COVID INQUIRY MODULE 2B

WRITTEN OPENING SUBMISSIONS FOR
HEARING COMMENCING 27 FEBRUARY 2024
JOHN'S CAMPAIGN AND CARE RIGHTS UK

Introduction

1. These submissions focus on core decision-making in Wales from the perspective of those needing and providing care ("the care sector"). This is for two reasons. Firstly, those needing care were one of the groups worst hit by the pandemic and its response, so should have received far greater and more urgent attention from core decision-makers. Secondly, the care sector is a useful context to illustrate some of the more general flaws in core decision-making.

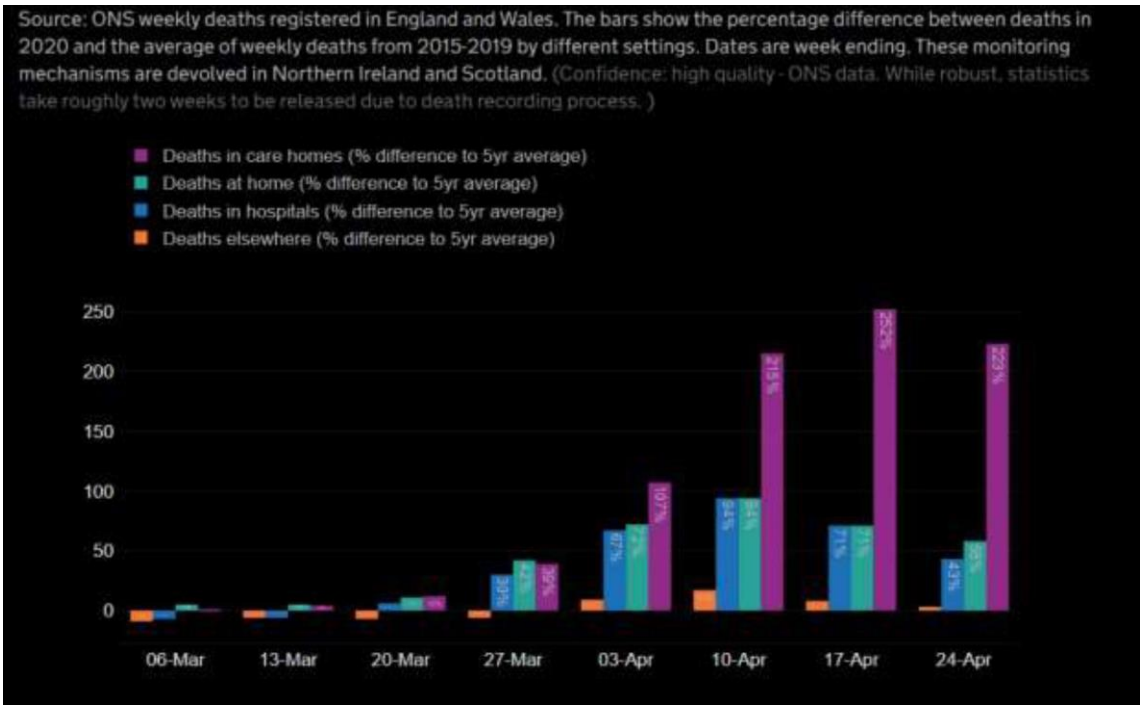
2. It is worth noting at the outset that people needing care are not a homogeneous group of elderly people living in care homes, they also comprise younger people who cannot live independently, people needing care in hospital, people in mental health institutions and people who are being cared for at home. All of them need care, due to a disability within the meaning of s.6 of the Equality Act 2010, or other condition. They should have been protected by equality legislation including the duty in s.20 and 21 of the 2010 Act to make reasonable adjustments for disabled people. But instead there were widescale breaches of those duties, exacerbating existing disadvantages and leading to worse outcomes than for any other sector of society.

