care homes to determine the extent to which general health and safety protocols surrounding discharge were followed.

In addition to the wisdom and impact of the discharge to care homes, we suggest that the lawfulness of the process should be investigated, particularly where individuals did not consent to the move or lacked capacity to consent.

Right to Life

The moving of persons who might have been, or were, infected with covid-19 calls into question whether the state's duty to protect life and health during an emergency was fulfilled in regard to existing residents. As already stated, the state's obligation to protect life, even in emergencies, is absolute and measures to ensure the right to health is respected are subject to proportionate limitation. Of course, this must also be balanced against the rights of vulnerable patients in hospital who lacked capacity and who were at risk of covid-19 infection if not moved to alternative settings.

Delayed Discharge: Background

There has long been a policy imperative for elderly or vulnerable patients whose condition has stabilised to be discharged from hospital as quickly as possible (**footnote 23**). Wherever possible, they should be discharged to their own home, but in some cases it is impossible to provide the necessary support, and the patient may be discharged to a registered care home or nursing home, either temporarily or permanently.

Despite this policy imperative, which was one of the drivers behind health and social care integration, there were still significant numbers of patients prior to the pandemic whose discharge from hospital was significantly delayed (**footnote 24**).

It is generally accepted that a well run care home provides a better environment to support someone's rehabilitation than a hospital ward, when they no longer need acute medical care. That said, it might be questioned whether this applied to the same extent if being discharged to a care home under lockdown conditions, with residents largely confined to their rooms.

Legal Authority to Transfer Patients

Transferring a person against their will to a care home is potentially unlawful and a breach of Article 5 of the ECHR. At the same time, there is no right to stay in a hospital if this is judged by the NHS to be clinically unnecessary.

There is Scottish Government guidance as to how disagreements regarding discharge from hospital should be

handled (**footnote 25**). We believe this was still in effect during the pandemic, but this needs to be confirmed.

Transfer of People Who Lack Capacity

There are more complicated provisions should the person lack capacity to consent, because of a condition such as dementia. This applied to a large percentage of those moved. Where the person has a welfare attorney or welfare guardian appointed under the Adults with Incapacity (Scotland) Act 2000 (AWIA), that person can consent (or refuse) on behalf of the adult.

If there is no welfare proxy, section 13ZA of the Social Work (Scotland) Act 1968 allows a local authority to move an adult who lacks capacity to a care setting.

Prior to the pandemic concerns already existed over the compatibility with Article 5 of using section 13ZA to move a person who lacks capacity to a setting where they are deprived of their liberty, in light of the absence of accompanying safeguards, notably the ability to apply to a court to challenge or authorise the legality of such deprivation of liberty (**footnote 26**).

Also relevant are an individual's right to respect for private and family life/autonomy (**footnote 27**) and what steps have been taken to ascertain the wishes and feelings of those transferred, bearing in mind the obligation under legislation and human rights standards to ascertain this, by supported decision-making where necessary. As already mentioned, the right to autonomy may be limited but only where it is lawful, necessary and proportionate, discrimination being a crucial element in determining such proportionality.

In 2014 the UK Supreme Court (**footnote 28**) set out a test for whether a placement constituted a deprivation of liberty, even if the adult did not object: is the person subject to continuous supervision and control and is the person free to leave? The precise effect of this has been widely debated (**footnote 29**), but it is undoubtedly the case that Article 5 would be engaged in many care home placements from hospital, particularly with the restrictions in the homes imposed as a result of the pandemic.

Concerns had been expressed about the practical implications of this when no welfare attorney was in place, since appointing a welfare guardian can take several months. In 2014 the Scottish Law Commission proposed changes to the AWIA (**footnote 30**), and the Government consulted on these proposals in 2018, but no changes have been made (**footnote 31**). The matter is now being considered by the Scott Review of Mental Health Law.

In 2020 the Equality and Human Rights Commission raised a legal action against NHS Greater Glasgow and Clyde and a care home owner for moving people from hospital to a care setting without legal authority (**footnote 32**).

Emergency Legislation Changes to the Powers of Local Authorities

The Coronavirus (Scotland) Act 2020 (**footnote 33**) included a provision amending s13ZA to remove the requirement on local authorities to take account of the views of the adult and guardians, attorneys, named persons and primary carers (**footnote 34**) and permitting section 13ZA to be used even if a guardian has been appointed, thus allowing for persons with incapacity to be moved possibly against their wishes. The stated aim was to put provisions in place to ensure the safety of the adult, for instance where they might be in an acute hospital

ward which was expecting a large influx of coronavirus patients, putting the adult at risk (**footnote 35**).

Ultimately this power was never brought into force, meaning that the legal and human rights requirements to authorise a move to a care home remained as they were before the pandemic. In short, these include:

- That decisions should be informed by the risk to life both of that patient and of any person who might be affected by coming into contact with them
- That the views and wishes of the person and, where appropriate, their proxy and family must be established and given due weight
- That consent or lawful authority must be obtained to the move
- That protocols for resolving disputes should be followed, where necessary.

Timeline of Events

Although the law did not change, practice certainly did. In the early months, there was a substantial and rapid process of moving people from hospitals to care homes. The first three two-monthly Coronavirus Acts reports to the Scottish Parliament noted, for example, that delayed discharge was reduced by 59% between 4 March 2020 (the baseline date) and 18 May 2020, by 45% between 4 March 2020 and 23 July 2020 and 36% between 4 March 2020 and 9 September 2020 (**footnote 36**).

Until 21st April, patients were generally not tested before discharge.

Public Health Scotland provided the following information in April 2021 (**footnote 37**):

"There were 3,595 discharges from hospital to a care home between 1 March and 21 April. The majority (82%) in this earlier period were not tested for COVID-19, in-keeping with clinical guidance which restricted testing to those with symptoms of infection. Of the 646 who were tested, 75 received a positive result while in hospital."

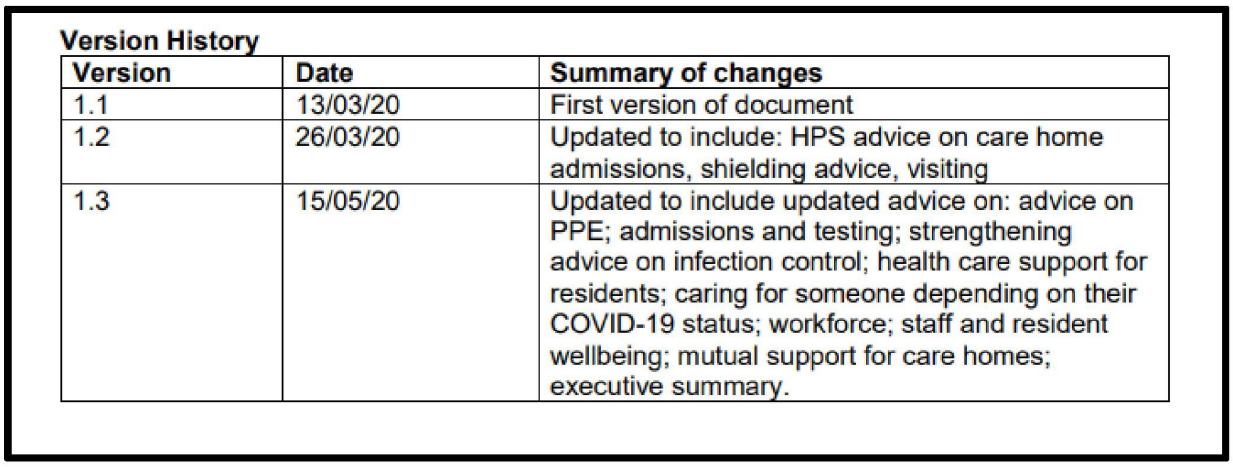
For the period between 1 March and 31 May 2020, it reported 5,198 discharges from NHS hospitals to care homes (4,804 individuals).

17 March 2020: the Cabinet Secretary for Health and Sport announced (**footnote 38**) a nationwide aim to increase NHS bed capacity from 13,000 by 3,000 and a goal of reducing delayed discharge by at least 400 by the end of March 2020. It was stated that specific advice on admission to care homes had been issued and HPS has published specific guidance for infection prevention and control in social or community care and residential settings.

24 March 2020: the national lockdown began.

26 March 2020: COVID-19 Clinical Guidance for Nursing Home and Residential Care Residents was updated to version 1.2, superseding that of 13 March 2020 1.1. The version history is shown in Figure 1.

Figure 1. Version History for COVID-19 Clinical Guidance for Nursing Home and Residential Care Residents



Version History

Version	Date	Summary of changes
1.1	13/03/20	First version of document
1.2	26/03/20	Updated to include: HPS advice on care home admissions, shielding advice, visiting
1.3	15/05/20	Updated to include updated advice on: advice on PPE; admissions and testing; strengthening advice on infection control; health care support for residents; caring for someone depending on their COVID-19 status; workforce; staff and resident wellbeing; mutual support for care homes; executive summary.

[Figure 1 shows a table containing the following text:

- **Version:** 1.1
  Date: 13/03/20
  Summary of changes: First version of document

- **Version:** 1.2
  Date: 26/03/20
  Summary of changes: Updated to include: HPS advice on care home admissions, shielding advice, visiting

- **Version:** 1.3
  Date: 15/05/20
  Summary of changes: Updated to include updated advice on: advice on PPE; admissions and testing; strengthening advice on infection control; health care support for residents; caring for someone depending on their COVID-19 status; workforce; staff and resident wellbeing; mutual support for care homes; executive summary.

End of Figure 1]

The guidance issued on these dates is no longer available to view. What is accessible is the "New admission/transfer form" that was appended to the guidance (**footnote 39**). The stated purpose and guidance on testing pre-discharge was given:

"The purpose of this document is to provide a means for safely handing over a resident and identifying that where possible they have been deemed clinically safe for transfer. Swab testing for coronavirus is not recommended for patients who do not have symptoms or are not unwell and so a clinical judgement on an individual's safety to be admitted into a nursing or residential home environment is key".

27 March 2020: DG Health and Social Care wrote to all partnerships asking for a reduction in that total of 400 (**footnote 40**). When this was achieved, he wrote again to partnerships on 27 March seeking a further reduction of 500 by the end of April.

16 April 2020: Chief Nursing Officer wrote to Chief Executives advising that Scotland will move to a system where any symptomatic patient in a care home will be clinically assessed and, where appropriate, offered testing for COVID-19.

"This is a departure from existing infection management procedures of only testing initial cases in order to establish whether an outbreak has occurred. We are making this change in acknowledgement of the unprecedented pressures on our care homes, in order to offer this additional level of reassurance during what will be a deeply unsettling time for both our vulnerable elderly population and their families."

21 April 2020: The Scottish Government introduced a new policy that required patients to have two negative Covid tests

before leaving hospital, and all new care home admissions to be isolated for 14 days.

30 April 2020: A paper on hospital and care home testing was discussed at the Scottish Government COVID-19 Advisory Group meeting (**footnote 41**). Recommendations included:

"8.4 Consider evaluation of COVID-19 screening of admissions to care homes. The discharge testing from hospitals and other admission screening intelligence in care homes should be used to inform an evaluation of this. Those admitted still required to be quarantined for 2 weeks and so the value of this screening, and any unintended consequences at the system level, need evaluated too. The priority for testing is currently for incident and outbreak management requirements."

Reviewing What Happened

4 June 2020: The Committee took evidence from the Cabinet Secretary for Health and Sport on the issue of COVID-19 in care homes (**footnote 42**). By this time, the number of deaths from Covid in care homes was higher than in hospitals (**footnote 43**).

Ms Freeman was pressed on decisions early in the pandemic to push to discharge patients to care homes without a requirement that they be tested. Her position can be summarised as:

- It was right to seek to move delayed discharge patients from hospitals to care homes, both because this was better for them in terms of their general care needs and because of the need to free up hospital beds in anticipation of a wave of patients

- Transitions from hospital should be 'screened clinically' to ensure that patients were not transferred inappropriately
- Care homes should already be familiar with infection control procedures, and were given additional guidance on isolating residents in their rooms and reducing contact
- At that time, there was not a consensus in favour of testing asymptomatic patients.

The Cabinet Secretary said that **"guidance on 13 March was very clear about undertaking the mutual clinical risk assessment before a person was discharged from hospital to a care home setting."**

A question arising from this may be how 'mutual' this felt to the care home, and how far they felt qualified or entitled to challenge the desire of the NHS to discharge patients.

29 July 2020: Health and Social Care Scotland published a report on 'lessons learned' from reducing delayed discharge and hospital admissions (**footnote 44**).

This took a largely positive perspective of a major joint effort to expedite discharge in a way which had not happened before the pandemic. Barriers to even faster discharge included 'confusion over changing guidance on testing', 'alarmist' reporting of care home deaths, coupled with the fear from care home providers of taking infectious people from hospital, the announcement of police investigations into deaths, and the adults with incapacity legislative framework. It said:

"There was some reluctance from families and care homes to admit people into them before testing became available. There was a lot of time spent working through and addressing these concerns. Testing has been helpful as it has given some reassurance about allowing people to be admitted. In some areas, testing was introduced locally

ahead of national roll out. With the benefit of hindsight, it would have been helpful to have been able to introduce testing earlier."

There is little discussion on whether family concerns may have been justified.

16 August 2020: the Sunday Post published a news story based on FOI requests that stated that at least 37 patients were transferred to care homes after a positive test (**footnote 45**).

18 August 2020: the Cabinet Secretary for Health and Sport commissioned Public Health Scotland to report on people who were discharged from an NHS Scotland hospital to a care home between 1 March and 31 May 2020. The report was initially published on 28 October 2020.

4 November 2020: Jeremy Balfour MSP asked the following question in Parliament (**footnote 46**): **"To ask the Scottish Government when the First Minister first became aware of hospital patients who had tested positive for Covid-19 being discharged to care homes."**

The discussion included concerns raised by Monica Lennon MSP about a media report on 19 April of a care home 'having to accept residents' and references to the Sunday Post story of 16 August. The Cabinet Secretary repeated an earlier statement from the First Minister that prior to the Sunday Post story, neither Scottish Ministers nor officials had information on the results of Covid tests prior to discharge (**footnote 47**).

21 April 2021: A revised version of the PHS report on discharges from NHS hospitals to care homes was published (**footnote 48**). The key conclusions given from the statistical analysis were reported as:

"Hospital discharge is associated with an increased risk of an outbreak when considered on its own. It is important to note that after accounting for care home size and other care home characteristics, the estimated risk of an outbreak due to hospital discharge reduces. No statistically significant association was found between hospital discharge and the occurrence of a care home outbreak. However, due to the uncertainty observed, we cannot rule out a small effect, particularly for those patients who were discharged untested or discharged positive."

20 May 2021: the Mental Welfare Commission published a report on decision making for people who lacked legal capacity during the period 1 March 2020 to 31 May 2020 (**footnote 49**). It set out a range of concerns, including a lack of clarity on capacity assessments and the law, and 20 moves that took place without legal authority. It made 11 recommendations for improved practice.

Areas for Further Investigation

There remains concern and conflicting accounts around the degree to which the motivation for discharging people to care homes in the Spring of 2020 was in fact primarily driven by a tacit prioritisation of NHS capacity. To some extent this has become an 'assumed' truth – with even international media reporting it as fact.

We have not had time to investigate the response in other countries, but it appears the English experience may be close to that of Scotland, with the NHS being told on 17 March to 'urgently discharge' patients to free up beds, with testing only being mandated on 15 April (**footnote 50**).

The 29 July 2020 'lessons learned' report stated that "COVID-19 has undoubtedly proved to be the stimulus needed to make significant reductions …in delayed discharge numbers".

The coinciding of a call from the Cabinet Secretary to increase NHS capacity with a new drive to reduce delayed discharge is for some reinforcing the concern that NHS capacity was prioritised over social care providers and the people they support. Public Health Scotland monthly data analysed by Professor Bell of Stirling University found what he described (**footnote 51**) as a **"remarkable turnaround between February and March 2020. The number of delayed discharges fell from 1627 to 1171 during this period, an overall reduction of 28%."** and that **"These data provide clear evidence of the imperative to clear hospitals prior to the pandemic"**

If there was indeed a prioritisation of the NHS over the care sector, a number of possible reasons could be investigated, including

- The political salience of the NHS, including the fact that it is directly accountable to the Scottish Government, whereas the care sector is largely independent
- The concerns that the NHS would be overwhelmed by a disease about which little was still known
- A possible lack of understanding of the nature of care homes and the risks of transmission within them, perhaps because care homes themselves were at one remove from the key decision makers.

Questions of transparency are also perhaps still being fuelled by the unavailability of versions 1.0 and 1.1 of the clinical guidance issued. There is value in unpicking the relationship between the literal interpretation of guidance and how it was enacted on the frontline and experienced by those discharged

and the receiving services; for example the reported 'pressurising' of care homes to accept admissions and the actual discharge and admission protocols in place at the time.

Discharging and receiving services should be asked to evidence how required health and safety protocols surrounding discharge were followed from late February to end of April. Below is a quote from a Care Home Manager who provided a response to the Committee Inquiry session exploring the impact of COVID-19 on care homes in June 2020:

"I felt pressure from Local Authority at the beginning to take in new admissions from hospital and the community. I did not take from hospital but did from the community. There was no mention of testing or monitoring prior to admission. At no time was there even a mention to the risks of my permanent residents with new admissions coming into the home. The priority was again to get beds empty for the hospital which was never a priority before when my care home was sitting with empty beds."

Further examination is needed of the specifics of guidance and protocols surrounding discharge to care homes from 17 March to 21 April 2020. Many care homes had made unilateral decisions in early March to 'lockdown' to both new admissions and visitors and their rationale for this should be heard and investigated in comparison to the evidence informing SG decisions and timing of guidance and the way in which national guidance was implemented on the ground. There would be value in taking evidence from secondary care clinicians and other ward-based staff, social workers involved in establishing discharge packages and destinations and receiving care homes.

It would also be important to hear from residents and their families, about whether and how their views were considered,

and whether informed consent was given to discharge from hospital to care settings.

The evidence supporting this decision and the key policy drivers at a national level for the decision to discharge patients to care homes **without testing** should be identified. It has been suggested that only 'hindsight' is an explanation for this decision. Perhaps of note is the First Minister and the then Health Secretary subsequently stating that the "right precautions had not been taken when elderly people were being discharged from hospital to care homes" (**footnote 52**). Understanding this may only be possible if a day by day account of the intelligence available and used by the SG to inform decisions at this critical time is produced.

In order to establish whether or not there could have been a more effective decision made a detailed unified timeline could be constructed using the various (and currently conflicting reports and opinions) sources of evidence available (reviews, media reports, parliamentary questions and FOI request) and any records of issues raised by providers and regional HSCP and NHS trusts of (a) dates the impact of the decision and possible harm was made known to SG and (b) the way in which this evidence and information was utilised in the response by SG.

In relation to the questions of legal authority to transfer patients, it may be helpful to investigate whether the MWC recommendations are being implemented, and whether there continue to be issues regarding ensuing that transfers from hospital to care settings are timely, while respecting human rights.

4. Restrictions on Residents and Families in Registered Care Settings

Key Messages

- Care home residents were subject to severe restrictions for many months, including bans on visits, being unable to leave the home, and being cared for primarily in their room.
- This caused great distress and is likely to have contributed in a number of cases to cognitive and emotional decline and even death.
- The need for some restriction was understandable, given the vulnerability of care home residents and the large number of deaths in the sector.
- However, the legal basis of the restrictions is unclear, and there was arguably discrimination in respect of this group, compared with the rest of the community.
- There is little evidence in the early months of consideration of the human rights of residents and their families, including the proportionality of measures generally or in individual cases.
- Matters improved from autumn 2020, although the guidance on outbreaks meant many residents still faced severe restrictions for many weeks.
- In early 2021, there was evidence of a more human rights based approach and greater involvement of relatives in producing more balanced guidance.
- The proposed Anne's law highlights the need to treat family members as essential caregivers in the same manner as staff are treated.

Legal and Human Rights Considerations

The stakeholder consultation highlighted a range of restrictions imposed on residents and their families, including bans or restrictions on visiting, and other restrictions on contact. Respondents sought scrutiny of policy decisions that were inconsistent and had a detrimental impact on residents and families, and specifically the rationale and legal basis for the length of care home restrictions, even when other areas of social life had reopened, the potential deprivation of human rights, and particular concerns about restrictions at the end of life.