3. The care sector was at the sharp end of the pandemic. Nearly 40% of deaths involving Covid-19 in the first three months of the pandemic were suffered by care home residents. There were many more deaths in domiciliary care. It was obvious from the beginning that those in care were extremely vulnerable to Covid-19 and to the restrictions which responded to it, as were some of those caring for them. In consequence, people requiring and providing care ought to have been a central focus in core decision-making. But they were neglected.

4. This was partly due to broader problems in core decision-making. For example, the views and evidence of those people receiving and providing care were not taken into account. There was a failure to inquire into or properly take into account the serious indirect harm resulting from the restrictions. This led to a series of flawed core decisions which impacted upon the care sector. They included the discharge of large numbers of people from hospital into care homes, without testing. They included the imposition of stringent and inappropriate restrictions on visits to, and from, those needing care, which had a severe adverse impact on those affected. Guidance produced by the government and Public Health Wales ('PHW') was confusing and contradictory. There was a lack of access to testing, to Personal Protective Equipment ('PPE'), and to other support and financial assistance. These issues will each be considered in more detail below.

Why people needing and providing care should have had a more central place in core decision-making

5. Those in care were among the most severely affected by the pandemic and its response. In week ending 17 April 2020, deaths in care homes in England and Wales were **252% higher than average –** a far higher increase than in hospitals or elsewhere:



INQ000185073, p30

6. This is a weekly rate of about 22 deaths per 1,000 residents (see Nuffield Trust report[1]). If that continued, it would kill the entire care home population in less than a year.

7. In the week ending 24 April 2020, 34% of Covid-19 deaths were in care homes (INQ000185073, p29). The number of deaths of care home residents (some of whom died after being taken to hospital) was even higher. From 1 March 2020 to the end of June 2020 **39% of deaths in the UK involving Covid-19 were deaths of care home residents** (see ONS statistics[2]). Given that care home residents make up only a small proportion of the total population, this means that the mortality rate for care home residents was far higher than for

[1] N. Edwards and N. Curry 'Deaths in care homes: what do the numbers tell us?' (*Nuffield Trust*, 1 May 2020) <www.nuffieldtrust.org.uk/news-item/deaths-in-care-homes-what-do-the-numbers-tell-us> accessed 20 February 2024.

[2] Office for National Statistics Webpage, 'Deaths involving COVID-19 in the care sector, England and Wales (*ONS*, 28 February 2022) https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsinvolvingcovid19inthecaresectorenglandandwales> accessed 20 February 2024; Office for National Statistics Webpage, 'Deaths involving COVID-19, England and Wales: deaths occurring in June 2020' (*ONS*, 17 July 2020) <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingcovid19englandandwales/deathsoccurringinjune2020> accessed 20 February 2024.

the rest of the population (see also INQ000252649, figure 9). There were a considerable number of additional deaths in domiciliary care. From 10 April to 19 June 2020 the rate of death in domiciliary care in England was 225% higher than average: (INQ000252649, p2 and 22).

8. In consequence, it should have been clear to core decision makers from late March 2020 that something was going badly wrong in the care sector. Care home residents were such a large proportion of those dying that they should have been front and center of core decisions (see report by International Long Term Care Policy Network[3]). The crisis in the care sector was not only apparent from the statistics. Stakeholders also informed the government about it. For example, on 7 May 2020 Care Forum Wales told the HSCSC that "*there is an enormous amount of trauma in the [care] sector*": INQ000183753, p36.

9. Yet despite this, the care sector was neglected by core decision-makers. Many of these deaths, and much of the wider harm to people in the care sector, was preventable. The Older People's Commissioner for Wales, Helena Herklots CBE, said in her 18 August 2020 report:

> "Many of these deaths could have been prevented had there been a better understanding of the risks faced by care home residents and the action required to ensure they had the protection and support they needed": INQ000184908, p11.

10. Some of the specific respects in which core decisions failed to prevent the catastrophe in the care sector are addressed below. Many of the flaws in decisions are not limited to the care sector, but are broader problems with core decision-making. They concern procedural deficiencies, and also substantive flaws. The former led into the latter so will be considered first. They include;

    a. Failure to properly identify or take into account indirect adverse effects of restrictions. This had a significant impact on the care sector because the indirect harm for those in need of care and their care-givers was severe;

    b. Failure by core decision-makers to obtain or take into account views and evidence from relevant experts or stakeholders, including in relation to the care sector;

    c. Substantive flaws in core decision-making included:

        i. The decision to discharge patients from hospitals to care homes early in the pandemic without testing;
        ii. Prolonged and stringent restrictions, including on safe visits to or by those needing care, while permitting unsafe staff mobility;
        iii. Blanket policies with insufficient flexibility to take into account individual risks and needs;
        iv. Chaotic and insufficient supply of PPE to the care sector;
        v. Conflicting and unclear guidance;

[3] D. Bell et al, 'Covid-19 mortality and long-term care: a UK comparison' (*International Long Term Care Policy Network,* 29 August 2020) < https://ltccovid.org/wp-content/uploads/2020/08/COVID-19-mortality-in-long-term-care-final-Sat-29-v1.pdf> accessed 20 February 2024.

vi. Lack of support, including financial support, for the sector and those working within it.
vii. Insufficient response to widespread reports of inappropriate 'Do not attempt resuscitation' decisions being made in respect of people needing care, without their consent.

Unpaid carers

11. It is also important to note that those providing and receiving unpaid care formed a huge part of the population, who were particularly badly affected, which again ought to have resulted in their prioritisation in core decision-making. Unpaid care is the largest source of adult care provision: INQ000232391 (Welsh government white paper on social care). Carers UK estimates that there are between 5.7 million and over 13 million unpaid carers in the UK. They outnumber medical and social care staff by between 2:1 and 4:1: INQ000099707, p1-2. There was a huge increase in the number of unpaid carers after the start of the pandemic, of about 4.5million: *ibid* p7.

12. Many of the flaws identified below apply equally to unpaid carers. This had serious consequences. 57% of unpaid carers felt overwhelmed by the pandemic and its response: Equality Impact Assessment, 6 July 2020, INQ000087143. Carers UK reported that:

> "of the 81% of carers who said they were providing more care, 78% said it was due to the condition of the person they were caring for deteriorating, and carers described loss of abilities such as walking, talking, eating themselves, cognitive decline that was faster than expected, more challenging behaviour, poorer mental health… this has been devastating for unpaid carers…" *Ibid.*

<u>Indirect harm was not given sufficient attention</u>

13. Core decision-makers failed to pay any, or sufficient, attention to, and failed to mitigate, the indirect harm of the Covid response: that is, harm caused by the response itself, rather than by Covid-19. For individuals in need of care, indirect harm was very serious indeed, and in some respects as severe as the harm caused by Covid-19 itself. Too much reliance was placed on data about Covid-19 that could be counted, rather than to evidence of indirect harms that built to a massive, to some extent avoidable, quantity of human suffering. Yet for a long time there was little or no acknowledgement of it.

Indirect harm

14. The pandemic response led to devastating indirect harm. First, it is important to note that during the pandemic, Covid-19 only accounted for a small proportion (16.7%) of deaths of care home residents (see ONS table 2, Section 1, 'Main points'[4]). This means that non-Covid-

[4] Office for National Statistics Webpage, 'Deaths involving COVID-19 in the care sector, England and Wales: deaths registered between week ending 20 March 2020 and week ending 21 January 2022' <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsregisteredbetweenweekending20march2020andweekending21january2022> accessed 20 February 2024.

19 causes accounted for 83.3% of those deaths. Dementia and Alzheimer's remained the leading cause of death in Wales in care homes throughout the pandemic, including between 14 March 2020 and 21 January 2022 (*ibid,* table 2). Covid-19 was therefore far from the only 'harm' relevant to whether restrictions were appropriate.