As discussed, the state's obligation to protect the right to life of all persons during emergencies is absolute (**footnote 53**). At the same time, care home residents (and those wishing to visit them) have the right to choose how one lives and who one spends time with. Such rights may be limited but proportionality governs the extent to which such limitation is both lawful and compatible with human rights requirements (**footnote 54**).

Similarly, deprivation of liberty (**footnote 55**) can manifest in many ways and can include a restricting of social contact and the right to be liberty must only be proportionately restricted. The rights of those in care home and their visitors should not have been disproportionately impacted during the pandemic (**footnote 56**). Any restriction of visiting rights must therefore have been kept under constant review throughout, assessed on an individual basis and in light of the prevailing situation regarding the pandemic in Scotland with clear and updated guidance being provided.

The WHO ad hoc Covid-19 Infection and Control Guidance Development Group agreed that visiting should be supported provided prevention and control measures are in place to prevent the risk of visitors contributing to infection transmission in care homes (**footnote 57**).

So far as we can establish, there were no new statutory provisions governing care home visiting during the pandemic, and the restrictions appear to have been put into effect through guidance from Scottish Government and Public Health Scotland.

The Coronavirus (Scotland) (No 2) Act 2020 Schedule 1 Part 7 gave Health Boards power to direct care home managers to 'take such steps as may be specified' if there was a material risk to health of people at the home. However, this appears to be related to measures such as infection control. It is not clear that this would operate on the rights of individual residents, and the power rests with Health Boards, not the Scottish Government.

This is, in itself, significant, in that it brings into question what the legal basis was for some of the restrictions, particularly those raising Article 5 issues of deprivation of liberty.

In effect, the guidance was policed by the monitoring and supervision of care homes by Government and its agencies, while the homes imposed it on residents and families through the contractual nature of their relationship with the resident. This is in striking contrast to the complex statutory framework which was put in place to authorise lockdown restrictions on everyone else, and in itself suggests that care home residents may not initially have been construed as rights bearers in the same manner as the rest of society.

To some extent, the restrictions in homes were analogous to quarantine but, again, the powers available to Government under Schedule 19 of the Coronavirus Act 2020 do not appear to have been used to authorise the detention or isolation of residents.

Much of the discussion around restrictions focuses on restricting visiting by families, which raises clear Article 8 issues, and questions of proportionality. Even more problematic legally is the fact that many residents were not allowed to leave the care home during the pandemic (or even their room in some cases), which is clearly a deprivation of liberty requiring lawful authority under Article 5.

Development of Government Guidance

Two sets of guidance were issued, from Scottish Government and Health Protection Scotland. HPS has an archive containing most of the versions of their guidance (**footnote 58**). We have not yet been able to find a complete archive of the SG guidance. Key developments are summarised below.

13 March 2020: Version 1.1 of SG guidance for care homes was issued. This was updated on 26 March.

21 April 2020: Version 1.0 of 'COVID-19: Information and Guidance for Care Home Settings' from HPS. This said:

"2:13 Visitors… This advice will significantly limit face-to-face interaction with friends and family in residential settings. Visitors should be restricted to essential visitors only. Efforts should be made to allow loved ones of a resident receiving end of life care to visit. … Visiting may be suspended if considered appropriate by the facility. Consider alternative measures of communication including phoning or face-time."

15 May 2020: An updated version of SG clinical and practice guidance for care homes was issued (**footnote 59**):

"8.7 Visiting policy – As per HPS guidance, visiting must be restricted to essential visitors only. Essential visitors include appropriate health and care staff based on resident need, for a person receiving end-of-life care, to support someone with a mental health issue such as dementia, a learning disability or autism where not being present would cause the resident to be distressed. … It is expected that homes will use sensitivity in balancing the risks to individuals with the need to show compassion in certain situations. Alternatives to in-person visiting should be explored, including the use of telephones or video calls."

This guidance was updated several times, apparently without any significant change to visiting restrictions until August 2020.

In the debate in the Health and Sport Committee on 4 June 2020, the Cabinet Secretary said that the Guidance from 13 March was that 'communal activity should be reduced by 75%, with residents remaining in their rooms as much as possible, and that only essential visitors should be allowed, with particular exemptions for end-of-life care and residents with dementia… The current easing of lockdown measures for the general population does not have a direct impact on the guidance that is offered to care homes.' She also indicated a willingness to look at mitigating the impact of the guidance on residents with dementia, for example by allowing them more time out of their rooms.

4 August 2020: V.1.6 of HPS guidance linked to revised SG visiting guidance (which we cannot find): **"The Scottish Government has produced COVID-19: adult care homes visiting guidance which outlines a staged approach to the re-introduction of extended visiting to adult care homes. Facilities must review their visiting policy in light of this."**

17 September 2020: V1.7 of HPS guidance:

"The Scottish Government has produced COVID-19: adult care homes visiting guidance which outlines a staged approach to the re-introduction of extended visiting to adult care homes. The phasing allows for increased numbers of visitors, frequency of visits and outdoor and window visits progressing to indoor visits over time. A staged process for a return to communal life will be possible in the next phase, providing there is no ongoing outbreak …This guidance on visiting takes a precautionary approach in relation to care homes where there has been infection and advises that 28 days must elapse from the last COVID-19 case."

The restrictions on visiting during an outbreak proved a problem– the prevalence of Covid meant that for some homes, particularly larger ones, there would always be someone testing positive, so restrictions were repeatedly extended.

16 December 2020: Jeane Freeman answered a PQ saying: **"Guidance was … most recently updated on 4 December for care homes over the festive period. It reiterates that care homes should support indoor visiting and asks for homes to support such visits generously and sympathetically, whenever it is safe to do so. … In order to increase confidence around visiting and add another layer of protection we are extending asymptomatic testing for designated visitors as an added measure."**

19 December 2020: V2.0 of HPS guidance said that suspension of visiting following an outbreak was reduced from 28 to 14 days.

The most substantial relaxation was on 21 February 2021, when the Government published its 'Open With Care' guidance (**footnote 60**). This made reference to human rights:

"Respect for human rights – local visiting policies should take account of the European Convention on Human Rights (ECHR), and in particular Article 8, which provides a right to respect for private and family life. Whilst it is important that any visiting policies take account of the evolving evidence about the harm posed from the virus, these need to be carefully balanced with the evidence about the positive impact on health and wellbeing from seeing family and loved ones has on residents in considering what is necessary, justified and proportionate."

It appears that this guidance was issued after more intensive engagement with the care home sector and particularly with representatives of relatives than was the case with previous guidance, and was issued with a considerable amount of support for care homes including posters, workshops etc. It stated:

"Care homes should work to increase the frequency and duration of meaningful contact with residents. In the first instance, resuming indoor visiting should involve up to two designated visitors weekly, visiting one at a time. This should however be seen as the minimum starting point with consideration given to increasing the number of visitors and frequency of visiting, as and when the care home judges it is safe to do so, with expert advice and support from oversight arrangements where appropriate. Some care homes for younger adults may be able to increase opportunities for visiting more quickly than other care homes as their population has a lower COVID risk profile."

17 May 2021: Additional guidance issued on outings, with a general presumption that outings for residents should follow the same restrictions as those affecting others in the local area.

15 September 2021: Guidance issued encouraging homes to allow residents to choose a named person who could continue to visit during an outbreak in the home.

10 December 2021: Guidance issued during the Omicron outbreak said:

"We ask that care homes use the protective measures summarised in this letter to continue to facilitate and support residents to meet in person with their family and friends. As detailed in previous communications the expectation is that visiting should have increased from the minimum of twice weekly, to more routine normalised visiting. unless an outbreak is suspected or has been declared."

The impact of the restrictions

There is substantial evidence of the harm and distress caused to residents and their families by the restrictions imposed in care homes. This includes concerns that, particularly for people with dementia, being unable to maintain contact with their family exacerbated cognitive and emotional decline, potentially hastening their death.

Some of these stories can be found in the Petition to the Scottish Parliament PE01841 (**footnote 61**) to allow designated visitors into care homes, followed by the development of 'Anne's law'. See, in particular, the responses to the Government consultation on this proposal (**footnote 62**) As an

example, the submission from Care Home Relatives Scotland said:

"Our group (current membership 2012) was established in August 2020 to support the growing number of friends and relatives, who for the previous 6 months had been totally denied any opportunity for meaningful contact with their loved one in residential care. The outpouring of anxiety, guilt, grief, sadness, anger, despair and heartbreak has been immense. The voices of the residents in care sadly remained silent and unheard.

- **Daughters were forced to watch from a distance as carers held a dying mother's hand**
- **Elderly husbands peered through windows to see their distressed wife reaching out for a familiar touch.**
- **Children and young adults were left distraught and with no comprehension as to why they were "abandoned" by their family.**
- **The use of prison style screens and intercom communication were cold, unfeeling and gave no comfort.**
- **IPads and online communication was impossible for the many residents with no understanding of zoom calls or facetime.**

Compared to the general population, residents within care home environments were considered at greater risk from the harms that any infection could present. This should not have legitimised the need for enforced restrictions or bans on freedoms, such as access to loved ones."

Key Questions for Investigation

We suggest the following issues merit detailed examination.

- Were human rights considerations understood and applied?
  - As we set out above, the specific human rights that were engaged were hardly mentioned by Government until February 2021, and only Article 8 was mentioned even then.
- Were the measures lawful?
  - We set out above our concern that the legal basis for the measures is unclear. Another issue that appears to have had limited consideration is the extent to which welfare guardians or attorneys may have specific authority to take some decisions on behalf of an adult with incapacity, and how this should affect restrictions?
- Were the measures clear?
  - There is some evidence of confusion in care homes, partly caused by the differing streams of guidance and frequent revisions.
  - The earlier guidance had limited references to care homes and staff being able to exercise judgement to allow visits in particular cases, but it is not clear that the homes felt empowered to do so.
  - Were homes able to get advice from local PHS/HPS and was that advice helpful and grounded?
  - Was there any advice on handling disputes or difficult issues?
  - There appears to have been no Government support or advice to residents and families until February 2021, when Alzheimer Scotland were funded to develop an Action on Rights service (**footnote 63**).
  - There was confusion on what constituted an 'essential visit', with some homes taking a very restrictive approach.

- Were some homes more restrictive than they needed to be?
  - There are suggestions that some homes operated an even more restrictive regime than guidance suggested, possibly driven by concerns about insurance and even the Crown Office investigation of deaths.
- Was there discrimination?
  - Most if not all residents were in at least one protected category under the Equality Act. Were they subject to direct or indirect discrimination, given that they were subject to restrictions which didn't apply to others who may have been equally at risk?
- What harms were caused?
  - There was a monitoring process for deaths caused by COVID but what monitoring took place of harms caused by restrictions, including distress, deterioration and death?
- Were measures justified and proportionate?
  - Was there a balance of risk against other harms, **and** against human rights?
  - What mitigations were considered, and were these practical?
  - What evidence was available, or sought, on the extent to which visits by families or residents leaving the homes for outings posed a particular risk, compared with other factors (discharge from hospital, use of agency staff etc.)?
  - In particular, how was dementia addressed, given the evidence of particular impact on people with this condition?
  - For most of the period, the guidance for care settings for younger people with disabilities was the same as for care homes for elderly people, even although they may have been at significantly lower risk from Covid-19.

- Was the way restrictions were devised sufficiently inclusive?
  - There is a notable shift in tone and approach from the publication of Open with Care; not just because the risks from infection had reduced but because there was greater involvement of a wider set of stakeholders, particularly relatives' organisations. Could and should this have been done earlier?

5. Oversight and The Role of the Care Inspectorate

Key Messages

- The Care Inspectorate's methods of inspection changed significantly, with a reduction in the normal visits.
- In May 2020, the Government gave NHS Executive Nurse Directors an oversight role in relation to care homes.
- There is evidence that some care homes felt unsupported during the pandemic, and at the same time overwhelmed by reporting requirements and frequently changing guidance.
- Concerns have been expressed by care homes and other stakeholders that social care and human rights concerns were marginalised in the interests of infection control.
- It has been suggested that the social care sector did not receive the attention it needed at the start of the crisis, reflecting a prioritisation that preceded COVID-19.

The Care Inspectorate registers and inspects a wide range of care services, including residential and nursing homes (**footnote 64**). Its website describes its role as being **"the national regulator for care services in Scotland. Care services cannot operate unless they are registered by us. We inspect services and evaluate the quality of care they deliver. We support improvement in individual services and across the care sector nationally. Where care is not good enough, we can deal with complaints and carry out enforcement action."**

Some responses during the consultation on COVID-19 Public Inquiry felt there had been a lack of support from the Care Inspectorate. The analysis report stated that "therefore, the investigation could also include the role of the Care

Inspectorate and their accountability in terms of inspections, effectiveness and oversight in care homes".

Key Events

The Coronavirus (Scotland) (No.2) Act 2020 Schedule 1 para 7 gave powers to Health Boards to issue emergency directions to care homes and for Scottish Ministers to apply to court for emergency intervention orders to enter care homes and direct and control their occupation.

17 March 2020: Suspension of routine and on-site inspections (**footnote 65**).

26 May 2020: Additional duties were placed on the Care Inspectorate as follows (**footnote 66**):

- The Care Inspectorate must lay a report before Parliament every two weeks, setting out which care homes it inspected during these two weeks and the findings of those inspections.
- Care home providers must report daily to the Care Inspectorate on numbers of deaths (suspected or confirmed COVID-19) and total number of deaths irrespective of COVID-19. The Care Inspectorate must report this information weekly to Scottish Ministers.

17 May 2020: the Cabinet Secretary for Health and Sport wrote to the Executive Nurse Directors of NHS Scotland Boards to vary their roles and responsibilities in order that they support the multi-professional oversight of care homes, by being accountable for the provision of nursing leadership, support and guidance (**footnote 67**). This variance included the responsibility to review care home safety huddle data and to identify where specific nursing support may be required and to develop and implement solutions [**to**] include clinical input to:

- Ensure that there are effective community nursing arrangements in place
- Identify where specific infection control and prevention support may be required [to] include recommendations and review re
  - Cleaning to prevent transmission and the appropriate use of PPE
  - Support the development and implementation of testing approaches …
  - Identify and support sourcing of staffing.

Joint inspection visits were instructed to be undertaken as required by the Care Inspectorate and Healthcare Improvement Scotland (HIS), working together, to respond to priorities and concerns. These arrangements to be put in place in every area in the week beginning 18 May (**footnote 68**).

A rapid review of outbreaks in four care homes reported in November 2020 the following: **"It was clear to the review team however that the process is not fully integrated, and that the methodologies employed, grading and reporting structures for CI and HIS differ; this brought inconsistency and challenges in agreeing applicable grades for one of the care homes in this review."** (**Footnote 69**)

10 June 2020: The Care Inspectorate add a new key question for care home inspections (**footnote 70**). The reason for this was given as **"In order to robustly assess care home arrangements to respond to the Covid-19 pandemic, our inspections are placing particular focus on infection prevention and control, personal protective equipment and staffing in care settings. using the answers to the 'new' question it appears that it will inform what they term "targeted inspections that are short, focused and carried out with colleagues from Health Improvement Scotland and**

Health Protection Scotland, to assess care and support for people experiencing care and support during the Covid-19 pandemic."

Accompanied by a 9-page review and scrutiny checklist this key question had three quality indicators associated with it. They are (**footnote 71**):

7.1 People's health and wellbeing are supported and safeguarded during the COVID-19 pandemic.
7.2 Infection control practices support a safe environment for both people experiencing care and staff.
7.3 Staffing arrangements are responsive to the changing needs of people experiencing care.

4 June 2020: Debate in Health and Sport Committee on the impact of COVID-19 in care homes (**footnote 72**). MSPs raised concerns over the complexity of and frequent amendments to guidance to care homes, whether the resources and powers of the CI needed to be supplemented to identify residents at risk, and the need to streamline reporting by homes.

11 June 2020: Social Work Scotland wrote to the Chief Social Work adviser to the Scottish Government to relay concerns of Chief Social Work Officers about the operation of the Enhanced Professional and Clinical Oversight Structures (**footnote 73**). The letter said: **"Although as complex and in many ways more vulnerable that the NHS, the social care sector did not receive the attention it needed at the start of this health crisis, reflecting an imbalance in prioritisation which predates covid-19."**

Concerns included that human rights were being undermined and **"professional concerns are often being marginalised in the pursuit to provide assurance on infection control."**

3 July 2020: The Scottish Parliament's Health and Sport Committee asks care providers for their experiences between March - June 2020 of the Care Inspectorate and what can be learned from these in relation to adult social care as well as its role and response during the COVID-19 pandemic.

1. **Considering the pandemic, and its impact on social care services, what role should the Care Inspectorate have in ensuring those receiving adult care and support services are better protected?**
2. **What role should the Care Inspectorate have in creating a more resilient and sustainable adult social care sector?**

The responses given to this are available on the Scottish Parliament website (**footnote 74**) however no collation or analysis could be found.

30 July 2020: Covid-19 Scrutiny Assessment Tool (SAT) announced (**footnote 75**). Described as a "trigger" tool to identify indicators of potential concerns in care homes, it was stated that from 14 August 2020 this would replace the Risk Assessment Rating (RAD) for all Care Homes (Adults, Older People, Children and Young People). Inspectors began this process from 30 July. The SAT was said to be not a risk assessment in the same way that the RAD was but to support the CI to identify what level of support and scrutiny is appropriate for a service taking account their current circumstances.

21 August 2020: publication by the Care Inspectorate providing their views and assessment of The Care Inspectorate's Role, Purpose and Learning during the COVID-19 Pandemic (**footnote 76**).

March 2021 The Care Inspectorate's report on its scrutiny and support of adult social care during the COVID-19 pandemic was published, which **"describes in more detail the scrutiny activity and support interventions we have been carrying out throughout the pandemic."** (Footnote 77)

Areas for further investigation

In relation to the Care Inspectorate's response to COVID-19 there may be value in interrogating the extent to which it acted on feedback received and recommendations made or issues arising they themselves identified, including such sources as:

- feedback which may have been reported into the centre from Inspectors out in the field
- on the 3rd of July 2020 the Health and Sport Committee of the Scottish Parliament began a consultation on the role of the Care Inspectorate. We have been unable to find a report on the consultation which closed on the 10th of August 2020, but the published consultation responses contain detailed views on the performance of the Inspectorate during the pandemic – see for example responses from Scottish Care (**footnote 78**).
- Recommendations made in the rapid review of factors relevant to the management of COVID-19 in the care home environment in Scotland published in November 2020 (**footnote 79**). Recommendations specifically in relation to inspection of care homes included:
  - Undertake a thorough review of the joint inspection process to ensure a truly integrated approach to inspection in care homes is in place.
  - Ensure that relevant professional national IPC expertise is at the centre of the process, to provide a consistent level of expertise and support.

- At present the operation of the wider company structure is out with the scope of Care Inspectorate scrutiny, and consideration should be given to extending its remit to corporate entities.

The relationship between inspection-related regulatory oversight of a service provider and the provision of clinical oversight by the NHS has been reported as at times confusing for care home providers. This may have impacted on the timeliness and efficiency of responses in individual care homes and regional teams and may be an area for further investigation. Perhaps deserving of particular attention is what one HSPC participant in the learning lessons exercise referred to as challenges inherent in involving parts of the system in an assurance role that are not normally familiar with the care home sector.

This may relate to the concerns raised by Social Work Scotland in their letter of 11 June 2020 about the increased oversight of care homes leading to the 'medicalisation' of this setting.

It is unclear from what we have reviewed whether the heart of the matter was one of management structure and clear lines of responsibilities or whether it was one of clarity of messaging to the providers being overseen and inspected.

The decision to suspend routine and on-site inspections was taken on 17 March 2020. The rationale for this very early action should be better understood. Questions have been raised by providers, academics (**footnote 80**) and within press media (**footnote 81**) as to the impact this may have had on services and residents. The replacing of onsite visits with technology-based contact may account for one partnership asking: **"where have the Care Inspectorate been?"** throughout the pandemic. Related to this move from business-as-usual inspections during the first lockdown was the reported reduction in the percentage

of complaints received by the Care Inspectorate that were investigated.