15. Second, the restrictions led to severe interruptions to the care and treatment available to people who needed it for reasons other than Covid-19. For example, the number of people awaiting medical treatment, including for serious conditions such as cancer, increased about 9 fold: INQ000300217, §2, pages 20, 22, 35-36. A Patient Association survey recorded that 67% of respondents had appointments cancelled as a result of the pandemic (INQ000273424, p22). The follow up survey recorded 66% struggled to access at least one form of care, and 56% delayed access to treatment (INQ000273425, p3). In the first lockdown, 54% fewer patients received operations in Wales (INQ000274189, §28). Ms Herklots has produced evidence that many older people or people needing care were unable to access a broad range of healthcare and treatment, including GP services: INQ000232394; INQ000181725 (21 June 2020); and INQ000184990.

16. Third, restrictions on access to carers had very serious adverse impacts. For many people needing care, access to familiar carers is very important, particularly for dementia or Alzheimer's sufferers, who rely very heavily on their carers for their critical needs. This is explained in detail in the reports by Ms Herklots (e.g. INQ000232394) and the witness statement by John's Campaign, Care Rights UK and the Patients' Association (INQ000283957). For example, they referred to the Alzheimer's Society report (INQ000273455), which concluded "*Lockdown isolation caused shocking levels of decline for people with dementia".* They explained: "*relatives or close friends often act as the eyes, ears or voice of people needing care, helping them to communicate or being a crucial confidant about health concerns or pain levels, as well as assisting with provision/facilitation of consent to medical procedures and treatment. Without this support, we heard of the impact on people's lives, including health concerns going undiscovered until they were serious, inappropriate medications being given, and treatment being more distressing without the reassurance provided by a family carer, or not taking place*." §61. This led to mental and physical health deterioration (§44, 101 and see also INQ000273453, and case studies at INQ000273460). Person-centred care is the only treatment known to improve dementia, and by removing family or familiar carers, this form of treatment was denied (§42).

17. Fourth, the fact of isolation itself had serious adverse impacts. A report by Amnesty International[5] about the UK government's failure to protect older people needing care homes during the pandemic (2020) contains detailed evidence collected by Amnesty, including by numerous interviews of those affected by the pandemic, concluded that: "*Every single one of the family members and care home staff interviewed by Amnesty International expressed concern that the prolonged isolation of care homes residents … had devastating consequences*." p39. (We recommend the Chair reads the Amnesty report in full for this module, in part due to the first hand evidence from the victims of the pandemic it includes,

[5] Amnesty International 'As If Expendable – The UK Government's Failure to Protect Older People in Care Homes During the Covid-19 Pandemic' (*Amnesty,* October 2020) < https://www.amnesty.org.uk/files/2020-10/Care%20Homes%20Report.pdf> accessed 20 February 2024.

which is lacking in the evidence obtained by the Inquiry.) The Welsh Government November 2022 paper (INQ000300217) refers to a number of studies of the effects of the restrictions on people in need of care, which included: "*depressive symptoms… increased somatic symptoms, physical deterioration and, in psychogeriatric residents, rapid cognitive decline and changes in neurospsychiatric symptoms including agitation and aggression as a result of the restrictions in visitations*": p35-36.

18. Those in care homes were, at times, prevented from being with their loved ones at the end of their lives, dying alone: INQ000273424, p39. Care Forum Wales explained that visiting restrictions in care homes caused untold pain and distress, leaving many patients and their families isolated at end of life. They also drew attention to the "*devastating experiences of caring for loved ones at home*": INQ000183756. Similarly, Ms Herklots' report (INQ000181725, June 2020) explained that the adverse impact of a ban on visits to care home residents, and isolation, caused a serious decline in their cognition and state of mind.

19. For those reasons (among others) the lockdown restrictions appear to have led to serious indirect harm, including a large number of excess deaths and physical and mental health problems. As to excess deaths, Cabinet Office data noted that from 6 March to 30 April 2020 there were 23,378 excess deaths from causes other than Covid-19 (similar to the number caused by Covid-19, 27,225: INQ000185073). More specifically, From 10 April to 19 June 2020 3,628 excess deaths of recipients of domiciliary care in England (225% higher than the normal death rate), of which the great majority (77.4%) were from non-covid causes.

20. As to the physical and mental health problems, an Equality Impact Assessment on 27 August 2020 identified, in respect of those with dementia, a worsening of functional independence and cognitive symptoms during the first month of lockdown (31% of people surveyed), exacerbated agitation, apathy and depression (54%) and deterioration of health status (40%): INQ000087134. The Alzheimer's Society Cymru stated: "*the effects of social isolation were severe*" INQ0001444934, (Dec 2020), p9. Age UK INQ000099714, noted that long periods of isolation had a profound impact on physical and mental health and caused trauma for families.

21. In summary, in respect of certain restrictions, particularly visiting restrictions, the harm caused by the restriction was greater than its benefit. Visiting restrictions caused large numbers of people in care homes to suffer serious mental and physical harm, and to die alone. The benefit of those restrictions was a comparatively small reduction in Covid-19. The balance between protecting people from Covid-19, and causing serious harm to the care, treatment, and quality of life of the great majority at the end of their lives, was not struck in the right place. The disproportionate nature of the restrictions was or ought to have been known from an early stage in the pandemic. Particular respects in which the restrictions should have been altered, in light of a full appreciation of indirect harm, are set out later.

Core decision makers did not properly understand or take into account this indirect harm

22. Core decision-makers failed to take into account, or decided to ignore, these indirect harms. They knew or at least ought to have known about them. Stakeholders repeatedly warned the government about the harm, particularly in respect of those with dementia and cognitive

impairment, and sought changes: e.g. Ms Herklots statement §3.6, 11.6, 11.27; and John's Campaign statement INQ000283957, §155-167, and exhibits INQ000273482, and INQ000273491 - INQ000273493. This occurred from an early stage in the pandemic, but the failure to take this into account and make appropriate changes persisted. For example, on 22 May 2022 a coalition of MPs signed a letter produced by Care Rights UK drawing attention to the continuing "devastating harm" on those in care, caused by the restrictions, and calling for a right for those in care to maintain contact with their loved ones and to have a 'care supporter': INQ000231923. Further:

a. Chief Information Officer, Cwm Taf Morgannwg University Health Board, Andrew Nelson: INQ000183828. He explained that the Technical Advisory Group ('TAG') "*did examine the impact on equity and indirect harm of covid in moderation, but lacked resources to get into great detail on this and as a result insufficient consideration was given to this as a matter…*" He is very critical of the availability of data during the pandemic and of people to analyse the data. He is concerned this remains the case: p7 of 10. As Ashley Gould from PHW recognised: "*Effective use of data and evidence to identify and address inequity is critical*": INQ000183825, §7.

b. Professor John Watkins explained: "*I highlighted early on, that people with mental health issues may be harmed by a lack of social contact, people with early stage cancer and CVD may not get the diagnosis and treatment they needed*" … "*I raised this many times and even provided the group with an evaluation matrix to track potential wider societal harms from isolation... Despite raising these issues there was no attempt to quantify, or consider, these when restrictions were being imposed*": INQ000183846.

c. Professor Chris Taylor noted that in TAG/Technical Advisory Cell ('TAC') meetings: "*Much of the discussion was focused on the virus itself and later the impact of vaccines*" rather than other issues: INQ000183842. Dr Chris Williams, Consultant Epidemiologist at PHW, describes how there was – at least initially – a "*strictly infection-focussed assessment of harms and benefits*)" (INQ000251938, §25). Dr Orford considered that the TAC/ TAG should have broader expertise through specialist subgroups to inform decision making. INQ000356177. On 1 March 2021 PHW identified the need for a "*much more sophisticated understanding of the benefits and harms*" of Covid-19 measures. INQ000056334.

d. Professor Michael Gravenor, Professor of Epidemiology and Biostatistics at Swansea University, observed that data on indirect effects was not generally available and this was frustrating as the potential for indirect effects of NPI interventions was recognised almost immediately; quantitative data to consider those factors formally, within any model framework, was unavailable; and this largely still does not exist today (INQ000347979, §77).