A case could be made that responding to complaints from residents, their families and/or staff and inspecting providers to ensure safety and regulatory compliance and high standards could be seen as the core remit of this body, yet it was these two areas that were restricted or reduced in 2020. The Scotsman newspaper reported in July 2021 that 122 of the 2,316 complaints made to the regulator about facilities for older people were fully investigated in 2020/21, down from more than 600 in previous years (**footnote 82**).

It may seem paradoxical that the Care Inspectorate and the wider assurance regime has been heavily criticised for being both too hands-off and too overbearing. Of course, there are compelling reasons as to why visits were scaled back during the early lockdown, and why increased support and scrutiny was put in place with respect to issues including infection control and monitoring of outbreaks. The issue may be around how best to ensure that, in a crisis, scrutiny can be both proportionate and effective.

6. Investigation of Care Home Deaths

Key Messages

- The Crown Office has initiated a process of reporting and investigation of all care home deaths.
- There are significant concerns in the care sector that this process has proved bureaucratic and distressing for staff, and they are not clear as to how the process will develop.
- It is also felt that a disproportionate burden is being placed on care homes, compared with the level of investigation into deaths in hospital and other settings.
- There are questions about how far the ECHR Article 2 requirement for investigation of state related deaths has been met.

Early in the pandemic, the Crown Office relieved doctors of the responsibility of reporting every death associated with COVID-19 'unless there was a substantial reason for doing so. (**footnote 83**). On May 13 2020 the Lord Advocate, James Wolffe QC, provided an update to the Scottish Parliament on arrangements for the reporting of deaths during the COVID-19/coronavirus outbreak (**footnote 84**). The Lord Advocate has instructed that the following are reported to the Procurator Fiscal:

- All COVID-19 or presumed COVID-19 deaths where the deceased might have contracted the virus in the course of their employment or occupation.
- All COVID-19 or presumed COVID-19 deaths where the deceased was resident in a care home when the virus was contracted.

The intention was that each of those deaths would be investigated, and that this would contribute to learning lessons for the future. This has been dubbed Operation Koper. As part of this process, the police issue a form requesting information on care home deaths, with 37 questions (**footnote 85**). This raised significant concerns in the care sector, because of the bureaucracy involved, and the perception that they were being treated more harshly than the NHS. It was reported on 29 May 2020 that 9 in 10 care home deaths were under investigation, but only one in ten hospital deaths (**footnote 86**). Scottish Care commented that: **"We believe these investigations are wholly disproportionate and are causing irreparable damage to the professional integrity of nurses and carers who have been exhausted beyond measure in fighting the virus."**

In April 2021 the BBC reported on information obtained from the Crown Office, publishing a full breakdown of care home deaths (**footnote 87**). A publicly accessible website allows people to track care home deaths attributed to COVID-19 by locality, operator or care home (**footnote 88**).

Prior to this, several providers and the Care Inspectorate had refused to provide a breakdown of care home deaths (**footnote 89**). In May 2021 the Scottish Information Commissioner found against the Care Inspectorate in relation to a refusal to disclose the number of deaths in care homes in a local authority area (**footnote 90**).

Key Issues for Consideration

- Is Operation Koper proportionate and equitable across sectors?
- Does the COPFS process satisfy Article 2 requirements, particularly as it has made clear that there will not be Fatal Accident Inquiries in every death?
- How will the Crown Office report?
- What more do we need to know about deaths in other sectors?
- What information should be made publicly available?

7. Prioritisation of Treatment: Ethical and Clinical Guidance

Key Messages

- Guidance was issued early in the pandemic on ethical and clinical issues concerning prioritisation for treatment.
- This guidance was problematic in terms of human rights and the law, and could potentially have led to discriminatory care.
- The guidance was later improved, but it is not clear what impact it had.
- There is a lack of evidence on how clinical decisions regarding access to critical care were made.
- There may be lessons about ensuring that issues of human rights and equality are properly embedded in guidance.

On 3rd April 2020, two linked documents were issued: 'Covid-19 Guidance: Clinical Advice' (**footnote 91**) and 'COVID-19 Guidance: Ethical Advice and Support Framework' (**footnote 92**). These were particularly concerned with the risk that the need for healthcare resource may exceed what was required, and that 'changes to healthcare delivery and scope may be necessary' (**footnote 93**), presumably meaning that there may need to be a more restrictive prioritisation of access to critical care and particular treatments such as ventilators.

The 'Ethical Advice and Support Framework' referred to the 'Clinical Advice', which it asserted was 'both clinically sound and on firm moral ground' (**footnote 94**). However, for 'a small number of complex situations in which additional ethical advice and support may be useful', it called for each Health Board in Scotland to establish an ethical advice and support group, and stated that a national ethical advice and support group would be

established to offer advice and support to local groups, as well as to consider national ethical issues and to offer advice.

A number of organisations expressed significant concerns about aspects of the guidance (**footnote 95**). These included the virtual absence of any reference to human rights; in contrast to the broader 'Covid-19: Framework for decision making' (**footnote 96**) which sets out the basis on which lockdown restrictions may be eased and which is at pains to emphasise that 'we must continue to provide additional support for those who need it and seek to advance equality and protect human rights in everything we do' (**footnote 97**).

In addition, the legal framework within which decisions must be taken was mentioned only in passing (**footnote 98**). Arguably, the focus on the original drafts was more on providing reassurance that clinicians would not be in legal jeopardy than giving clear advice about what the law and human rights require (**footnote 99**).

Subsequent revisions to the 'Ethical Advice and Support Framework' included a new section on Equality and Human Rights, and changes to 'reflect concerns around disability and age discrimination'. An Equality and Impact Assessment was carried out, informed by a review by Inclusion Scotland, the Equality and Human Rights Commission and the Scottish Human Rights Commission (**footnote 100**).

We believe that the National Ethical Advice and Support Group may have been established, but have been unable to find any information about its membership or activities.

The original version of the 'Clinical Advice' encouraged anticipatory care planning but arguably focused less on the need to maximise respect for patient autonomy, and more on ensuring that people who are perceived as less likely to benefit

will agree not to be admitted to critical care. It stated that patients identified as suitable for critical care should receive a full assessment if their condition deteriorates, including the likelihood of provision leading to survival 'with an acceptable quality of life'. The concept of quality of life as a criterion for access to treatment has been criticised by both disability organisations and also the UN Secretary- General (**footnote 101**) as subjective and potentially discriminatory.

An area of controversy in England and Scotland concerned the extent to which the Clinical Frailty Score (**footnote 102**) should be used to determine whether patients would benefit from critical care. Following an outcry from disability organisations, guidance was amended in both jurisdictions (**footnote 103**). A letter (dated 5 May and published 18 May 2020) issued from the Principal Medical Officer of the Scottish Government (**footnote 104**) to Health Boards which referred to the Clinical Advice, stating that an updated version would be issued once approved, and further stating that:

"To provide absolute clarity, a stable long-term physical need, learning disabilities or autism should never be a reason for issuing or encouraging the use of a DNACPR order. Social care needs, health conditions or disabilities that are unrelated to a person's chance of benefiting from treatment must not be a part of clinicians' decision making regarding accessing treatment."

The potentially discriminatory approach of the original guidance was also seen in the Template Treatment Escalation and Limitation Plan, which lists a set of factors to consider in setting the level of escalation, including 'Is the patient dependent for ADLs (Activities of Daily Living)?' and 'Nursing Home Resident', with the clear implication that these factors, whatever their cause, weigh against access to critical care.

The emphasis on anticipatory care planning as a tool for clinical prioritisation can also be seen in the Anticipatory Care Planning (ACP) template. A more human rights focused approach to anticipatory care planning would be to emphasise its value in maximising the autonomy of the patient) and as a form of support for decision making.

Another concern about the templates was the apparent lack of any space to document the reasoning behind decisions. As the Royal College of Physicians and Surgeons have stated (**footnote 105**):

"To provide accountability across the pandemic, documentation of the decision-making process is very important. As far as possible, conclusions should be in writing, and the reasons for any decision should be clearly set out."

We understand that the 'Clinical Advice' was indeed updated to reflect concerns around human rights and equality, but unfortunately the document seems to have disappeared from the Government website. It may have been withdrawn after concerns about intensive care being overwhelmed abated. Details of the changes that were made can be found in the Government's Equality Impact Assessment (**footnote 106**).

There is more detailed analysis of these human rights concerns in the article 'Scottish mental health and capacity law: the normal, pandemic and new normal' (**footnote 107**).

Important Areas for Further Enquiry

Concerns in this area include:

- What in fact happened? We have not yet found any analysis of whether individual treatment decisions on admission to hospital, to intensive care, or to a ventilator, may have been affected by discriminatory attitudes.
- Why was the original guidance lacking in awareness of these issues? The authorship of both documents was dominated by medical professionals. It is not clear that disabled people or organisations of disabled people were consulted in advance of the issuing of this guidance, or that statements by disabled peoples' organisations (**footnote 1**) and international human rights bodies (**footnote 108**) were considered.
- Did the guidance have any effect, either in its original or amended form?
- Even where guidance discussed the broader legal and rights issues, these were not reflected in various templates to inform decision making. The templates are more likely to have been consulted day to day than the detailed explanation behind them, which may have exacerbated any discriminatory effect.
- Has there been any central or local ethical advice to clinicians, and what did it say?

8. Anticipatory Care Planning and DNACPR

Key Messages

- There is concern that vulnerable individuals were pressurised to agree to DNACPR notices, or placed on them without their consent.
- If done, this would be unethical and potentially a breach of Article 8 of ECHR.
- Early guidance appears to encourage anticipatory care planning, including DNACPR, but there appears to have been confusion over what was expected of clinicians and care staff.
- The purpose and scope of DNACPR may have been misunderstood, at the expense of more user focused and comprehensive anticipatory care to better understand the wishes of patients.
- It is unclear what impact the use of DNACPR notices may have had on wider decisions including on escalation of care (see also prioritisation of treatment chapter).

Concerns Raised by Stakeholder Consultation

The stakeholder engagement identified the following areas of concern:

"the 'breach of human rights' in relation to the use of inappropriate and/or blanket DNAR orders, including:

- **The number of orders applied in 2020 and 2021 and how this compares to previous years**

- **Use of DNARs without informed consent**
- **Family pressures to sign DNARs**
- **If there was a criterion for people to be called or approached, such as age, disability and underlying medical condition."**

We are not aware of any monitoring or central recording of DNAR orders, so evidence on the first point may be lacking. More generally we suspect there will be little statistical evidence on the use of DNACPR processes with particular groups or in particular settings. Within the care sector, we believe recording of DNACPR documentation is something that is looked at by the Care Inspectorate when they inspect homes, and they may have evidence of how it is generally done and what changed.

There is significant anecdotal evidence during the pandemic of 'blanket' DNACPR forms being used, and of people being informed of a DNACPR form being put in place without their involvement, or feeling pressurised to agree to one. There are also suggestions of particular groups, such as people with learning disabilities in care settings, being made subject to DNACPR when this was not clinically justified.

Other Areas of Concern

There is evidence that some of the clinical guidance issued by Scottish Government, particularly in the early stages, made assumptions about the implications of a DNACPR notice for treatment choices which were unjustified and discriminatory. We do not know whether this had a real world effect with disabled individuals wrongly denied access to treatment such as admission to ICU or being placed on a ventilator.

It is important, also, to view DNACPR in the wider context of anticipatory care planning (ACP), and consider whether this was given sufficient priority, and carried out effectively.

Policy and Legal Background to ACP and DNACPR

In general, anticipatory care planning (ACP) is an important means to support patient autonomy, and to improve the quality and appropriateness of care patients receive.

There is no legally mandated form of ACP, but Healthcare Improvement Scotland have encouraged its use in the NHS, and produced a range of guidance to support its adoption (**footnote 109**).

ACP allows patients to set out what kind of care and support they do, or do not, wish to receive, should they become too unwell to make informed choices. It should be the patient's plan, driven by their needs and wishes, and should not be seen as a tool to assist in rationing of healthcare.

DNACPR deals with a more narrow question – the decision as to whether cardio-pulmonary resuscitation should be used if someone experiences a cardiac arrest. Updated guidance was issued by the Scottish Government in 2016 (**footnote 110**).

A DNACPR form is essentially a clinical tool, to guide health professionals during an emergency situation. There are broadly two reasons why a DNACPR form might be created: (a) because CPR would not work and (b) because even if it were to be successful, the outcome is likely to be so poor that the patient would not value it. The guidance makes clear (p7) that, in the latter situation, the wishes of the patient should be paramount.

The guidance is also clear that a DNACPR form does not mean 'do not treat' and that, even if a DNACPR form is in place, other treatment, including admission to an ITU, may be appropriate. At the same time, a decision to initiate a DNACPR may prompt consideration of what other treatments may or may not be needed, wanted or appropriate.

Particularly where it is clear that CPR would be futile, it is not a legal requirement that the patient consents to a DNACPR decision. However, there is English caselaw that the DNACPR process engages ECHR Article 8, and that the patient or their family must be consulted and have an opportunity to contribute to the decision (**footnote 111**).

In human rights terms, the CRPD is supportive of advance planning as a means of supporting a person who is or may become mentally impaired to exercise legal capacity (**footnote 112**). The CRPD also stresses the importance of non-discrimination in access to healthcare (**footnote 113**).

Key Events

Development of Guidance

On 17th March 2020, general guidance was issued to GPs suggesting that 'Practices should review vulnerable patients Anticipatory Care plans and Key Information Summaries (eKIS). This may also be an opportunity to discuss with patients issues such as DNACPRs, Power of Attorney' (**footnote 114**).

On 23rd March 2020, a Community Pathway Model was initiated, intended to reduce patient flow through GP practices, partly to allow GPs to do more to 'consider proactive anticipatory care for those who need it most' (**footnote 115**). It

said that **"The Living Well in the Community Portfolio will focus on supporting practice teams with proactive Anticipatory Care Planning activities."** However, the document seemed to suggest a minimal approach to anticipatory care, suggesting (Annex B) contacting people with severe frailty and asking if they were happy to have a Key Information Summary, which would identify that the person was living with frailty.

A primary care update on 24th March 2020 (**footnote 116**) said: **"Vulnerable/High Risk Patients A letter will shortly be going out to GP Practices alongside updated guidance on Anticipatory Care planning."**

On 26th March 2020, a guidance package was issued regarding high risk patients (those advised to shield) (**footnote 117**). There was virtually no reference to anticipatory care, other than the statement that **"for some patients in this group it may be appropriate to discuss their Anticipatory Care Plan."**

Guidance sent to patients said that if the patient had received a letter because of being at high risk, **"someone from your care team will be in touch as soon as possible to discuss your options for creating an ACP."**

Guidance to the NHS and care homes also encouraged anticipatory care planning, but do not seem to replicate the clear statement to patients that someone would contact them about an ACP.

On 10 April 2020, guidance was issued to GP Practices and NHS Boards on ACPs for vulnerable and high risk patients (**footnote 118**). This included a simplified Anticipatory Care Template, which was an adapted and shortened version of the general templates promoted by Healthcare Improvement

Scotland. The guidance encouraged 'all clinical staff to consider and have ACP conversations with patients'.

Guidance for care homes also stated that ACPs 'should be in place for as many residents as possible.' and they 'do not assume or limit individual choice or decisions' (**footnote 119**).

The simplified ACP template contained very little space to record patient wishes and arguably encouraged a sense that the point of an ACP discussion was partly to lower the patient's expectations about what care to expect, stating that **"Specific care options e.g. ventilation in intensive care may not be available or appropriate. It may help to explore this further and consider whether comfort options such as symptom control would be a priority."**

On 10th April 2020, specific guidance was issued on 'Anticipatory Care Plans for Vulnerable and High Risk Patients' (**footnote 120**). This included a revised and simplified ACP template. The guidance encouraged 'all clinical staff to consider and have ACP conversations with patients', (although, confusingly, it also suggested that 'for many of the patients in the very high risk group it would be more appropriate for them to have their ACP conversation with their treating consultant').

In relation to DNACPR, the document said: **"We recognise that DNACPR discussions are always difficult ones to have, even more so when being done over the telephone. It is also recognised that CPR has a very low chance of success when cardiopulmonary arrest is in the context of severe Covid illness. Therefore we would like to reassure clinicians that there is no specific requirement to have a DNACPR discussion as part of this ACP conversation, unless the patient raises this and wishes to discuss it, or the clinician feels strongly that they need to discuss it. Instead the focus should be on supportive discussions**

with patients about what matters to them should they fall ill with Covid."

A similar statement appears in guidance to care homes (15 May 2020 version para 6) (**footnote 121**). This guidance also states (para 4) that 'Anticipatory Care Plans (ACPs) should be in place for as many residents as possible.'

While this appears to contradict any suggestion that doctors were told to issue DNACPR certificates, it is puzzling that the justification is that CPR in the context of severe COVID-19 has a very low chance of success – which would be precisely the reason why a DNACPR certificate should be considered – and if it is considered, it should be discussed with the patient.

Also, there appears to be evidence that different advice was given earlier. According to the Times in July 2020 (**footnote 122**):

"Ms Freeman sent a letter to the joint boards which oversee general practice and social care services as well as others in the sector on March 13 — ten days before lockdown …The letter included "targeted clinical advice for nursing home and residential care residents" by Dr Calderwood.

As well as advising keeping residents out of hospital, the letter says: "Do Not Resuscitate paperwork should be in place where appropriate and communicated appropriately with patients or carers."

Emerging Concerns

Whatever the guidance actually said, concerns were raised that DNACPR certificates were being used inappropriately.

A group of UK age sector organisations including Scottish Care and Age Scotland issued a statement on 7 April 2020 (**footnote 123**) stating that: **"We are seeing shocking examples where blanket decisions seem to be being made about the care and treatment options that will be available to older and vulnerable people, who have felt pressurised into signing Do Not Attempt CPR forms."**

Age Scotland stated (**footnote 124**) that its helpline received several calls from pensioners who felt they were being coerced by GPs to sign Do Not Attempt Resuscitation forms.

On 3rd April 2020, the case of an 86 year old woman contacted by telephone by a locum doctor to consent to a DNACPR form was raised with the First Minister at her COVID-19 briefing (**footnote 125**). The First Minister said that 'nobody … should be pushed into anything like that'.

On 17 April 2020, a letter was sent to GP practices regarding care homes and COVID-19 which included the following advice:

Should DNACPR decisions be discussed with Care home residents?

There is no requirement to discuss DNACPR unless the patient (or next of kin/guardian) wishes it or the GP or other clinician feels it is important to do so. These are usually sensitive and difficult discussions at any time but can feel especially difficult during a pandemic. DNACPR forms should never be sent to care homes without prior sensitive person-centred discussion and agreement.

Is CPR appropriate for residents in care homes?

For the majority of residents in care homes, who have significant underlying health problems and are generally very frail, CPR is unlikely to work if they were to have a cardiopulmonary arrest due to falling ill with Covid, and it would be inappropriate to attempt it because it would be futile and may indeed cause harm and distress. However, each resident should be assessed according to their individual circumstances, and it would not be appropriate to make a blanket decision to not attempt CPR, based purely on the fact that a patient is a resident of a care home.

In May 2020, the Mental Capacity Report contained an article highlighting concerns raised by the Law Society of Scotland over the response to COVID-19, including a number of case studies contributed by solicitors (**footnote 126**). Case A concerned a patient apparently placed on a DNACPR inappropriately and without their knowledge. Furthermore, the practice of the hospital completing such a form was linked to decisions about whether the patient should have access to a ventilator.

A Freedom of Information response on 15 July 2020 to the question 'Were any DNR's (Do not resuscitate) issued on Government / health authority orders?' said:

"3. Neither the Scottish Government, nor individual Health Boards, have 'ordered' the use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms for any individuals or groups of patients and there has been no change to the Scottish Government guidance on the use of DNACPR forms during the Covid 19 outbreak.

As with all other clinical treatments, decisions about CPR should be made by clinicians, based on the individual

clinical circumstances and wishes of the patient, recorded appropriately and updated when medical circumstances change." (Footnote 127)

It is correct that the general guidance on DNACPR was not changed during the period but, as shown above, how that guidance should be operated during the pandemic was a subject of several pieces of advice.