23. Records of core decisions during 2020 and 2021 pay lip service to indirect harm, but fail to appreciate the extent or severity of it, particularly for those needing care. That is despite repeated attempts to bring such harms to decision-makers' attention and ensure they were reflected in decision-making (see above). For example, minutes from a cabinet meeting on

16 April 2020 record that "*concerns remained about whether sufficient attention was being paid to non-coronavirus related health outcomes. The number of non-urgent cancer referrals has fallen sharply*": INQ000089020. In July 2021, TAG published guidance on the "*Five Harms Arising from COVID-19: Consideration of Potential Baseline Measures*" INQ00027356, which acknowledged "*indirect harms are less well understood and measured*" (p3).

24. Core decision-makers failed to take into account the extent and severity of the indirect harm and harm that was not easily quantifiable. The emphasis on 'following the science' often meant that a factor was ignored unless it could be counted. Policy cannot be based solely on quantifiable harms. Indirect harms may be very serious, and may be evidenced, even if they can't be counted. Decision-makers erred by too often looking for numbers in circumstances where much broader evidence should have been informing decision-making holistically.

Core decision makers did not take account of relevant expertise or data

25. There was a linked problem, which was that core decision-makers did not do enough to obtain and take into account information from experts or stakeholders. This is particularly apparent in respect of the care sector, older people and disabled people:

    a. **Homecare** consider that home care was not properly considered by government, especially in the early stages. INQ000099681. The government did not ensure sufficient input from stakeholders, and the data on this sector obtained by government was inadequate. **Disability Rights UK** consider that the government failed to consult with disabled people, and to make reasonable adjustments. They recommend that the government improve data collection about disability: INQ000099696. **Disability Wales** raise similar concerns INQ000099697. The **National Care Forum** consider that government engaged but did not listen or take concerns of the care sector into account, and data collection was problematic: INQ000099701, p2-3. **Age UK** state that there was a lack of knowledge and understanding by the government of the older population and the care sector. A specific example is a lack of knowledge of how common it was for staff to work in multiple settings: INQ000099714. **Ms Herklots'** 21 June 2020 report INQ000181725 concluded with a call for action, that the views and experiences of people in care homes should be central in shaping policy. She also drew attention to inadequacies in early data on vaccinations in care homes: WS §9.2-9.5.

    b. **Care England** consider that the care sector was "*not adequately considered by the UK Government when decisions about the response to COVID-19 were made*" and "*decision-makers across Government generally did not have a clear and sufficient understanding of the social care sector*": §8.1-8.6, INQ000099684. The views of SAGE and Public Health bodies were given precedence over care sector professionals who were presenting lived experiences and real-time data of the reality on the frontline (§8.3). Care England illustrates this by a number of examples of core decisions, such as (i) the withdrawal of NHS community services from care homes, (ii) prioritisation of the NHS in PPE distribution, and (iii) insufficient funding given to the care sector to pay for the greater costs of the pandemic. Care England

considered that this was partly because of a lack of meaningful data about, or understanding of, the care sector. Those comments appear to apply equally in Wales.

c. **Professor Wincott** noted that "*Craiger Solomons' witness statement suggests that the Welsh authorities 'did not have social care data … raising serious questions about its ability to manage social care-related aspects of the pandemic*" (at §109) and says there was "*an absence of data on social care*" which is a "*serious gap in the evidence base for policy making in Wales*" (§164). **Professor Debbie Foster**, author of the Locked Out Report (INQ000227530) said that prior to the report (despite her obvious expertise) her views or evidence were not sought (INQ000274189, §80). **Dr Robert Hoyle**, Head of Science for the Welsh Government Office for Science, said that TAG members applied their own life standards and experiences to deliberations "*and these did not correspond to life and situational experiences of other parts of the populations*", which "*inevitably produced subtle biases*" INQ000347980, §§28, 30.