The collation of evidence from care home managers to the Health and Sport Committee included several references to DNACPR, including **"DNACPRs put in place which were not in place prior to Covid 19"** and **"What was disappointing at the outset was the way we are asked to get DNRs in place, were issued with anticipatory (end of life) meds and had poor initial Government guidance"** (footnote 128).

In England and Wales, the CQC carried out a review of DNACPR decisions during the pandemic (footnote 129). This reported evidence of 'blanket' DNACPR decisions, the lack of a consistent approach to ACP and DNACPR, and an urgent need for improved oversight and assurance. We are not aware of any similar review in Scotland.

Summary

We summarise the key areas for investigation as:

- Were people made subject to DNACPR notices in a way which was unethical, discriminatory or unlawful?
- Were these notices used for inappropriate purposes, beyond their true scope?
- Were opportunities missed for wider advance planning, which may have more appropriately given effect to the wishes and views of patients?

In assessing this, a number of more specific questions arise, including:

- If the Government was clear that no-one was being pressured into agreeing to DNACPR, why do people report feeling that this was so?
- Was guidance confused, inconsistent or ambiguous?
- How was it disseminated and operationalised? What support was available?
- Was there clarity on who was supposed to do what?
- Is there evidence of 'blanket' DNACPRs, e.g., all residents in any particular care home?
- Were particular groups made unjustifiably subject to DNACPR, e.g. people with learning disabilities?
- Did professionals see this process as a tool for avoiding unjustifiable treatment or even rationing, or as a way of ensuring that patients received the kind of treatment that they wanted to receive?
- Given much wider knowledge of DNACPR, did professionals default to that, rather than take a wider approach to ACP?
- Was the revised ACP template used, and who used it? GPs, clinicians, nurses?
- Was there any impact of being subject to DNACPR or having an ACP on wider decisions such as admission to critical care?

9. Decision Making on the Front Line: Care Home Practitioner Experiences

Key Messages

- There is a dearth of academic literature examining the decision-making process of care home staff and managers during the COVID-19 pandemic.
- What is present indicates high levels of stress, flexibility in processes, lack of evidence-based practice, and coping with fast-paced changes to guidance day-to-day leading to inconsistent practices and high levels of uncertainty in decision making.
- An examination of the grey literature supported these experiences, finding:

i. A high level of complexity within the guidance available;
ii. There were high volumes of information for care home staff to read, interpret and implement into practice;
iii. There was a high number of updates and adaptations to the rules on a regular basis, meaning that staff had to update and re-interpret guidelines regularly;
iv. People – staff and visitors – were not always found to follow the rules, and at times this was due to interpretation of rules;
v. People felt overwhelmed by the situation and this caused breakdowns in normal communication.

In this section, we explore the factors affecting decision making by frontline practitioners and managers of care homes. Identification of factors which affected decision making positively and barriers to effective decision making will be discussed, taking both the academic and grey literature into account. These should also be considered in light of the timelines of key events and publications, as discussed in the earlier sections. This section considers the range of decisions

that practitioners were responsible for making, including discussions around restrictions on care home visits, clinical and relational care practice, implementing government guidelines, and managing increased deaths within the workplace.

Decisions and the Lived Experience: Evidence from the Academic Literature

Academic literature on care home staff and managers lived experiences of implementing government and clinical guidelines and the effect on their decision making is sparse. This section therefore combines literature which explored care home staff decision making, implementation of guidelines, and more generalised pandemic-experiential information as secondary or non-primary aims of the studies. A key recommendation emerging from this aspect of the report is the need to explicitly investigate and understand the lived experience and procedural aspects of how care home practitioners came to understand, implement and manage the Government, regulatory, and clinical guidelines during the COVID-19 pandemic; the impact on changing guidelines on decision making and staff implementation of guidance; and how the pace and modes of communication used for the guidance acted in a positive and in a negative way for optimal decision making. This recommendation is supported by the evidence as follows.

Of most relevance, papers which reported directly on lived experiences of care home staff during the pandemic indicated that staff were experiencing stress and anxiety at higher levels than before, and were at greater risk of long-term health concerns and burnout (**footnotes 130, 131**), with Van Bavel et al. (2020) (**footnote 132**) making early calls to better understand the psychosocial experiences of lockdown restrictions. While more is known about the effects of the

pandemic and lockdowns on people generally, care home workers are a unique group and therefore specific inquiry into the effects of the increased stress during the pandemic period on wellbeing, delivery of care and effective decision making is needed.

Two key studies were identified which met this niche (**footnotes 130, 133**). In Bunn et al.'s (2021) (**footnote 130**) mixed methods study, staff reported on adherence to infection control measures (ICMs), indicating concern over the strict application of ICMs and the need to provide the optimal personalised care experience. This was a source of conflict, with staff experiencing anxiety in knowing when and how to adapt ICMs to balance safety and compassionate care. To reduce this anxiety and increase adherence to ICMs, managers increased the use of rationales within training, explaining the reasons for processes that were being implemented – the 'why' and not just the 'how' – explaining that this helped to empower staff to make decisions. However, there was acknowledgement that the guidance needed to be adapted to fit their practice, and that this relied on colleagues interpreting the guidance and communicating this with staff.

This need to change communication processes and to adapt guidance was also identified (**footnote 133**). Extending the findings of Bunn et al. (2021) (**footnote 130**), Marshall et al. (2021) (**footnote 133**) indicated care home managers' concerns over the guidance being interpreted and applied differently across staff working in different areas; particularly noting that care home staff and hospital staff interpreted and/or adhered to rules around transfer of care differently, leading to conflict and stress.

Both studies identified the guidelines provided by Government and other relevant bodies as confusing, constantly changing, and not well suited to care home settings. The need to adapt

the guidelines was seen as essential due to this poor fit, either being too broadly written or written without care homes in mind, and this added to the physical and mental workload for managers and for staff. Staff expressed concern over the piecemeal nature of information being shared, with multiple sources from numerous authoritative bodies being received, sometimes with conflicting guidance (**footnote 130**). The disjointed nature of correspondence coming from different parts of Government, Health Boards and Councils was commented upon “which did not reflect nor capture the spirit of integration and focused too much on individual functions rather than taking an integrated approach”. One manager posed the question “could Scottish Government not have thought whole system from the beginning?” One partnership described “the speed and pace at which some of the advice and guidance came out was frightening.”

This was an additional source of frustration, with people expressing that they did not feel that care home workers had been consulted in the creation of these policies. For both studies, this time burden was acknowledged, with staff picking over documents for hours with minimal applicability to their practice. Managers recognised that time for training should be paid, but were frustrated about the reality that many staff regularly worked beyond their hours unpaid to be able to meet basic needs (**footnote 130**). In addition, there was frustration that staff were held accountable by regulatory bodies for the safety of residents whilst concurrently being provided un-workable general guidelines that needed adaptation to fit real practice (**footnote 131**).

In addition to these barriers to effective implementation of the guidelines, both studies identified the shortage of PPE and other resources, the need to drive innovation through trial and error, and the changing environment towards more ‘clinical’ as being highly stressful and impeding decision making. These

findings are echoed by others (**footnote 134**), who explored ethical care practice within care homes during the pandemic. This work (**footnote 134**) complements selfless and ethical practices such as implementation of social distancing prior to Government guidance to do so and the maintenance of end-of-life and palliative care.

Facilitators to implementing guidelines and making effective decisions included working with other care homes, experts and community partners to interpret and implement guidance and to shape decision making (**footnotes 130, 133**), increasing team cohesiveness and camaraderie through shared experience (**footnote 135**), the removal of non-essential administrative tasks (**footnote 131**), and having leaders communicate current best practice with their teams in a clear, compassionate and direct manner (**footnotes 130, 131**). Finally, Dewey et al. (2020) (**footnote 131**) propose that anxiety can be reduced for care home workers through the use of a central source of updated information and clear communication of protocols, expectations, and other practical resources using multiple communication channels.

Decision Making: The Guidance, and Policy Documents

Issues raised by public and stakeholder responses during consultation on COVID 19 Public Inquiry included how guidance was developed during the pandemic and government communication to key stakeholders around changes to guidance.

In response to a FOI request it was stated:

"To date the COVID-19 guidance has had two routes of production. The first is public health guidance via PHS, and the second route is clinical guidance produced via SGHSCD. ARHAI Scotland have led the IPC components of these various guidance documents, so have worked with the existing guidance groups to date. There has been a recognition that the guidance landscape for IPC is challenging from the perspective of the IPCTs, HAI executive leads and wider care home sector. Recently, ARHAI Scotland has undertaken a process to co-produce a national infection prevention and control manual (NIPCM), specifically for care homes with all relevant IPC guidance in one place, and is working collaboratively with the NHS, the care home sector and other relevant stakeholders. This guidance is envisaged as a resource which enables a single source of national IPC guidance for the care home sector. It is due for publication in December 2020."

The rapid review ordered by the Cabinet Secretary of factors relevant to the management of COVID-19 in the care home environment in Scotland published in October 2020 made the following recommendations to improve guidance and its local adoption:

- HSCP planning using a multimodal approach to IPC is required; this may be supported by national IPC lead organisations such as ARHAI Scotland
- The new national care home manual for IPC planned for completion in December 2020 should be produced with a multimodal strategy plan for dissemination and implementation
- National organisations should be mindful of the impact of publication of guidance on days towards the end of the week or over weekends, and the availability of senior managers to support interpretation, dissemination planning should be considered as part of the guidance development process

- Most recent versions of guidelines should clearly highlight additional information or changes from the previous version.

To identify the scope and ease of access of guidance relevant to people working in care homes, on the assumption that people would seek this information online prior to, after, and between work-shifts, grey literature was searched. Key terms used in the search were purposefully broad to mimic what people might normally use when trying find guidance for care home rules and guidance relating to COVID-19 within Scotland and to allow the search to capture as broad a range of sources as possible. The search was carried out using a standard Google search engine, with the search string: ("care home" + (covid* | coronavirus | sarscov2) + (rules | guid*) + Scot*) on 13 February 2022. No date or article type restrictions were applied and only articles written in English language and which were directly relevant to the Scottish response were considered. The search returned 1,050,000 results. Of these, the first 100 pages returned were considered and any title which explicitly identified Scotland-specific guidance and/or rules for managing COVID-19 within care homes was further explored (N= 64 pages) for relevance. After duplicates were removed, 28 pages remained. Of these, following an assessment of relevance to the current report section, 17 were retained to inform the following section of this report. The key descriptive information from these 17 pages is shown in Table 1. The key messages and findings relating to each article are shown in Table 2.

Of particular note is the generally consistent messaging presented across the non-Government articles to that published within the Government recommendations. This is positive as, from a public health perspective, consistent messaging ought to reinforce knowledge about and implementation of the guidance. However, as shown in the articles where quotes from the public and others were presented, it can be observed that there was

confusion and subsequent frustration over what the guidance was.

This is particularly clear when considering the protest by family members which was supported by a Scottish Labour representative, as reported in the article “'Imprisoned' - Families call for better care home visiting arrangements during Covid-19 crisis to stop declining mental health in elderly” within the Scotsman news reporting. The protest asked for more visiting allowance over concerns for resident mental health, yet, during the same time period, the actual guidance stated that visits to care homes could resume following local approval by Directors of Public Health. This is indicative that there were some misconceptions over whether visits could happen at this point. The question as to why that may be is therefore highly relevant.

There are myriad reasons for public health and government communications being misunderstood or misinterpreted. Based on the data drawn for the purposes of this section of this report, the following shall be focused upon: (1) Complexity of guidance; (2) High volume of information; (3) High number of updates and adaptations to the rules on a regular basis; (4) People not following the rules; and (5) Staff being overwhelmed by the situation causing breakdown in normal communication. This is not an exhaustive list, and there are likely to be intersections across these sub-topics; these specific sub-topics were selected based on the evidence drawn from Tables 1 and 2. Following discussion, recommendations based on the academic understandings of communication and decision making will be made.

Complexity of Guidance

The complexity of the guidance was difficult to follow, with some Government documents evaluated requiring the reader to click

additional hyperlinks to associated and supplementary guidance. For example, the Government document **"Coronavirus (COVID-19): adult care homes guidance"** requires the reader to click through 30 different hyperlinks to associated pages, which then also link to further pages. Without clicking further links, the reader has no substantive knowledge of the actual guidance in place. The language used, was, however simple to understand. It is suggested that to avoid overwhelming readers that either:

a. Guidelines are presented succinctly with all of the key information needed on that page and only 'linking out' to other documents as essential; or
b. If the document/guideline has been developed to bring together/amalgamate a list of existing and inter-related guidance, this could be presented in a basic listed format with sub-headings and minima narrative.

Both of these suggestions reduce the need for additional and effortful information searching, reducing the cognitive load of the reader. Examples of successful documents following the suggested format of (a) above include **"Coronavirus (COVID-19): care homes guidance"** while successful examples in the format of (b) include **"Open with Care – supporting meaningful contact in care homes: guidance"** and the linked **"Coronavirus (COVID-19): Guidance for visiting loved ones in an adult care home."**

Overall, there was very good consistent messaging between all of the article types, meaning that government guidance was being interpreted and reported appropriately into third sector, public sector and mainstream media messaging.

High Volume of Information

As highlighted in the section above, and throughout Table 2, there is an enormous volume of information available to people searching for policy, government, clinical, and other guidelines around working in care homes during the COVID-19 pandemic. The "Covid-19 Guidance Compendium" published by the Care Inspectorate exemplifies this issue well, as it brings together 125 guidance documents into a single compendium to try to support staff in their information searching. Given the high volume of existing guidance and the pace at which it was developed, in addition to evolving versions, this helpful compendium will either grow further or become out-dated. Resources such as this, and the other collated collections highlighted in Table 2 are important in improving decision making and implementation of the guidance into practice, however.

As information grows in volume and complexity, cognitive load – our capacity to take in and manage information (**footnote 136**) – increases, and risks becoming "cognitive overload", which is detrimental to good decision making. In situations where cognitive overload is reached, our ability to learn, interpret information and make effective decisions reduces (**footnote 137**), and we fall back on more heuristic or intuitive decision making, increasing the risk of bias and error (**footnote 138**). It is therefore imperative to support ease of information searching and interpretation for frontline staff.

High Number of Updates and Adaptations to the Guidance on a Regular Basis

Compounding the issue of increasing cognitive load and complexity for care home staff who need to read, understand, interpret and implement the most up to date guidelines is the high number and frequency of changes to the guidelines issued

by the Government and professional bodies. Examples identified within the current search (see Table 2) include guidelines on Lateral Flow Testing in care homes being updated 20 times over the course of 14 months (i.e., **"Coronavirus (COVID-19): adult care home lateral flow device testing"**), although the guidance was clearly presented and easy to follow; 30 updates over 19 months to **"Coronavirus (COVID-19): adult care homes guidance"**; and seven updates over two months to **"Coronavirus (COVID-19): minimising the risk over winter and updated protective measures for Omicron variant."** While there is, of course, need for updates due to the evolving nature of the pandemic situation, how this pace of updating affects the implementation of guidance and decision making of practitioners working under pressure and uncertainty must be better explored, with the aim of identifying the most optimal approaches to communicate changes to guidance to teams, both in terms of volume and timing.

People not Following the "Rules"

Although the congruence between the Government guidelines and other reporting media (third sector, public sector, mass media) was found to be high within this study, there was still concerns identified of people not following the rules set out within the guidance, with Health Secretary Jeane Freeman being reported as saying that some institutions might not have followed the initial COVID-19 rules in a news article in the Scottish Sun newspaper **("More than 5,300 Scots care home residents feared to have Covid-19 with over 1,400 killed by bug")**, with this being supported by the findings of academic research on the lived experience of care home staff and decision making during the pandemic (**footnote 133**). As discussed earlier, in relation to the interpretation of both academic and grey literature, it is likely that staff were not intentionally breaking rules; rather that they were overwhelmed

with the situation, highly stressed, and needing to take on board new and changing processes and guidance regularly.

Overwhelmed by the Situation - Breakdown in Normal Communication

Clearly linked to the previous section, this section highlights the breakdown of normal communication pathways, with guidance being mis-interpreted, mis-applied or staff feeling that they were under intense scrutiny and being criticised. Over the course of the pandemic, reporting of outcomes – both the number and nature of reporting metrics – has increased dramatically, with governing bodies, employers/operators, and The Government requiring regular reports. These reports are then published in the media and discussed at a societal level via social media. Often in media reporting, family members, protestors, and others are quoted criticising care home staff. This intense scrutiny and increased reporting is very likely to increase the already high levels of stress that care home workers and managers are experiencing. Scrutiny of policy, process, guideline implementation is a necessity and is wholly appropriate; however, the effect of this on the daily work and lives of care home workers must be considered.

Table 1. Key descriptive information for the 17 included articles.

- **Article Title from Search Return:** Coronavirus (COVID-19): adult care home lateral flow device testing - gov.scot (**www.gov.scot**)
  Article Source: Scottish Government
  Article Type: Government Communication
  Primary Source: Yes
  Publication Date: 04/02/2022
  Version Number: 20

- **Article Title from Search Return:** Coronavirus (COVID-19): adult care homes guidance - gov.scot (**www.gov.scot**)
  Article Source: Scottish Government
  Article Type: Government Communication
  Primary Source: Yes
  Publication Date: 02/02/2022
  Version Number: 30

- **Article Title from Search Return:** Coronavirus (COVID-19): care homes guidance - gov.scot (**www.gov.scot**)
  Article Source: Scottish Government
  Article Type: Government Communication
  Primary Source: Yes
  Publication Date: no date
  Version Number: no version

- **Article Title from Search Return:** Open with Care - supporting meaningful contact in care homes: guidance - gov.scot (**www.gov.scot**)
  Article Source: Scottish Government
  Article Type: Government Communication
  Primary Source: Yes
  Publication Date: 24/02/2021
  Version Number: 1

- **Article Title from Search Return:** Coronavirus Scotland: Care home visiting given green light to restart from March - Edinburgh Live
  Article Source: Edinburgh Live
  Article Type: Local Media
  Primary Source: No
  Publication Date: 21/02/2021
  Version Number: 1

- **Article Title from Search Return:** Care home visitor limits lifted as Covid restrictions eased | Scotland | The Times
  Article Source: The Sunday Times
  Article Type: Mainstream Media
  Primary Source: No
  Publication Date: 20/01/2022
  Version Number: 1

- **Article Title from Search Return:** Care homes only allowed three visitors per resident as Omicron variant spreads | HeraldScotland
  Article Source: The Herald Scotland
  Article Type: Mainstream Media
  Primary Source: No
  Publication Date: 10/12/2021
  Version Number: 1

- **Article Title from Search Return:** Covid Scotland: Care home isolation requirements eased | The Scotsman
  Article Source: The Scotsman
  Article Type: Mainstream Media
  Primary Source: No
  Publication Date: 20/01/2022
  Version Number: 1

- **Article Title from Search Return:** Covid: Scotland's new care home visiting rules explained | The National
  Article Source: The National
  Article Type: Mainstream Media
  Primary Source: No
  Publication Date: 13/10/2020
  Version Number: 1

- **Article Title from Search Return:** 'Imprisoned' - Families call for better care home visiting arrangements during Covid-19 crisis to stop declining mental health in elderly | The Scotsman
  Article Source: The Scotsman
  Article Type: Mainstream Media
  Primary Source: No
  Publication Date: 16/09/2020
  Version Number: 1

- **Article Title from Search Return:** More than 5,300 Scots care home residents feared to have Covid-19 with over 1,400 killed by bug (**thescottishsun.co.uk**)
  Article Source: The Scottish Sun
  Article Type: Mainstream Media
  Primary Source: No
  Publication Date: 23/05/2020
  Version Number: 1

- **Article Title from Search Return:** Nicola Sturgeon announces new guidance for care home and hospital visiting in Scotland - Daily Record
  Article Source: Daily Record
  Article Type: Mainstream Media
  Primary Source: No
  Publication Date: 14/12/2021
  Version Number: 1

- **Article Title from Search Return:** The full picture of Covid-linked deaths in Scotland's care homes - BBC News
  Article Source: BBC News
  Article Type: Mainstream Media
  Primary Source: no
  Publication Date: 19/04/2021
  Version Number: 1

- **Article Title from Search Return:** Self-isolation exemptions for social care staff in Scotland - LaingBuisson News
  Article Source: Laing Buisson
  Article Type: Market Analytics
  Primary Source: no
  Publication Date: 27/07/2021
  Version Number: 1

- **Article Title from Search Return:** Coronavirus (COVID-19): Guidance for visiting loved ones in an adult care home | NHS inform
  Article Source: NHS Inform
  Article Type: Public Sector
  Primary Source: No
  Publication Date: no date
  Version Number: no version

- **Article Title from Search Return:** Covid-19_Guidance_Compendium_090222.pdf (careinspectorate.com)
  Article Source: Care Inspectorate
  Article Type: Public Sector
  Primary Source: No
  Publication Date: 09/02/2022
  Version Number: no version

- **Article Title from Search Return:** COVID-19: Managing the COVID-19 pandemic in care homes | British Geriatrics Society (**bgs.org.uk**)
  Article Source: British Geriatrics Society
  Article Type: Third Sector Org
  Primary Source: Yes
  Publication Date: 18/11/2020
  Version Number: 4

Table 2. Key findings and messages from each of the 17 included articles.

- **Article Title from Search Return:** Coronavirus (COVID-19): adult care home lateral flow device testing - gov.scot (**www.gov.scot**)
  Key Messages: different LFT guidance for family/friend visitors, care home staff, visiting professionals, outbreak management staff. Details when and how to stock LFTs. Provides a helpline and videos and how to upload barcodes/results. Twenty updates over 14 months. Clearly written.

- **Article Title from Search Return:** Coronavirus (COVID-19): adult care homes guidance - gov.scot (**www.gov.scot**)
  Key Messages: Outlines the recent documents that have been issued around visiting. No substantive information - there are hyperlinks to guidance documents, making finding the relevant information arduous and time consuming (there are 30 hyperlinks to associated guidance documents in the article). Thirty updates over 19 months. Links to another page which combines all of the key guidance - this is good, but the title "Coronavirus (COVID-19): minimising the risk over winter and updated protective measures for Omicron variant" is not suggestive of this being a single source page for all guidance. This second page has also been updated seven times over two months.

- **Article Title from Search Return:** Coronavirus (COVID-19): care homes guidance - gov.scot (**www.gov.scot**)
  Key Messages: Collection of guidance documents using simple bullet-point hyperlinks to key documents. Clearly set out with minimal narrative; this helps clarity and speed of locating the relevant information.

- **Article Title from Search Return:** Open with Care - supporting meaningful contact in care homes: guidance - gov.scot (**www.gov.scot**)
  Key Messages: Very detailed guidance on opening care homes up to support meaningful contact. Ten-part multi-page document with clear headings and purposes per part. Easy to navigate. Information dense, but helpful in reducing ambiguity. Feels like it is written with visitors in mind but the language/tone is more 'professional' focused.

- **Article Title from Search Return:** Coronavirus Scotland: Care home visiting given green light to restart from March - Edinburgh Live
  Key Messages: Indoor visits restart in March 2021, two designated visitors each per week.

- **Article Title from Search Return:** Care home visitor limits lifted as Covid restrictions eased | Scotland | The Times
  Key Messages: Care home restrictions being eased reduced or removed self-isolation times; no visitor limits; isolation requirements removed following acute admission to hospital overnight.

- **Article Title from Search Return:** Care homes only allowed three visitors per resident as Omicron variant spreads | HeraldScotland
  Key Messages: Care home residents will only be able to have three visitors and one essential care worker, following Department of Health and Social Care guidance amid the Omicorn variant spread. Visitors must take LFTs. If resident is not vaccinated they need to isolate following a visit outside of the home. Staff testing to be increased from two to three times a week plus a PCR test. Although this is on the Herald Scotland, is this the English rules - unclear.

- **Article Title from Search Return:** Covid Scotland: Care home isolation requirements eased | The Scotsman
  Key Messages: People moving from hospitals from an overnight stay to care homes no longer need to self-isolate for 14 days as long as no symptoms and a negative PCR are present. Must also not have been in touch with anyone with the virus for 14 days. Residents still able to have visits, even if COVID-19 positive. The Care Home Relatives Scotland campaign groups want more easing. Social care Minister Kevin Stewart acknowledged the balance between safety and distress caused by isolating. Scottish Government recommends no set limits to number of households visiting residents.

- **Article Title from Search Return:** Covid: Scotland's new care home visiting rules explained | The National
  Key Messages: Care home restrictions being relaxed; comparison with previous rules; allows more people to visit; visitors can support personal care etc. and be in person's room; personal contact permitted with PPE; gifts and pets allowed with discussion with care home; care homes must be COVID-19 free for 28 days; makes clear that the guidance is under continual review; considers planning needs of care homes and safety.

- **Article Title from Search Return:** 'Imprisoned' - Families call for better care home visiting arrangements during Covid-19 crisis to stop declining mental health in elderly | The Scotsman
  Key Messages: A protest of family members appealing to Scottish Government for better care home visiting amid concerns of declining mental health. 50 people. Scottish Labour health and social care spokeswoman Monica Lennon supported the protest. Suggestions that people are imprisoned in care homes. Scottish Government responded that there was a balance between visiting and safety from the

virus, and stated that indoor visits could resume after approval by local director of public health. The two conflicting perspectives indicate that there are some misconceptions over whether visits could happen at this point.

- **Article Title from Search Return:** More than 5,300 Scots care home residents feared to have Covid-19 with over 1,400 killed by bug (**thescottishsun.co.uk**)
  Key Messages: First minister has vowed to use emergency laws to protect care home workers and residents; care home 'bosses' could be jailed if PPE is not provided; extra testing for residents. Health Secretary Jeane Freeman said that some institutions might not have followed the initial rules - no further information provided on this.

- **Article Title from Search Return:** Nicola Sturgeon announces new guidance for care home and hospital visiting in Scotland - Daily Record
  Key Messages: First Minister announced new recommendations for care homes amid Omicron variant concern. Omicron variant was new at this point and uncertainty reported over transmission risk and severity. Ensuring visiting can continue, with no more than two households at hospitals and LFT's by visitors; staff take LFT's daily.

- **Article Title from Search Return:** The full picture of Covid-linked deaths in Scotland's care homes - BBC News
  Key Messages: Care home industry claims that it was let down at the start of the pandemic. Family members interviewed reported being dismissed over concerns over their relative's health when video-call visiting - feels that complaints were brushed under the carpet. Had no communication about other residents having COVID-19. A review of the case found no issues with the care provided. First Minister called for UK-wide inquiry but that a Scottish

probe would go ahead if agreement wasn't made in good time. Also stated that mistakes were made with care home residents at the start of the pandemic. Health Secretary Jeane Freeman stated that the right precautions had not been taken when people were discharged from hospital to care homes. Scottish Care Spokesman stated that social care was let down in the early stages if the pandemic with insufficient attention to the needs of the care sector. Care home operators were quoted, with the overarching message that times were uncertain, many locked down prior to the national lockdown, many published their own daily figures for families, and that staff had worked tirelessly to protect residents in light of immense challenges.

- **Article Title from Search Return:** Self-isolation exemptions for social care staff in Scotland - LaingBuisson News
  Key Messages: Reports on changes to self-isolation rules to allow essential staff in critical roles, including social care. Staff would apply for exemption, need to be double-vaccinated, and have a negative PCR test. This is voluntary for staff. Only in cases where there is a risk to business continuity and safety.

- **Article Title from Search Return:** Coronavirus (COVID-19): Guidance for visiting loved ones in an adult care home | NHS inform
  Key Messages: interprets the Scottish Government's "Open With Care" guidance (and links directly to it) for people visiting care homes. Clearly described with to the point, practical guidance on what people need to do and what the rules are for different visiting situations.

- **Article Title from Search Return:** Covid-19_Guidance_Compendium_090222.pdf (careinspectorate.com)
  Key Messages: Presents a comprehensive list of 125 guidance documents. 31 pages in length with 10 sub-sections. Although it is very clearly presented, this demonstrates the complexity and volume of guidance available to care home staff - is it even possible for someone to be able to read, understand and embed all of the guidance into practice, given the volume of guidance and the regular updates to guidance?

- **Article Title from Search Return:** COVID-19: Managing the COVID-19 pandemic in care homes | British Geriatrics Society (**bgs.org.uk**)
  Key Messages: Presents guidance to care home residents, staff, care teams, hospital discharge teams in 'plain language'. Very long. Presents lots of stats and additional detail, attempting to summarise government and other guidance. Quite complex; may be confusing as an 'extra' consideration as the government guidance evolved so quickly.

Key Issues for Consideration

A key question is how best to maintain excellent, necessary reporting, appropriate scrutiny, supporting family and residents to share their experiences, while also mitigating the negative effect on staff. In essence, how can care home staff be supported to deliver excellent care and make effective decisions which are underpinned by the appropriate guidelines?

To answer this it is suggested that there must first be greater and explicit study into the lived experiences of care home staff

and managers in terms of how they understand, implement and manage the various guidelines that they need for their roles. There is need to understand the impact that changing guidelines had on decision making and implementation of guidance, and to understand the effect that the high pace of communication had on staff decisions. What were the barriers to implementation and to effective decision making? And what were the facilitators? Are there areas of good practice which could be applied when writing and communicating the guidelines? And are there examples of good practice that have been developed within care home teams which could be applied more broadly?

This fundamental knowledge is limited within the academic literature, as demonstrated by the current report, yet the outcomes of such work would help inform: (1) areas of existing good practice; (2) areas that could have been improved and supported better during the COVID-19 pandemic; and (3) the development of processes to support practitioners to make effective decisions, interpret and implement guidance in a way that is evidence informed and which reduces pressure on staff should another emergency situation such as the current pandemic occur in the future, to avoid re-making mistakes and streamline processes as much as is reasonable.

10. Lived Experience of the Pandemic

Key Messages

- Unintended consequences of action to protect the public led to vulnerable populations being left with no services or very reduced provision. Families and carers were left to support vulnerable people in the community with little or no support over the prolonged lockdown.
- Communication issues with understanding of public health messages and importantly some of the changes to services resulted in some people having little or no input to decision making about their own care or others.
- Digital provision implementation was not suitable for all and did not recognise the need for additional infrastructure, support, and finance.

Context

We examined a range of surveys of how people had been affected by the pandemic. Details are at Annex A.

The Scottish reports located collected data from June 2020 through 2021. Six reports identified number of Participants: Age Concern (**footnote 2**) with 3,562 participants; Mental Health Foundation (**footnote 3**) had 2039 participants; Scottish Govt (**footnote 4**) had 25 participants, Alliance Scotland (**footnote 5**) with 1000 participants and Scottish Parliament (**footnote 6**) with 723 respondents. In total, here, 7329 people participated mostly via surveys online and postal, some limited face to face data collection and two focus groups. Other data came from services own processes/services staff.

Key Findings

A key issue arising across the research to date is that people living with dementia and care experienced young people were negatively impacted by the policies to support wider population.

- Access to and withdrawal of health and social care services, such as, homecare, community groups and day services with little notice or time to put in other supports led to uncertainty and stress; leaving individuals isolated, lonely and distressed with some being unable to access basics such as food. Additionally, families and carers were left to fend for themselves in supporting people in the community with little support by services. Safety and continuity of care were raised as aspects of concern. This situation resulted in both people with dementia and their carers experiencing stress, anxiety and physical health decline and importantly for people with dementia increased cognitive decline as social contacts and routines were lost.
- Communication of public health messaging and understanding of the guidelines re social distancing were difficult for those with dementia both in the community and in care homes to comprehend and led to additional stress and decline in mental health, most significantly lack of visitors to their place of residence. However, changes in care home processes and PPE procedures were confusing for residents. Highlighted in several reports was that poor communication impacted on not being informed or involved in the decision-making process about their own or their relatives' care, particularly related to young people in care with access to panels and reviews without their involvement.
- Health and social care provision was transferred to phone calls or 'near me' online calls – these communication methods were not accessible to all, seen as not appropriate for their needs; while some indicated these alternatives were not offered. Importantly, while digital access was

implemented at speed across health services: the need to ensure that people had adequate access to this digital solution was not addressed including the ability to use such systems. As highlighted in the various reports this includes having access to devices, internet, and data packages. The need for services to be delivered face to face going forward is recommended and that digital solutions is not the dominant provision of care.

- The COVID-19 crisis has had wide and deep emotional impacts on Scottish adults with the Mental Health Foundation longitudinal data demonstrating increased loneliness and feelings of hopelessness in this data set.

Overall, there is convincing evidence that while public health measures were brought in to protect the Scottish population, the impact of these changes on the daily lives of some vulnerable populations and people involved in their care were not fully considered. They were negatively impacted in a multifactorial manner. Notwithstanding best intentions, there was insufficient understanding of many systems, processes, and contexts, leading to unintentional harm.

11. Reduction in Home Care and Support

Key Messages

- Emergency legislation reduced the requirements on local authorities to undertake assessments of care needs, but not the general duties to provide care.
- Despite assurances early in the pandemic, there were substantial reductions in home care for elderly and disabled people, with considerable harm caused.
- There are human rights questions as to whether elderly and disabled people were disproportionately affected, and whether enough was done to ensure their urgent needs continued to be met.

An emergency provision that came into force immediately upon the enactment of the Coronavirus Act 2020 was that relating to social care needs assessments by local authorities. Sections 16(1) and (2)(a) of the Coronavirus Act removed Scottish local authorities' statutory duty under section 12A Social Work (Scotland) Act 1968 to assess social care needs where it would be impractical to do this or where to do so would cause unnecessary delay in providing community care services to the individual concerned. Where a local authority did not carry out an assessment, or only carries out a partial one, then it additionally did not have to comply with the general principles of the Social Care (Self-directed Support) (Scotland) Act 2013, which include those in section 1 requiring involving and collaborating with the person in the assessment and providing support or assistance to express their views and make an informed choice on the options available to them. These emergency provisions were subsequently suspended on 30 November 2020 (**footnote 139**).

Human Rights Considerations

The amendment raises issues relating to the rights to the highest attainable standard of physical and mental health, respect for private and family life (autonomy), life, inhuman or degrading treatment (dignity), personal integrity and independent living. As stated in Chapter 1, the rights to life and not to be subjected to inhuman or degrading treatment can never be limited even in emergencies. However, the restriction of other rights must be proportionate and, as also stated above, non-discrimination on the basis of disability is an essential component of such proportionality. Adhering to the requirement to protect life must not therefore be at the expense of dignity or equality in the enjoyment of rights by persons with disabilities.

Moreover, Article 19 CRPD requires states to recognise “the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”. This includes choice of living arrangements and access to support and personal assistance to support living and inclusion in the community and to prevent isolation (**footnote 140**).

Whilst the emergency measure may have been introduced to ease the provision of community services to those requiring them during the pandemic it was important that this was not used in such a way that persons with physical and mental disabilities were disproportionately adversely impacted by the allocation of such resources (**footnote 141**).

Commentary

Many persons in need of social care are persons with disabilities. Notwithstanding the emergency measures, human rights standards therefore make it incumbent on local authorities to ensure that sufficient resourcing is allocated so that there are appropriate accommodations in place to ensure the ability of persons with disabilities to live in the community on an equal basis with others.

The Scottish Government June and August 2020 reports to the Scottish Parliament on the use of the emergency legislation noted that whilst the provisions allowed Local Authorities flexibility in order to focus on prioritising the most urgent needs and protecting the lives of the most vulnerable they were still expected to do as much as they could to meet people's needs (**footnote 142**). Statutory guidance (**footnote 143**) and the Deputy First Minister and Cabinet Secretary for Health and Sport direction to key stakeholders were also clear that the power to disregard assessment duties would remain whilst it was absolutely necessary to protect people. Scottish Government surveys of Chief Social Work Officers regarding use of the provisions during the periods 5 April to 16 May 2020 and 17 May to 3 July 2020 indicated that not all local authorities used the provisions (**footnote 144**).

Time constraints mean that we are not entirely sure that all the relevant literature is included in this report, that being located appearing in Annex D of this report. However, what emerges from the literature located is that despite the Health Minister's assurance at the start of the COVID-19 restrictions in Scotland that home care would not be impacted, indications are that the pandemic not only exacerbated existing inadequacies in social care allocation but disproportionately affected persons with disabilities (**footnote 145**). Reduced amounts of, and reduced

quality of, home care and support and dislocation have been particularly noted (**footnotes 146, 147**).

Transparency over the decisions made local authorities across concerning social care assessments and resource allocation for persons with disabilities is therefore essential in order to assess the impact and use of measures relating to home care during the pandemic and to inform forward planning.

Staff Support and Preparedness: Key Events

- 12 April 2020 - Social care staff to receive a 3.3.% pay increase, backdated to 1 April 2020 **https://www.gov.scot/news/pay-rise-for-social-care-staff/**
- 29 April 2020 Health Secretary Jeanne Freeman confirms that **all families of frontline NHS staff who die as a result of coronavirus (COVID-19) will receive financial support.**
- 11 May 2020 - **National Wellbeing Hub** is launched. The Hub is a new partnership between national, local and professional bodies looking after the emotional and psychological wellbeing of Scotland's health and social services workers.
- 24 May 2020 - Scottish Government announces that **extra financial support will be given to social care workers** in Scotland during the Coronavirus emergency. These include Plans for death in service cover and enhancements to statutory sick pay
- 17 July 2020 -Reported delays in the implementation of the Social Care Staff Support Fund **https://unison-scotland.org/care-home-staff-are-still-not-receiving-sick-pay-putting-clients-and-staff-at-risk-says-unison/**
    - Many care home staff are still not receiving the sick pay, months after they were promised they would by the Scottish government, putting staff and residents at risk

says the trade union for care workers. Coronavirus (Scotland) (No2) Act 2020 and the Social Care Support Staff Regulations.

- 20 July 2020 - Scottish Government announce **additional mental health support for health and social care staff**.
  - The Scottish Government is funding the wellbeing helpline for those who need further psychological support, including in light of the coronavirus (COVID-19) crisis.
- 30 November 2020 - Scottish Government announce a one-off **£500 payment for health and social care staff**.
- 26 February 2021 - Scottish Government launch the **Workforce Specialist Service**, which offers confidential mental health assessment and treatment to health and social care professionals.
- 27 June 2021 - Scottish Government announce **£8 million funding package for health and social care workforce wellbeing**.
  - The priority areas for action will include the ongoing development of the National Wellbeing Hub, National Wellbeing Helpline, and psychological interventions and therapies for staff. Coaching for Wellbeing, digital apps and the Workforce Specialist Service for regulated staff will also be provided, along with time and training for staff to support each other as teams. More practical support for staff like rest spaces will also be provided.
  - Social care and primary care will be targeted with £2 million of support in recognition of the specific needs of staff working in those services in responding to the Coronavirus (COVID-19) pandemic
- 2 February 2020 - Scottish Government announce a new **£1 million fund to support projects which look after the wellbeing of staff working in social care**.

Preparedness

- 17 July 2020 - The Committee's evidence sessions on COVID-19 resilience and emergency planning. The purpose is to understand how prepared we were for the pandemic and whether the Scottish Government could better manage future outbreaks of coronavirus or other pandemics. Evidence submitted in the following link: **https://archive2021.parliament.scot/parliamentarybusiness/report.aspx?r=12704&mode=pdf**
- 23 June 2020 - NHS email addresses available for all care homes. The 14 Health Boards across Scotland are to provide up to three NHS mail addresses to all care homes (adults, older people and children's residential services)
- 8 August 2020 - Public health officials around the world excluded nursing homes from their pandemic preparedness plans and omitted residents from the mathematical models used to guide their responses
- 7 February 2022 - **Covid in Scotland: 'Lack of planning' put NHS in crisis - BBC News**

Key Strategic Response (care home data)

- 30 May 2020 - **Coronavirus (COVID-19): care home staffing and escalation resources - gov.scot (nrscotland.gov.uk)** - referred to as the Safety Huddle – a template (excel)
- 13 August 2020 - online version of safety huddle **Identifying care home risks earlier - gov.scot (www.gov.scot)**

12. Notes to Annexes B and C

The development of a COVID-19 care home guidance spreadsheet and calendar

Excel spreadsheet and document search

We aimed to establish the type of guidance issued during the 2020 and 2021 relating to COVID-19 and care homes, and where to locate such guidance. We found four websites which informed our search. The websites are as follows: The Antimicrobial resistance and healthcare associated infection (ARHAI) COVID-19 Compendium website; The Care Inspectorate Covid Compendium; The Scottish Government Archive; and the HPS archive guidance for health and social care settings. Within the time available for this research commission, two of the four sources located were fully scanned for relevant guidance, compared, and compiled into our findings.