26. Given the obvious vulnerability of those receiving and providing care to Covid-19 and indirect harm, decision-makers should have invited, and taken into account, the views and evidence of experts, such as those listed above. An example of good practice in is that in May 2020, when it became apparent that BAME people were hit harder by the pandemic, an expert group was quickly established by the Welsh Government to identify why and what could be done to prevent this: INQ000023243 and INQ000023260. Those in the care sector were no less hard hit. Yet no equivalent expert group with a focus on Wales was established and even where experts were consulted they were not listened to.

<u>Substantive flaws in core-decision making, relevant to the care sector</u>

27. There was a wider pattern by which core decision-makers neglected people needing or providing care. There was a "complete breakdown" (Amnesty p17)" of protection for the care sector in earlier stages of the pandemic. This included inconsistent guidance, inadequate PPE, inadequate testing, inappropriate restrictions on visits, and inadequate systems regarding staff mobility. Given the very obvious vulnerability of those in care to Covid-19 and the restrictions imposed, this failure was a serious one. It indicates that core decision-makers did not pay sufficient attention to the care sector; or that the lives of those needing care were valued less than the lives of others; or both. This would appear to result from discrimination against the elderly or those needing care (e.g. Ms Herklots' statement at §14.1.1). Core decision-makers largely neglected the duties imposed on them by the Human Rights Act 1998 and by the Equality Act 2010. There is very little reference to those duties in the records of core decisions. Had those duties been respected, it would have been necessary to give the lives and needs of those needing care equal value to those of other members of the population.

Discharge from hospitals to care homes

28. The policy first announced by the Welsh government on 17 March 2020 to discharge patients from care homes into hospitals without prior testing, was dangerous, inappropriate, and carried out with disregard for the evidence of asymptomatic transmission.

29. The risk of asymptomatic transmission, and the importance of testing, were well-known by the time of the 17 March 2020 decision, and subsequent decisions to maintain the policy. Detailed evidence to demonstrate that asymptomatic transmission was well-recognised by the time of these decisions is set out in *R (Gardner) v Secretary of State for Health and Social Care, Public Health England* & Another [2022] PTSR 1338, **at §34-125**. The Chair is entitled to take that evidence into account, pursuant to her broad powers in s.17(1) IA 2005. There is also evidence within the disclosure provided by the Inquiry, to show asymptomatic testing was well-recognised. For example, Professor Watkins states "it was clear, early on, that infected individuals with [covid-19] could be asymptomatic". He wrote a widely cited editorial in the BMJ on 28 February 2020 which explained this: INQ000183846, p9 and 12-14. See also Professor Wincott, §108. By 1 April 2020 Dr Chris Williams at PHW had said to Dr Orford "potentially a high proportion of those testing positive (and therefore likely shedding [or infectious]) are asymptomatic": INQ000224062. Yet this was not translated into a requirement for appropriate precautions such as pre-discharge testing until much later.

30. The importance of testing was also well-known by the time of these decisions. For example, on 11 March 2020 the World Health Organisation declared Covid-19 to be a pandemic and said (Amnesty p16) "We cannot say this loudly enough, or clearly enough, or often enough: … test, treat, isolate, trace, and mobilize". It repeatedly emphasised this, such as on 16 March 2020: "we have not seen an urgent enough escalation in testing, isolation and contact tracing…: test, test, test" (*ibid*). Care Home providers urgently called for testing for staff and residents from at least as early as 24 March 2020 (*ibid* p17). Experts such as the Francis Crick Institute contacted the Government in March to emphasise the importance of systematic testing (*ibid* p27).