An excel spreadsheet was designed to effectively and comprehensively present each piece of COVID-19 guidance provided to care-homes during the COVID-19 pandemic from March 2020 to February 2022. The ARHAI COVID-19 Compendium (published 27th January 2022) and the Care Inspectorate Guide to Covid-19 information (updated 9th February 2022) were used to gain access to a robust list of guidance issued relating to COVID-19 in care homes. Guidance related to ACP/DNACPR during the pandemic was also incorporated into the spreadsheet to represent the guidance provided in this area.

While accessing the ARHAI covid compendium, a search strategy was developed which would guide the location of

relevant information. COVID-19 guidance which included the terms “care homes”, “residential settings” and “ACP/DNACPR” were located within the document. Use of a search strategy made it easier to locate the relevant guidance within the document which presented COVID-19 guidance issued between 2020 and January 2022 more broadly. The Care Inspectorate document was subsequently utilised to access any further guidance. This document was categorised based on the type of guidance issued, with pages 2-8 of the document used to cross-reference any guidance extracted from the ARHAI covid compendium and add any missing guidance.

The spreadsheet was designed to comprehensively display the date at which each piece of guidance was issued, grouping each of the guidance documents into categories. The categories chosen were as follows: general guidance; clinical guidance; infection prevention control; staffing; visitation; hospital discharge and admission; testing; and ACP/DNACPR. Each piece of guidance was grouped into one category. The excel spreadsheet was formatted to present the colour coded categories along the top with the date at which each piece of guidance was issued along the side. Where guidance was issued on the same date, these were categorised into different categories on the same row, unless two pieces of guidance grouped into the same category was presented on the same day. In this case, a second row for the same date was created to present the second piece of guidance of the same type issued that day. Hyperlinks were embedded into the title of each piece of guidance to enable readers to simply click on the title to read the full guidance document.

The ARHAI website specified the author for each piece of guidance, and as such the author was presented in the spreadsheet underneath the title in brackets. The care inspectorate document did not list the author, so the best interpretation of each piece of guidance was used to denote the

author. The guidance was colour coded and transferred to 2020 and 2021 yearly calendars so that the type of guidance by date issued can be observed at a glance.

Findings and content of the guidance

During our investigation, we found that some pieces of guidance are no longer publicly available. Not all of the guidance was collated into one file, but it was placed sporadically throughout the four websites. Some of the guidance was repeated across several websites.

Patterns Found

The majority of the guidance presented in the ARHAI website was issued in 2020 whereas more of the guidance included in the Care Inspectorate document was issued in 2021, with a larger amount of guidance issued in 2022. Comparison of the guidance issued using the spreadsheet and calendars revealed that the most commonly issued category of guidance in 2020 was testing, followed by general advice, then jointly visitation and infection prevention control (IPC). In 2021, guidance on IPC became much more frequently issued, with 11 separate documents of guidance issued. Also more frequently issued in 2021 was guidance pertaining to loved ones visiting care homes, with eight distinct pieces of guidance issued. Guidance on testing became less frequently issued in 2021 (four issued).

In 2020, patterns regarding the dates at which guidance was issued were observed. The days on which guidance was most frequently issued were Thursday and Friday. 30.8% of all guidance was issued on a Thursday, and 28.2% of all guidance was issued on a Friday. In total 59% of all guidance was published on a Thursday or Friday. The days which saw the

least guidance issued across all of 2020 were Saturdays and Sundays.

In 2021, different patterns were revealed. Guidance was issued more sporadically across the week, with less clear differences between days on which guidance was more likely to be issued and days on which guidance was less likely to be issued. The most commonly used day to issue guidance was again Thursday, but this was only a marginal majority with 20% of the guidance issued on that day of the week. This was followed by Wednesday and Friday, days which both represent 16.67% of the days on which guidance were issued respectively.

Certain types of guidance were issued in quicker succession than others and the spread of the type of guidance issued by date varied across the data. General guidance was issued more frequently in the later months of 2020 and tended to be released in quick succession compared to other types of guidance which was spread across the year more evenly. However, in the months of June and July of 2020, testing guidance was distributed in quicker succession, with the majority of this guidance issued over four days within this period. The majority of testing guidance was issued in July 2020, and clinical guidance was issued in April and May of 2020.

Similar but distinct patterns were revealed in the data for the year of 2021. Visitation guidance was sporadically issued in the early to middle months of 2021, but the majority of this type of guidance was issued in the later months of the year (August, September, and December). General guidance was entirely issued in the middle to late months of 2021, with all of the guidance issued across the months of July, August, and September. Testing guidance was distributed evenly in the early months of the year but was again issued later in the year in quick succession, specifically in late December. Staffing

guidance was one of the least frequently distributed types of guidance, but this was issued ain quicker succession later on in the year between the months of September and October.

Another pattern identified was differences in the frequency of the distribution of different versions of the following guidance: COVID-19: Information and Guidance for Care Home Settings (Adults and Older People). Different versions of the consistently updating guidance were distributed frequently in 2020 by Health Protection Scotland (HPS). In 2021 however, far fewer versions of this guidance were issued, and by Public Health Scotland rather than HPS.

Patterns regarding the type of guidance issued were also identified. In 2020, the most frequently issued types of guidance were general guidance (as expected, with a large proportion of this guidance different versions of general guidance provided by HPS) and testing. However, in 2021 the most frequently distributed types of guidance included Infection Prevention Control (IPC) and visitation. Testing guidance was much more frequently issued in 2020 (nine compared with four) as was general guidance (eighteen compared with five). Similarly, in 2021 visitation guidance was more frequently distributed (eight compared with four) and an even larger difference between frequency of distribution of IPC guidance was identified (eleven compared with four). Across both years, hospital discharge and admission, staffing and ACP/DNACPR guidance were the least frequently issued types of guidance.

Annex A. Summary table of research into experiences of pandemic.

Organisation and Title:
Alzheimer's Scotland (reference 1) (2020)

Covid 19: The Hidden Impact: A report on the impact of the COVID-19 pandemic on people with dementia and carers living at home

Research Focus:

Impact of the pandemic, and the unintended harms to their health and wellbeing caused by the measures intended to keep them safe from the virus.

Study design:

Desk-based research methods to review emerging literature about the impact of the COVID-19 pandemic on people with dementia and carers.

Information collated from what people with dementia and carers have been telling our 24 hour Freephone Dementia Helpline and our frontline staff.

Two surveys for Dementia Advisors and Post Diagnostic Support Link Workers to complete in August and October.

Participants:

People with dementia and carers

Dementia advisers and Post Diagnostic Support link workers

Key Findings:

People with dementia and their carers have been negatively impacted, directly and indirectly by the COVID–19 pandemic

For People with dementia

- Increased frailty and a decline in mobility
- Increased mental health issues such as anxiety and depression, most prominent health issues
- The disruption to daily routines, social interactions, and health and social care support has had a negative impact on the physical and mental health.
- The disruption of community-based therapeutic/activity groups run by Alzheimer Scotland and other third sector organisations has had a negative effect.
- Faster cognitive decline and acceleration of the progression of the symptoms of dementia
- Increase in the complexity of needs of people with dementia
- Difficulty among people with dementia in understanding and complying with the need for the restrictions in their daily routines and social interactions
- Increased and substantial stress and distress among people with dementia because of these factors

For Carers

- Carers have increased responsibility for supporting relatives and friends with dementia often alone and with little or no support, and no meaningful respite breaks
- Carers are experiencing significantly higher stress levels as a direct result of trying to manage the increased needs of those they care without support and meaningful respite
- Carers are experiencing a significant decline in their physical and mental health due to the demands of caring for people with increasingly complex needs

- Clear evidence that the public health measures intended to prevent the spread of COVID-19 infections are causing harm to people with dementia and carers

Recommendations:

1. The safe remobilisation of small-scale therapeutic day service provision continues and is given the appropriate support by public health

2. Health and Social Care Partnerships act urgently
   - to ensure that people with dementia and their carers have access to an assessment/ reassessment of the changes in their levels of need
   - ensure that carers of people with dementia are better supported by have accessing to appropriate levels of respite care
   - work to safely reinstate social care that has been Reduced/stopped at a level which reflects the current levels of needs of people with dementia and their carers

3. The Scottish Government establishes a dedicated national Post Diagnostic Support fund, to double the capacity of Scotland's Health and Social Care Partnerships to offer high quality personalised post diagnostic support to every person diagnosed with dementia in Scotland

4. As a matter of priority Health and Social Care Partnerships to ensure access to diagnosis or, where necessary develop appropriate alternative diagnostic processes for as timely an early a diagnosis as possible

Organisation and Title:
Age Scotland (reference 2)

The Big Survey 2021: A snapshot

Research Focus:

Focus the impact of 2nd lockdown and national restrictions had on respondents and on their interactions with family, friends and health professionals.

Study design:

Survey
Of 3,562 responses, 1,766 were submitted online and 1,796 were completed on paper.

Participants:

Two thirds of respondents (66%) were women
The sample included respondents across all age groups but primarily in the 65-69, 70-74 and 75-79

- 71% of respondents were retired, 19% of respondents were in employment (full-time, part-time and self-employed) and 5% were unable to work due to disability/illness.
- 42% respondents lived alone and 44% with one other person. The majority of respondents owned their home outright

All 32 local authorities were represented in the sample of respondents although they were most likely from the City of Edinburgh Council area, Highland, Fife and Glasgow.

Key Findings:

Impact of Covid-19
The pandemic has clearly impacted the majority of respondents' lives. Of note, 46% chose to shield themselves and limit their interaction with others during lockdown: suggesting that at the beginning of the lockdown period respondents were sufficiently concerned about their health and safety that they made this decision.

A further 15% of respondents shielded during lockdown following advice to do so. As the country opened up following the 2021 lockdown, it will be important to note how confident older people feel in regaining contact with others and any longer-term impact on mental health and well-being as a result of a sustained period of time without interaction with others.

Access to health professions was a difficulty that emerged during the pandemic. However, 61% of respondents took part in a telephone consultation with their GP during lockdown and 15% had an online consultation. The findings suggest that although access was perceived as being more difficult due to the pandemic, GPs had made themselves available for consultation with older people, however, evidence captured by Age Scotland throughout the pandemic highlighted that some patients had concerns that a phone or video consultation wasn't ideal for their needs. 30% of people struggled to get a GP appointment, and 24% struggled to access other healthcare professionals

Two thirds of respondents had experienced higher energy bills as a result of staying at home more during the lockdown period with 38% of these stating they had struggled to pay increased bills and 4% now in arrears.

Respondents in their 50s and 60s
Respondents in their 50s and 60s were more likely to disagree that they felt more mentally and physically prepared as they entered lockdown in January 2021 compared to those aged 70+. They were also more likely to agree that they felt more anxious entering another lockdown.

They were less likely to describe their mental health as good and more likely to state that it had got worse over the past five years. This particular demographic is more likely to be part of the 'sandwich generation' juggling children, caring for older family members and still in employment

Organisation and Title:
The Mental Health Foundation Scotland (2021) (reference 3)

Mental health in the pandemic

Research Focus:

Impact of pandemic on mental health

Study design:

Online 4 Nation Longitudinal study

Various data points via YouGov

Participants:

Adults 18+
March 2020: 1015 participants
March 2021 2039 participants

Key Findings:

Crisis has had wide and deep emotional impacts on Scottish adults

The research reveals some positive signs including falling levels of anxiety, from 64 per cent of those surveyed in March 2020 to 44 per cent in February 2021, the overall picture is more mixed.

Loneliness has become much more common, increasing from 11% of those surveyed in March 2020 to 29% in February 2021.

Feelings of loneliness have not returned to their pre-lockdown levels at any point over the past year, including when most restrictions were lifted over the summer.

Losing connections means less emotional support, at a time of global crisis that has challenged almost everyone.

Ten per cent of Scottish adults in April 2020 said they had had thoughts and feelings about suicide in the previous two weeks. This rose to 13% in February 2021.

Hopelessness has also risen among Scottish adults.

In March 2020, 15% per cent said they had felt hopeless because of the pandemic, rising to 20% in February 2021.

Young adults (18-24 year olds), full-time students, single parents, people who are unemployed and those with pre-existing problems with their mental health continue to be significantly more likely to be feeling distressed, across a range of measures, compared with Scottish adults generally.

Recommendations:

While the Scottish Government has addressed the needs of higher-risk social groups in its Transition and Recovery Plan, we now need to see full delivery of that plan to ensure that everyone can recover their mental wellbeing as restrictions are lifted.

Scottish Government needs to go further with a commitment to a Wellbeing Society that can overcome the root causes of poor mental health.

This must include radical measures to prevent a COVID-19 unemployment crisis and tackle poverty.

Good mental health and wellbeing at the heart of the decision-making processes across all levels of government.

Organisation and Title:
Scottish Gov (2021) (reference 4)

'Covid Conversations': experiences of the pandemic in Scotland People, Communities Places

Research Focus:

Opportunity to share their experiences of the pandemic and the public health measures that have been in place, focusing on what has gone well and what could be further improved

Study design:

Four online focus groups were held between December 2020 and February 2021

Participants:

25 people participated

Key Findings:

The COVID Conversations
4 Themes

1. Health and wellbeing: experiences of mental health and accessing support services
2. Finances and employment: experiences bills, shopping, work and supporting home schooling
3. Communities and families: experiences of social connections, looking after children and transport
4. Communication: experiences of accessing and understanding guidance

Participants talked about types of support that makes it easier for them to manage and stay safe:

- support from community groups and friends
- resources from school
- council payments

were spoken about as making a real difference in helping participants follow government guidelines.

Participants also talked about struggles, and areas where they felt they had been left out of decision-making.
COVID-19 guidance on shopping and public transport were problematic.

Participants questioned the assumption that everyone is able to afford buying face coverings, increases in heating and electricity bills, and a good internet connection.

Concern for the future impact of COVID-19 on

- mental health
- job prospects
- young people.

Participants provided their ideas for how the government could communicate better, and suggested actions and priorities for agencies in the short and medium term.

Recommendations:

Future Policy Interventions

- Involve people and households on low-incomes as early as possible in policy development to raise important practical issues.

- Enhance out-of-school activities and community-based youth work to give young people the chance to build missed social connections.

- Develop additional mental health services for young people across Scotland

Widen opportunities for employment for young people, in particular amongst those at risk of poverty.

- Tackle the 'digital divide' in a way that recognise there are ongoing costs of data, internet connections and power, and devices.

- Work with retailors to expand access to face coverings at entrances, and to assist low-income families to be able to use delivery systems.

- Ensure that frontline third sector organisations have the necessary resources to continue to deliver vital preventative as well as acute services.
- Increase the capacity of public transport, including taxi drivers, to support people on low incomes, especially to access hospital appointments.

- Link with local activists and trusted emissaries supporting some of Scotland's most vulnerable citizens to test and develop messaging and practice. Strengthen these links as channels of information about the virus.

Organisation and Title: Alliance Scotland (reference 5)

Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future

Research Focus:

The lived health and wellbeing experience of a broad range of people living in Scotland during the COVID-19 pandemic, as captured by the People at the Centre Engagement Programme (PATC) shares their experiences and stories

Study design:

Online and non-digital engagement options available. Throughout the activities there were opportunities for people to

take part using telephone, postal service, or face to face in line with current physical distancing guidelines

qualitative data

Participants:

1000 participants

Key Findings:

Themes
Reduced and disrupted access

Poor communication is a barrier to accessing healthcare

Health inequalities have been exacerbated and population groups disproportionately impacted

Power imbalance

Organisation and Title:
Scottish Parliament (Nov 2020) (reference 6)

How has Covid-19 impacted on care and support at home in Scotland?

Research Focus:

Views from people who provide, or receive, care and support at home.

The survey was created to understand the impact of Covid-19 on care at home services, and what issues the pandemic has highlighted, improved, or made worse.

Focus Groups to learn more about the findings of the survey and bring the all important lived experience from those who receive care at home and those who provide care at home

Study design:

Online Survey ran 10 August 2020 to 7 September 2020
Focus groups x 2 (Oct 2020)

Participants:

723 responses.

Group 1: individuals receiving care at home, receiving 93 responses.

Group 2: family members of those receiving care at home and unpaid carers, receiving 415 responses.

Group 3: staff, managers or owners of a care at home services, or personal assistants providing care, receiving 215 responses.

125 who indicated they wished to participate in remote video focus group sessions.

care at home to the attention of the Committee.

Key Findings:

The reduction of care as a result of the pandemic, and suggests many families felt they were ‘left to get on with it’ and that

neighbours had to ‘step in’ to provide care and support. Some respondents told us that their care services were ‘completely withdrawn’.

The need for greater recognition and support for unpaid carers.

Praise for the hard work of care staff and that they need to be recognised for this, with respondents suggesting care at home staff do not receive the same support or recognition as NHS staff.

The need for safety was highlighted by respondents as the most important issue in relation to the provision of care at home services during the pandemic, only a few respondents indicated that they chose to deliver care for family members for safety reasons. Instead, concern regarding safety mainly related to access to and appropriate use of PPE as well as testing and training of care staff.

Ensuring continuity of care was the second most important issue to respondents, with concerns around quality and consistency of care as well as the need for designated carers to reduce the number of staff entering homes.

Employers also expressed concerns about the difficulty to ensure consistency of care due to staff absences, self isolation requirements and shielding.

This led to increased challenges in the recruitment and training of new staff, with some employers indicating they were only able to take on people with previous experience in delivering care due to a lack of time available for training.

Wellbeing and mental health was also a significant theme

Many respondents indicated that the reduction of visits and activities, and resulting loss of a routine, increased feelings of loneliness and isolation for those in receipt of care.

Respondents also told us that additional pressure on unpaid carers due to closures of day-centres and respite services has resulted in increased feelings of anxiety, depression and mental exhaustion.

With the reduction of formal care and formal additional support services

- non-formal means of care, such as faith groups, third sector groups and neighbour support, were crucial and had they not been present many would have struggled to cope.

For staff, despite a reduction in care being delivered, many told us about their increased workloads, with new tasks required as a result of the pandemic such as additional staff training, increased staff meetings and increased paperwork.

Many managers told us that a move to home working also resulted in an also resulted in an increase in hours, with less time away from work and additional pressure due to childcare and other family responsibilities.

Respondents also felt that access to additional support and services was one of the most important things to consider within the context of the pandemic, to ensure the safety and wellbeing of those being cared for. This included access to food, prescription deliveries, access to activities and entertainment (and the technology needed to engage in these), and access to hospital, GP services and medical equipment.

Whilst respondents largely praised the advice and information from the Scottish Government, it was felt that one to one

communication between services and service users needed to improve.
Finally, it was suggested that more needs to be done to listen to the needs of those receiving care and involve them in decision making. This includes more flexible spending of Self-directed Support (SDS). These are issues that have existed long before COVID-19 but which have been exacerbated since the pandemic began.

Recommendations:

It was suggested that more needs to be done to listen to the needs of those receiving care and involve them in decision making.

This includes more flexible spending of Self-directed Support (SDS). These are issues that have existed long before COVID-19 but which have been exacerbated since the pandemic began.

Organisation and Title:
Who Cares? Scotland 2020 (reference 7)

The Impact of covid-19 on guidance on Scotland's Care Experienced Community

Research Focus:

Overview of how Covid-19 and the associated safety measures have impacted Care Experienced people in contact with Who Cares?

Study design:

An analysis of the helpline, examples of advocacy tasks relating specifically to Covid-19 and the questions most commonly asked by the Who Cares? Scotland workforce, as well as wider partners and friends

Participants:

Care Experienced people

Key Findings:

The evidence gathered so far by Who Cares? Scotland displays how many Care Experienced people are experiencing the negative effects of competing rights

4 Themes

- Poverty

Those experiencing poverty, insecure housing and homelessness will experience significant challenge in accessing support and applying preventive measures during the Covid-19 pandemic

- Health and wellbeing,

One of the most common issues faced by Care Experienced people of all ages has been the daunting prospect of social isolation and loneliness.
Not being able to be in close physical proximity to their networks of supports, friends and family, felt overwhelming by many.

Additionally, complicated family dynamics have been exacerbated during this time and without the usual supports, many are descending into crisis.

Exacerbated many Care Experienced people's mental health issues, especially when combined with ill health associated with the fear of Covid-19

- Information and Participation

It is widely accepted that one of the best ways to protect the rights of children and young people is to help ensure they are fully informed about their rights and the world around them.
14
Confidential and for intended parties only
Individuals should access up to date advice and information daily.
Equally, many children and young people in care rely on the workforce and carers to explain the complicated nature of Covid-19 to them.

It is imperative that the workforce and carers are provided with clear and simple information to help them inform those they support.

The implications of not explaining the Covid-9 pandemic calmly and clearly can lead to fear, disregard for the guidance and poor mental health. No/limited Digital access cause of distress.

There is concern about how the digital divide experienced by many could exclude some from being able to remain connected to the people, groups and discussions that they care about.

This is particularly important where individuals have specific needs, disabilities or are subject to legal systems that determine their day to day care.

There has been a lack of emphasis on maintaining the participation of Care Experienced people in the decision making processes which affect their lives, re reviews and Hearings.

- Provision of care

Carers, providers and local authorities have been attempting to interpret the general government guidance and use this to help them make decisions about how to provide care and support to those currently still in care.

The complicated nature of providing state care to children and young people means that general guidance is making it hard for the care sector to understand how to safely care for those they look after, while also respecting their wider human rights.

Recommendations:

Scottish Government and others can continue to take a human rights-based approach to protecting the health of society, ensuring any guidance or legislative developments do not limit the everyday protections that exist to support those who need it.

There is concern of a lack of tailored guidance for the workforce providing care for accommodated children and young people in Scotland's care system, especially for children's homes and schools where there is a group living environment.

The response to covid-19 has focused on care homes and health settings in a variety of areas, but there has been a gap in understanding for those working in the care system about how to cope with the pressures and impact of the outbreak, whilst still providing the support and care all looked after children and young people are entitled to from statutory services.

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2. Age UK (2020): **https://www.ageuk.org.uk/globalassets/age-scotland/documents/policy-and-research/high-4967-scotinfrom-age-scotland-big-survey---summary.pdf**
3. Mental Health In Pandemic(2021): **https://www.mentalhealth.org.uk/news/pandemic-one-year-landmark-mental-health-study-reveals-mixed-picture-scotland-anxiety-falls**
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5. Alliance Scotland: C:/Users/40012712/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/CBX2D74T/Health-Wellbeing-and-the-COVID-19-Pandemic-Final-Report.pdf
6. Scottish Parliament (2020) How has Covid-19 impacted on care and support at home in Scotland? **https://archive2021.parliament.scot/S5_HealthandSportCommittee/Inquiries/Care_at_Home_Survey_Results_Nov_2020.pdf**
7. Who Cares Scotland (2020) The Impact of covid-19 on guidance on Scotland's Care Experienced Community **file:///C:/Users/40012712/Downloads/WCS-09.04.2020-Impact-of-Covid-19-on-Care-Experienced-Community%20(1).pdf**

Annex B. Spreadsheet of Guidance.

See attached MS Excel Sheet.

Annex C. COVID-19 Guidance by Date Released

- Friday 13 March 2020: General Guidance
- Thursday 26 March 2020: Hospital discharge and admission
- Monday 30 March 2020: Visitation
- Tuesday 31 March 2020: ACP/DNACPR
- Thursday 16 April 2020: Testing
- Wednesday 22 April 2020: Testing
- Wednesday 22 April 2020: Infection prevention control
- Sunday 26 April 2020: General Guidance
- Wednesday 29 April 2020: General Guidance
- Thursday 30 April 2020: Clinical Guidance
- Friday 1 May 2020: General Guidance
- Friday 15 May 2020: Clinical Guidance
- Friday 15 May 2020: Staffing
- Sunday 17 May 2020: General Guidance
- Monday 18 May 2020: General Guidance
- Friday 22 May 2020: General Guidance
- Friday 22 May 2020: Infection prevention control
- Thursday 28 May 2020: General Guidance
- Monday 1 June 2020: Infection prevention control
- Thursday 4 June 2020: General Guidance
- Monday 15 June 2020: General Guidance
- Wednesday 24 June 2020: Testing
- Thursday 25 June 2020: Visitation
- Friday 26 June 2020: Testing
- Friday 3 July 2020: General Guidance
- Friday 3 July 2020: Testing
- Friday 3 July 2020: Testing
- Thursday 23 July 2020: Testing
- Thursday 23 July 2020: Visitation
- Tuesday 4 August 2020: General Guidance

- Thursday 17 September 2020: General Guidance
- Wednesday 7 October 2020: General Guidance
- Thursday 8 October 2020: General Guidance
- Tuesday 13 October 2020: General Guidance
- Tuesday 27 October 2020: Testing
- Friday 20 November 2020: Infection prevention control
- Tuesday 8 December 2020: Visitation
- Saturday 19 December 2020: General Guidance
- Thursday 24 December 2020: Testing
- Thursday 31 December 2020: General Guidance
- Friday 15 January 2021: Infection prevention control
- Wednesday 27 January 2021: Testing
- Saturday 20 February 2021: Infection prevention control
- Saturday 20 February 2021: Infection prevention control
- Wednesday 24 February 2021: Visitation
- Tuesday 30 March 2021: Testing
- Monday 24 May 2021: Infection prevention control
- Monday 24 May 2021: Infection prevention control
- Thursday 24 June 2021: Infection prevention control
- Thursday 24 June 2021: Infection prevention control
- Friday 25 June 2021: Visitation
- Thursday 15 July 2021: General Guidance
- Thursday 22 July 2021: General Guidance
- Saturday 24 July 2021: General Guidance
- Thursday 12 August 2021: General Guidance
- Monday 16 August 2021: Infection prevention control
- Tuesday 17 August 2021: Visitation
- Wednesday 15 September 2021: Visitation
- Friday 24 September 2021: General Guidance
- Friday 24 September 2021: Staffing
- Monday 4 October 2021: Infection prevention control
- Tuesday 26 October 2021: Staffing
- 2 December 2021: Visitation
- 3 December 2021: Infection prevention control

- 14 December 2021: Visitation
- 15 December 2021: Visitation
- 20 December 2021: Infection prevention control
- 20 December 2021: Testing
- 20 December 2021: Testing
- 22 December 2021: Visitation

Annex D. Reduction of social care delivered at home during COVID-19 in Scotland

Part I: Organisational Reports, Parliament submissions, and grey literature

- Scottish Government (1) 'Coronavirus Acts: first report to Scottish Parliament (June 2020)'. Available at: **https://www.gov.scot/publications/coronavirus-acts-two-monthly-report-scottish-parliament/pages/8/**

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- Health and Social Care Alliance Scotland, Social Care Assessment COVID-19 Human Rights Concerns (May 2020). Available at: **https://www.alliance-scotland.org.uk/blog/news/social-care-assessment-covid-19-human-**

- Scottish Human Rights Commission (2020). Social care and human rights: impact monitoring report (October 2020). Retrieved from: **https://www.scottishhumanrights.com/media/2102/covid-19-social-care-monitoring-report-vfinal.pdf**
  Sections of the report deal with human rights concerns regarding home care in Scotland during COVID-19

- Scottish Government (2020). Supporting those who provide and receive social care (November 2020). Retrieved from: **https://www.gov.scot/news/supporting-those-who-receive-and-provide-social-care/**
  Scottish government strategy for responding to lessons learned from covid-19 regarding care homes and social care at home

- Scottish Government (2020). Adult social care- winter preparedness plan: 2020 to 2021. (November 2020). Retrieved from: **https://www.gov.scot/publications/adult-social-care-winter-preparedness-plan-2020-21/**
  The plan sets out measures to comprehensively protect those who use social care support whether in community, homely or residential settings

- Care Inspectorate (2020). Delivering care at home and housing support services during the COVID-19 pandemic. Care Inspectorate inquiry into decision making and partnership working. Retrieved from: **https://www.careinspectorate.com/images/documents/5816/Delivering%20CAH%20and%20HSS%20during%20the%20COVID-19%20pandemic%20-%20%20FINAL%2022092020.pdf**
  Care Inspectorate Inquiry

- Scottish Parliament (2020). How has Covid-19 impacted on care and support at home in Scotland? (November 2020). Retrieved from: **https://archive2021.parliament.scot/S5_HealthandSportCommittee/Inquiries/Care_at_Home_Survey_Results_Nov_2020.pdf**
  Scottish parliament inquiry into covid-19 and care at home

- Age Scotland (2020). Covid-19 and Care at Home. Submission to Scottish Parliament Inquiry (November 2020). Retrieved from: **https://www.ageuk.org.uk/globalassets/age-scotland/documents/politics-and-government/consultation-responses/2020-pdf/age-scotland-submission_covid19-and-care-at-home---september-2020.pdf**
  Discusses the removal of care at home packages from March 2020 onwards and consultation with individuals with lived experience

- Inclusion Scotland (2020) How has Covid-19 impacted on care and support at home in Scotland? Submission to Scottish Parliament Social Care Inquiry (November 2020). Retrieved from: **https://archive2021.parliament.scot/S5_HealthandSportCommittee/Inquiries/HS-S5-20-SOC-7_Written_Submission_from_Inclusion_Scotland.pdf**
  Inclusion Scotland submission to November 2020 Scottish parliament social care inquiry

- The Royal College of Occupational Therapists (2020). COVID-19 impacts on care and support at home. Submission to Scottish Parliament Health and Sport Committee Inquiry. Retrieved from: **https://archive2021.parliament.scot/S5_HealthandSportCommittee/Inquiries/HS-S5-20-SOC-4_Written_Submission_from_RCOT.pdf**
  Royal College of Occupational Therapists submission to November 2020 regarding covid-19 impacts on care and support at home

- Scottish Care (2020). How has Covid-19 impacted on care and support at home in Scotland? Submission to Scottish Parliament Social Care Inquiry (November 2020). Retrieved from: **https://archive2021.parliament.scot/S5_HealthandSportCommittee/Inquiries/HS-S5-20-SOC-8_Written_Submission_from_Scottish_Care.pdf**
  Scottish Care submission to Scottish parliament on covid-19 impacts on care at home

- UNISON Scotland (2020). Care at Home Workers and Covid 19 Survey results Sept 2020. Submission to Scottish Parliament Social Care Inquiry (November 2020). Retrieved from: **https://archive2021.parliament.scot/S5_HealthandSportCommittee/Inquiries/HS-S5-20-SOC-9_Written_Submission_from_Unison_Scotland.pdf**
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  SCLD survey which found that care at home packages have been reduced or removed in many cases for people with learning disabilities.

- Inclusion Scotland (2020). Rights at risk: Covid-19, disabled people and emergency planning in Scotland **https://inclusionscotland.org/wp-content/uploads/2021/05/Rights-At-Risk-Main-Report.pdf**
  The report discusses survey findings from over 800 disabled people, and the focusing on reductions to home care using the CRPD to discuss the human rights context.

- Inclusion Scotland (2020). Initial findings of Inclusion Scotland's Covid-19 Survey. Retrieved from: **https://inclusionscotland.org/wp-content/uploads/2021/05/Initial-Findings-Report-.pdf**
  Around 30% of respondents who answered this question said that the social care support they receive has either been stopped completely or reduced

- Scotland in Lockdown (2020). Left out and locked down. Impacts of COVID-19 lockdown for marginalised groups in Scotland. Report of the Scotland in lockdown study. Retrieved from: **https://scotlandinlockdown.files.wordpress.com/2020/12/scotlock_project_report_full_dec2020-2.pdf**
  The study employed qualitative methodology to assess the lockdown's impact on marginalised groups including disabled people who rely on social care at home.

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Part II: Academic Articles

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  The study involved qualitative interviews with disabled people in Scotland and England, exploring their experiences of social care during the pandemic.

- Flynn, S., and Hatton, C. (2021). Health and social care access for adults with learning disabilities across the UK during the COVID-19 pandemic in 2020. 'Tizard Learning Disability Review'. **https://doi.org/10.1108/TLDR-06-2021-0014**
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Part III: News Articles

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Annex E. Academic Articles on Scottish Government responses to the pandemic with regard to care homes, the delivery of healthcare, and palliative care and DNACPR in Scotland.

Part I: COVID-19 and Care and Nursing Homes in Scotland

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  The study found that a blanket ban on visiting did not significantly impact covid-19 rates in care homes, but cohorting residents and staff was more effective.

- Baister, M. J., McTaggart, E., McMenemy, P., Megiddo, I., and Kleczkowski, A. (2021). COVID-19 in Scottish care homes: A metapopulation model of spread among residents and staff. Doi: **https://doi.org/10.1101/2021.08.24.21262524**
  The model developed by the researchers demonstrated that visitation to care homes and transfer of patients from hospital to care homes were not primarily responsible for driving infection rates up; the main mode of entry into care homes was staff interacting with the community.

- Giebel, C., Hanna, K., Cannon, J., Marlow, P., Tetlow, H., Mason, S., ... and Gabbay, M. (2022). Are we allowed to visit now? Concerns and issues surrounding vaccination and infection risks in UK care homes during COVID-19. 'Age and ageing', 51(1). Doi: **https://doi.org/10.1101/2021.05.20.21257545**
  Family carers were overall frustrated and angry at the strict measures in place for their visitation compared to less strict measures for staff; variability in vaccination rates and logistics around planning visits can act as barriers to family visitations.

- Palattiyil, G, Jamieson, L, McKie, L, Jain, S, Hockley, J, Sidhva, D, Tolson, D, Hafford-Letchfield, T, Quinn, N, Iversholt, R, Musselbrook, K, Mason, B and Swift, S 2021, Understanding and Reducing the Psychosocial Impact of Coronavirus Social Distancing and Behavioural Changes on Families of Care Home Residents in Scotland. Chief Scientist Office
  The inability to touch and see their loved ones was associated with mental distress, and concerns were raised over the implications of blanket bans to face to face family visits on human rights.

- Bell, D., Comas-Herrera, A., Henderson, D., Jones, S., Lemmon, E., Moro, M., ... and Patrignani, P. (2020). COVID-19 mortality and long-term care: a UK comparison.
  This article discusses transfer of patients to care homes to a limited extent, and suggests that data on patient transfers to care homes during the pandemic is lacking.

- de Caestecker, and von Wissmann, B. (2021). COVID-19: decision-making in public health. The Journal of the Royal College of Physicians of Edinburgh, 51(S1), S26–S32. Doi: **https://doi.org/10.4997/JRCPE.2021.238**
  The article briefly discusses the impact of strategic responses to covid-19 in care homes, in particular the impact of reduced or a ban on visitation on staff, as part of a broader evaluation of public health decisions in Scotland.

Part II: The impact of the Scottish Government response to COVID-19 on healthcare provision

- Mulholland, R. H., Wood, R., Stagg, H. R., Fischbacher, C., Villacampa, J., Simpson, C. R., ... and Sheikh, A. (2020). Impact of COVID-19 on accident and emergency attendances and emergency and planned hospital admissions in Scotland: an interrupted time-series analysis. 'Journal of the Royal Society of Medicine', **113**(11), 444-453. Doi: **https://doi.org/10.1177/0141076820962447**
  The UK lockdown is likely to have had a strong impact in reducing A&E attendances in Scotland.

- Fixsen, D. A., Barrett, D. S., and Shimonovich, M. (2021). Supporting Vulnerable Populations During the Pandemic: Stakeholders' Experiences and Perceptions of Social Prescribing in Scotland During Covid-19. 'Qualitative Health Research', Doi: **https://doi.org/10.1177/10497323211064229**
  Some patients faced barriers when social prescribing moved online as a result of government policies.

- Campbell, C., Sommerfield, T., Clark, G. R. ., Porteous, L., Milne, A. M., Millar, R., Syme, T., and Thomson, C. S. (2021). COVID-19 and cancer screening in Scotland: A national and coordinated approach to minimising harm. 'Preventive Medicine', **151**, 106606–106606. **https://doi.org/10.1016/j.ypmed.2021.106606**
  This article discussed the government's decision to suspend cancer screening during covid-19.

- Cardno, S. J., and Sahraie, A. (2021). The expanding backlog of mental health patients: Time for a major rethink in COVID-19 policy. Doi: **https://doi.org/10.31234/osf.io/st5b2**
  This article discusses the impacts of government policies which resulted in a reduction of referrals to psychology services despite increase in need

- MacDonald, D.R.W., Neilly, D. W., Davies, P. S. E., Crome, C. R., Jamal, B., Gill, S. L., Jariwala, A. C., Stevenson, I. M., and Ashcroft, G. P. (2020). Effects of the COVID-19 lockdown on orthopaedic trauma: a multicentre study across Scotland. 'Bone and Joint Open', **1**(9), 541–548. **https://doi.org/10.1302/2633-1462.19.BJO-2020-0114.R1**
  Covid 19 lockdown resulted in fewer patients undergoing operations for orthopaedic trauma, and higher death rates for patients with the trauma.

- Wherton, J., Greenhalgh, T., and Shaw, S. E. (2021). Expanding Video Consultation Services at Pace and Scale in Scotland During the COVID-19 Pandemic: National Mixed Methods Case Study. 'Journal of Medical Internet Research', 23(10). Doi: **https://doi.org/10.2196/31374**
  This investigation of video call consultations found Scotland to be very well placed to use online platforms effectively

- Torjesen. (2021). Covid-19: First doses of vaccines in Scotland led to a substantial fall in hospital admissions. 'BMJ (Online)', **372**, Doi: **https://doi.org/10.1136/bmj.n523**
  Government policy to administer mass first dose of vaccinations= fewer hospital admissions in Scotland.

- Dick, L., Green, J., Brown, J., Kennedy, E., Cassidy, R., Othman, S., and Berlansky, M. (2020). Changes in emergency general surgery during Covid-19 in Scotland: a prospective cohort study. 'World Journal of Surgery', **44**(11), 3590-3594. Doi: **https://doi.org/10.1007/s00268-020-05760-3**
  Covid-19 and associated government measures such as restrictions to surgery and lockdown have resulted in far fewer emergency surgeries taking place in Scotland.

- Vasileiou, Simpson, C. R., Shi, T., Kerr, S., Agrawal, U., Akbari, A., Bedston, S., Beggs, J., Bradley, D., Chuter, A., de Lusignan, S., Docherty, A. B., Ford, D., Hobbs, F. R., Joy, M., Katikireddi, S. V., Marple, J., McCowan, C., McGagh, D., … Sheikh, A. (2021). Interim findings from first-dose mass COVID-19 vaccination roll-out and COVID-19 hospital admissions in Scotland: a national prospective cohort study. 'The Lancet (British Edition)', **397**(10285), 1646–1657. Doi: **https://doi.org/10.1016/S0140-6736(21)00677-2**
  Mass roll out of the first dose of covid vaccinations significantly reduced the risk of hospital admission due to covid-19 in Scotland.

- Speyer, Marryat, L., and Auyeung, B. (2022). Impact of COVID-19 public health safety measures on births in Scotland between March and May 2020. Public Health (London), 202, 76–79. **https://doi.org/10.1016/j.puhe.2021.10.013**
  The article investigates the impact of government covid-19 policies on births in Scotland- findings show public health policies generally did not impact post-natal and neo-natal outcomes

- Clarissa, C., Quinn, S., and Stenhouse, R. (2021). "Fix the issues at the coalface and mental wellbeing will be improved": a framework analysis of frontline NHS staff experiences and use of health and wellbeing resources in a Scottish health board area during the COVID-19 pandemic. 'BMC Health Services Research', **21**(1), 1–1089. **https://doi.org/10.1186/s12913-021-07103-x**
  The article investigates NHS staff experiences of healthcare organisations provisions for staff mental health support.

- Greensmith, T. S. W., Faulkner, A. C., Davies, P. S. E., Sinnerton, R. J. H., Cherry, J. V., Supparamaniam, S., MacInnes, A., and Dalgleish, S. (2021). Hip fracture care during the 2020 COVID-19 first-wave: a review of the outcomes of hip fracture patients at a Scottish Major Trauma Centre. 'Surgeon (Elsevier Science)', **19**(5), Doi:. **https://doi-org.napier.idm.oclc.org/10.1016/j.surge.2021.01.012**
  Care of patients with hip fractures has been maintained throughout the pandemic, government restrictions haven't had an impact.

- Shah, O.M. and Alaouabda, N. (2021). Knowledge, attitudes and practices regarding COVID-19 among healthcare professionals in anaesthesiology and intensive care. 'British Journal of Healthcare Management', 27(6), 1–8. **https://doi.org/10.12968/bjhc.2020.0141**
  Healthcare staff in Scotland require more professional support with a focus on physical and psychological well-being

- Khoo, Jesudason, E., and FitzGerald, A. (2021). Catching our breath: reshaping rehabilitation services for COVID-19. 'Disability and Rehabilitation', **43**(1), 112–117. **https://doi.org/10.1080/09638288.2020.1808905**
  This article discusses the impact of covid-19, and related government policies, on rehabilitation services.

- McKeigue, P.M., McAllister, D. A., Caldwell, D., Gribben, C., Bishop, J., McGurnaghan, S., Armstrong, M., Delvaux, J., Colville, S., Hutchinson, S., Robertson, C., Lone, N., McMenamin, J., Goldberg, D., and Colhoun, H. M. (2021). Relation of severe COVID-19 in Scotland to transmission-related factors and risk conditions eligible for shielding support: REACT-SCOT case-control study. 'BMC Medicine', **19**(1), 149–149. **https://doi.org/10.1186/s12916-021-02021-5**
  Policies encouraging clinically vulnerable individuals to shield are limited by factors like living with other adults and the receipt of hospital care in Scotland.

- Alsallakh, M.A., Sivakumaran, S., Kennedy, S., Vasileiou, E., Lyons, R. A., Robertson, C., Sheikh, A., and Davies, G. A. (2021). Impact of COVID-19 lockdown on the incidence and mortality of acute exacerbations of chronic obstructive pulmonary disease: national interrupted time series analyses for Scotland and Wales. 'BMC Medicine', **19**(1), 124–124. **https://doi.org/10.1186/s12916-021-02000-w**
  Lockdown policies were associated with reduced acute COPD and mortality related to COPD in Scotland and Wales (study took place in Scotland and Wales)

- Cheng, K.K., Anderson, M. J., Velissaris, S., Moreton, R., Al-Mansour, A., Sanders, R., Sutherland, S., Wilson, P., and Blaikie, A. (2021). Cataract risk stratification and prioritisation protocol in the COVID-19 era. 'BMC Health Services Research', **21**(1), 153–153. **https://doi.org/10.1186/s12913-021-06165-1**
  Restrictions to non-essential surgery in Scotland has led to a long waiting list for cateract surgery, which needs to be addressed.

- Dean,N. (2021). Hospital admissions due to COVID-19 in Scotland after one dose of vaccine. 'The Lancet (British Edition)', **397**(10285), 1601–1603. **https://doi.org/10.1016/S0140-6736(21)00765-0**
  Discussion on the effect the vaccine first dose had on hospital admissions for covid in Scotland.

- Holdsworth, L., Provan, D., Nash, G., Beswick, M., Curran, C., Colhart, I., and Hunter, A. (2021). Can webinars support the implementation of video consultations at pace and scale within the allied health professions? 'British Journal of Healthcare Management', **27**(2), 1–9. **https://doi.org/10.12968/bjhc.2020.0127**
  Education webinars were an effective tool in enhancing healthcare staff confidence in conducting video consultations during the covid-19 pandemic in Scotland.

- Magowan R and Smith, K. (2020). Fast-track training of temporary healthcare support workers to supplement hospital staff during the COVID-19 pandemic. Nurs Older People. Doi: 10.7748/nop.2020.e1303.
  The article discusses the benefits of Scotland's strategic response to rapidly training volunteers/staff from non-clinical backgrounds to supplement hospital staff during the Covid-19 pandemic.

- Parsons, J.A., and Romanis, E. C. (2021). 2020 developments in the provision of early medical abortion by telemedicine in the UK. 'Health Policy (Amsterdam)', **125**(1), 17–21. **https://doi.org/10.1016/j.healthpol.2020.11.006**
  The article charts the updated clinical guidance on rules related to terminating pregnancies, in line with Scottish policy, with a focus on Scotland. (part 2 of the study discusses English policy)

- Torrance, F., Purshouse, K., Hall, P., Mackean, M., and Phillips, I. (2021). MA10. 10 Lung Cancer Admission Rates During the COVID-19 Pandemic to a Tertiary Cancer Centre in South East Scotland. 'Journal of Thoracic Oncology', **16**(3), S172.
  The lockdown may have prevented patients with lung cancer from seeking medical care in Scotland; patients seeking medical care presented with more advanced symptoms, patients with lung cancer are a particularly vulnerable group.

Part III: The Delivery of end-of-life care and DNACPR

- Hetherington, L., Johnston, B., Kotronoulas, G., Finlay, F., Keeley, P., and McKeown, A. (2020). COVID-19 and Hospital Palliative Care – A service evaluation exploring the symptoms and outcomes of 186 patients and the impact of the pandemic on specialist Hospital Palliative Care. 'Palliative Medicine', **34**(9), 1256–1262. **https://doi.org/10.1177/026921632094978 6**
  The impact that covid-19 has had on palliative care in Scotland.

- Nyatanga. (2021). Achieving palliative care access for all: A lens on Scotland. British Journal of Community Nursing, 26(6), 307–307. **https://doi.org/10.12968/bjcn.2021.26.6.307**
  The article discusses the link between measures brought in during the pandemic e.g. social distancing and barriers to palliative care.

- Johnston, B., and Blades, S. (2020). COVID-19: using "knitted hearts" in end-of-life care to enable continuing bonds and memory making. 'International Journal of Palliative Nursing', **26**(8), 391–393. **https://doi.org/10.12968/ijpn.2020.26.8.391**
  Covid-19 restrictions meant that family members and other loved ones weren't able to visit patients in person, and "knitted hearts" were introduced as a mechanism to help individuals make memories with their loved one before their passing (Glasgow).

- Ellis, K., and Lindley, L. C. (2020). A Virtual Children's Hospice in Response to COVID-19: The Scottish Experience. Journal of Pain and Symptom Management, 60(2), e40–e43. **https://doi.org/10.1016/j.jpainsymman.2020.05.011**
  The researchers discuss the barriers to the provision of hospice care for children online as a result of Covid-19 in Scotland.

Footnotes

1. Article 2 European Convention on Human Rights (ECHR); Article 10 Convention on the Rights of Persons with Disabilities (CRPD).
2. Article 5 ECHR; Article 14 CRPD.
3. Article 8 ECHR; Article 12 CRPD.
4. Article 3 ECHR; Article 15 CRPD.
5. Article 17 CRPD.
6. Article 6 ECHR; Article 13 CRPD.
7. Article 25 CRPD; Article 12 International Covenant on Economic Social and Cultural Rights.
8. Article 19 CRPD.
9. Article 14 ECHR; Articles 3 and 5 CRPD.
10. Article 14 ECHR; Article 5 CRPD.
11. J Stavert and C McKay 'Scottish mental health and capacity law: The normal, pandemic and 'new normal'' (2020) 71(July-August) 'International Journal of Law and Psychiatry' 101593 **https://doi.org/10.1016/j.ijlp.2020.101593**
12. Sections 2, 3 and 6 Human Rights Act 1998
13. Sections 2, 3 and 6 Human Rights Act 1998; sections 27(2)(d) and 57(2) Scotland Act 1998.
14. Sections 35(1)(a) and 58(1) Scotland Act 1998.
15. HC Deb 23 March 2020, vol 674, col. 36 (Secretary of State for Health and Social Care (Matt Hancock)). Available at **https://hansard.parliament.uk/Commons/2020-03-23/debates/F4D06B4F-56CD-4B60-8306-BAB6D78AC7CF/CoronavirusBill**; SP OR 1 April 2020, col. 6–8 (The Cabinet Secretary for the Constitution, Europe and External Affairs (Michael Russell)). Available at: **http://www.parliament.scot/parliamentarybusiness/report.aspx?r=12602&i=113926#ScotParlOR**

16. The UK Coronavirus Act 2020 expires after 2 years (section 89(1)) and the Coronavirus (Scotland) Act 2020 is reviewed every 6 months over a maximum period of 18 months (section 12).
17. Article 15(2) ECHR; Articles 10 and 11 CRPD.
18. Article 5 CRPD; Committee on the Rights of Persons with Disabilities 'General Comment No 6 (2018) on Equality and Non-Discrimination' CRPD/C/GC/6 28 April 2018.
19. No exceptions with COVID-19: "Everyone has the right to life-saving interventions" – UN experts say (26 March 2020) **https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=25746&LangID=E**
20. Articles 12 (supported decision-making), 2, 5(3), 14(2), 24(2) (c), 24(5) and 27(1)(i) (reasonable accommodation and 2 and 4(1)(f) CRPD (universal design). See also Committee on the Rights of Persons with Disabilities (1) 'General Comment No 1 (2014)' (op cit); (2) 'General Comment No 5 (2017) on living independently and being included in the community' CRPD/C/GC/5 27 October 2017; and (3) 'General Comment No 6 (2018) (ibid)'.
21. United Nations Committee on the Rights of Persons with Disabilities (Chair), on behalf of the Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, 'Joint Statement: Persons with Disabilities and COVID-19'. Available at: **https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25765&LangID=E**
22. Committee on the Rights of Persons with Disabilities General Comment No 1 (2014) Article 12 – Equal recognition before the law, CRPD/C/GC/1, 11 April 2014.
23. **Healthcare standards: Delayed discharge - gov.scot (www.gov.scot)**

24. **https://publichealthscotland.scot/publications/delayed-discharges-in-nhsscotland-monthly/delayed-discharges-in-nhsscotland-monthly-figures-for-may-2021/**
25. **CEL2013_32.pdf (scot.nhs.uk)**
26. Para 4.12 **Adults with incapacity: code of practice for local authorities - gov.scot (www.gov.scot)** Scottish Government Guidance 'for local authorities: provision of community care services to adults with incapacity' CCD5/2007, 30 March 2007. **https://www.sehd.scot.nhs.uk/publications/CC2007_05.pdf**
27. Article 8 ECHR; Article 12 CRPD.
28. **P (by his litigation friend the Official Solicitor) (Appellant) v Cheshire West and Chester Council and another (Respondents), P and Q (by their litigation friend, the Official Solicitor) (Appellants) v Surrey County Council (Respondent) (supremecourt.uk)**
29. Mental Welfare Commission for Scotland 'Mental Welfare Commission response to queries related to when to use s13ZA v Guardianship following the Cheshire West Supreme Court decision' 17 September 2014. Available at: **https://www.mwcscot.org.uk/sites/default/files/2019-07/cheshire_west_draft_guidance.pdf**
30. **Scottish Law Commission :: Adults with incapacity (scotlawcom.gov.uk)**
31. **Adults with Incapacity Reform - Scottish Government - Citizen Space (consult.gov.scot)**
32. **Equality and Human Rights Commission reaches settlement on ending unlawful detention of adults with incapacity by NHS Greater Glasgow and Clyde | Equality and Human Rights Commission (equalityhumanrights.com)**
33. Sch 3, para 11(1) Coronavirus (Scotland) act 2020.
34. Section 13ZA must adhere to section 1(4) Adults with Incapacity (Scotland) Act 2000.

35. Para 7.1.3.4. **Coronavirus Acts: first report to Scottish Parliament (June 2020) - gov.scot (www.gov.scot)**
36. Coronavirus Acts: First Report to the Scottish Parliament (June 2020), para 7.1.3.5; Coronavirus Acts: Second Report to the Scottish Parliament (August 2020) , para 7.1.3.5; Coronavirus Acts: Third Report to the Scottish Parliament (October 2020) , para 7.1.3.5. [links to add]
37. **Discharges from NHSScotland hospitals to care homes - Between 1 March and 31 May 2020 (revised) - Discharges from NHSScotland hospitals to care homes - Publications - Public Health Scotland**
38. **Coronavirus (COVID-19): speech by Cabinet Secretary for Health and Sport 17 March 2020 - gov.scot (www.gov.scot)**
39. **new+admission-transfer+form.docx (live.com)**
40. **www.ohb.scot.nhs.uk/sites/default/files/publications/Response%20Letter%20FOI%20Request%20202021-087.pdf**
41. **Hospital and care home admissions discussed by Covid-19 Advisory Group: FOI release - gov.scot (www.gov.scot)**
42. **Official Report (parliament.scot)**
43. **Publication (nrscotland.gov.uk)** NRS statistics 2020 week 22
44. **lessons-learned-report-final.pdf (hscscotland.scot)**
45. **Hospitals in five Scottish health boards sent patients into care homes after they had tested positive for Covid-19 - The Sunday Post**
46. **<unspecified> (parliament.scot)** S5O-04709
47. See also **Sturgeon refuses to say when she knew patients with Covid put in care homes | HeraldScotland**
48. **Discharges from NHSScotland hospitals to care homes - Between 1 March and 31 May 2020 (revised) - Discharges from NHSScotland hospitals to care homes - Publications - Public Health Scotland**

49. **AuthorityToDischarge-Report_May2021.pdf (mwcscot.org.uk)**
50. **Coronavirus: More than 25,000 patients discharged to care homes in crucial 30 days before routine testing | The Independent | The Independent** and **What went wrong (and right) in hospital discharge for older adults during the pandemic | Comment | Health Service Journal (hsj.co.uk)**
51. **Delayed Hospital Discharges in Scotland: What Happened in March 2020? – Resources to support community and institutional Long-Term Care responses to COVID-19 (ltccovid.org)**
52. **Covid in Scotland: Government 'failed' social care sector during pandemic - BBC News**
53. Articles 2 and 15(1)-(2) ECHR; Articles 10 and 11 CRPD.
54. Article 8 ECHR; Article 12 CRPD.
55. Article 5 ECHR; Article 14 CRPD.
56. Scottish Human Rights Commission 'Visiting Guidance for Care Homes' 1 September 2020. Available at: **20_09_01_carehomesvisitingletter.pdf (scottishhumanrights.com)**
57. WHO, 'Infection prevention and control guidance for long-term facilities in the context of COVID-19', Interim guidance 8 January 2021.
58. **HPS Website - Covid-19 guidance archive (scot.nhs.uk)**
59. **Coronavirus (COVID-19): clinical and practice guidance for adult care homes - gov.scot (webarchive.org.uk)**
60. This and subsequent guidance are at **Coronavirus (COVID-19): adult care homes visiting guidance - gov.scot (www.gov.scot)**
61. **PE01841: Allow a designated visitor into care homes - Getting Involved : Scottish Parliament**
62. **https://consult.gov.scot/pandemic-response/annes-law-legislation/**

63. **https://www.alzscot.org/news/the-launch-of-a-new-action-on-rights-team**
64. It was originally established (as the Social Care and Social Work Inspectorate) by the Public Services Reform (Scotland) Act 2010
65. **A_message_from_Care_Inspectorate_CEO_17_March_update.pdf (careinspectorate.com)**
66. Coronavirus (Scotland) (No 2) Act 2020, Schedule 1 Part 9
67. **Coronavirus (COVID-19): care home oversight - gov.scot (www.gov.scot)**
68. **Coronavirus+%28COVID+19%29+-+enhanced+professional+clinical+and+care+oversight+of+care+homes+%28003%29.pdf (www.gov.scot)**
69. **Coronavirus (COVID-19): care home outbreaks - root cause analysis - gov.scot (www.gov.scot)**
70. **Inspection during Covid-19 (careinspectorate.com)**
71. **Quality_indicators_Key_question_7.pdf (careinspectorate.com)**
72. **Official Report (parliament.scot)**
73. **Care-Home-Assurance-11.06.2020-CSWA-Scottish-Government.pdf (socialworkscotland.org)**
74. **Published responses for How well is the Care Inspectorate fulfilling its statutory roles? - Scottish Parliament - Citizen Space**
75. **Inspection during Covid-19 (careinspectorate.com)**
76. **CI Role Purpose Learning during COVID-19.pdf (careinspectorate.com)**
77. **Adult scrutiny report Mar 21.pdf (careinspectorate.com)**
78. **How well is the Care Inspectorate fulfilling its statutory roles? - Scottish Parliament - Citizen Space**
79. **https://www.gov.scot/publications/root-cause-analysis-care-home-outbreaks/pages/6/**

80. **The suspension of routine inspections renders care homes invisible to scrutiny and costs lives | British Politics and Policy at LSE**
81. **Covid Scotland: 14 care homes had some of highest deaths and complaints, now we must ask why | The Scotsman**
'There must be an investigation into the Care Inspectorate': Scottish councillor speaks on death of father in care home | The Scotsman
82. **Covid Scotland: Just one in 20 care homes complaints investigated by Care Inspectorate during pandemic | The Scotsman**
83. **Double standards claim over NHS and care home deaths (healthandcare.scot)**
84. **Revised guidance on reporting of deaths during coronavirus outbreak (copfs.gov.uk)**
85. **20-2008-form-for-applicant-q1.pdf (scotland.police.uk)**
86. **Double standards claim over NHS and care home deaths (healthandcare.scot)**
87. **The full picture of Covid-linked deaths in Scotland's care homes - BBC News**
88. **Tracking care home deaths in Scotland | Tableau Public**
89. **Coronavirus in Scotland: What is known about care home deaths? - BBC News**
90. **Decision 076/2021 (itspublicknowledge.info)**
91. Scottish Government, 'COVID-19 Guidance: Clinical Advice', 3rd April 2020, version 2:3. This appears to have been deleted from the Government's online coronavirus information
92. Scottish Government, 'COVID-19 Guidance: Ethical Advice and Support Framework', 3rd April 2020, version 2:2. Later version available at: **https://www.gov.scot/publications/coronavirus-covid-19-ethical-advice-and-support-framework/**

93. Key Summary, 'Ethical Advice and Support Framework (ibid)'.
94. 'Ibid', p4.
95. See, for example, Scottish Human Rights Commission 'Letter to Equalities and Human Rights Committee on COVID-19 Emergency Legislation' (28 April 2020). Available at: **https://www.scottishhumanrights.com/media/2012/letter-in-response-to-ehric-committee-270420.pdf**; The ALLIANCE comments on draft COVID-19 clinical and ethical guidance. Available at **https://www.alliance-scotland.org.uk/blog/news/the-alliance-comments-on-draft-covid-19-clinical-and-ethical-guidance/**; Centre for Mental Health and Capacity Law (1) 'Comment on Scottish Government CMO COVID-19 Guidance: Clinical Advice (version 2:3)', 3 April 2020.Available at: **http://blogs.napier.ac.uk/cmhcl-mhts/2020/04/08/comment-on-cmo-covid-19-guidance-clinical-advice-version-23-3rd-april-2020/**; and (2) 'Comment on Scottish Government CMO COVID-19 Guidance: Ethical Advice and Support Framework (version 2:2)', 6 April 2020. Available at: **http://blogs.napier.ac.uk/cmhcl-mhts/2020/04/06/comment-on-scottish-government-cmo-covid-19-guidance-ethical-advice-and-support-framework-version-22/**
96. Scottish Government, 'Coronavirus (COVID-19): Framework for Decision-Making', 23rd April 2020. Available at: **https://www.gov.scot/collections/coronavirus-covid-19-framework-for-decision-making/**
97. 'Ibid', p8
98. For example, the 'Ethical Advice and Support Framework' states as an ethical consideration that doctors should act 'in accordance with their legal obligations' without saying what they are (p6).

99. The Key Summary of the 'Ethical Advice and Support Framework' says that 'Doctors should be assured that decisions taken in good faith, in accordance with national actions and guidance to counter COVID-19, will not be held against them'.
100. **Coronavirus (COVID-19): clinical guidance and ethical advice and support framework - impact assessment - gov.scot (www.gov.scot)**
101. UN Secretary General, 'Policy Brief: A Disability-Inclusive Responses to Covid-19', May 2020, pp5-6. Available at: **https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2020/05/sg_policy_brief_on_persons_with_disabilities_final.pdf**. See also WHO 'Disability Considerations during the COVID-19 outbreak', WHO/2019-nCoV/Disability/2020.1, 2020, p10. Available at: **https://www.who.int/publications-detail/disability-considerations-during-the-covid-19-outbreak**
102. NICE, 'Critical Frailty' Scale, 2009. Available at: **https://www.nice.org.uk/guidance/ng159/resources/clinical-frailty-scale-pdf-8712262765**
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