31. The policy to discharge without prior testing, introduced on 17 March 2020, was maintained for some time, including in guidance issued on 2 April 2020. As the Welsh Government Science Evidence Advice report of November 2022 (INQ000300217) states, the 2 April guidance "overlooked the potential risk for asymptomatic transmissions by establishing that if a resident had no symptoms of Covid-19 upon discharge, the care home should provide care as normal." (p103) It also explains that, despite recognition of the importance of asymptomatic testing late in April 2020, it was not until 18 June 2020 that testing was "almost complete" (p104). Only on 1 May 2020 did the First Minister approved testing of patients on discharge from hospital into care homes (more than 2 weeks later than in England): INQ000371209, §157. There remained limitations in supply of testing for the care sector for some time after that.

32. The decisions to discharge patients into care homes, made by the Welsh government, and guidance produced by PHW, failed to have proper regard to the evidence of asymptomatic transmission. The relevant decision-making documents contain no recognition of the risk of asymptomatic transmission: see, for example: 13 March 2020 announcement by the First Minister INQ000250976; and 2 April 2020 guidance: INQ000237817; INQ000081078 and INQ000080971.

33. The following three factors mean the policy to discharge without prior testing was inappropriate: (a) asymptomatic transmission was well-recognised, (b) there were very high

rates of Covid-19 in hospitals, and (c) the care home population was highly vulnerable to Covid-19. Those three factors meant the policy would cause serious harm.

34. The decision has been subject to widespread criticism. Professor Watkins explains that he advised PHW against the discharge action they were taking: INQ000183846, p13-14. Dr Robert Hoyle said it was "*an obvious high-risk strategy even before it became clear that Covid-19 was a mostly airborne-transmission virus…This was to have a big impact on care home patients. I was not involved in the subsequent decision to tell hospitals to test patients before discharging them, but it was an obvious thing to do*" INQ000347980, §59. Patients should have been tested pre-discharge. That appears now to be accepted. In August and September 2020 the TAG published a consensus paper on what should happen prior to discharge, which included a recommendation that testing twice prior to discharge reduced the risk nearly to zero: INQ000356177, §149, Dr Orford.

35. Other aspects of the Government's policy were flawed (for more detail see (Amnesty pp18-21). For example, care homes were required to accept patients who were infected with Covid-19, regardless of whether the care home had sufficient staff, facilities and PPE to ensure the person was isolated. Many did not. This is a good example of core decision-makers failing to have regard to the expertise of those on the ground in the care sector. It is also a good example of core decision-making prioritising the needs of the NHS at all costs and to the detriment of those in care.

36. There is a striking correspondence between the introduction of discharge without prior testing after 17 March 2020, and the rate of Covid-19 sky-rocketing shortly afterwards. (Please see the chart in §4 above). After pre-discharge testing was introduced, death rates in care homes reduced: INQ000371209 §164.

Restrictions, including blanket restrictions and limits on visits

37. There were stringent restrictions which applied to those needing and providing care, including in respects of visits. They included:
    a. 23 March 2020 – 5 June 2020: visits should only take place when "absolutely essential". Family and friends should not generally attend: INQ000080878.
    b. 5 June 2020: providers encouraged to facilitate outdoor visits in certain circumstances: INQ000144921, §2.
    c. 19 October 2020 – 9 November: Welsh firebreak lockdown, and ban on visits: INQ000048802.
    d. 26 December 2020 – 8 March 2021: lockdown and ban on visits: see, e.g. INQ000273496.
    e. 8 March 2021 guidance INQ000273459 said visits were only to be considered for care home residents of working age and only in exceptional circumstances (interpreted as end of life) for older residents. It imposed a requirement to isolate for 14 days upon return from any visits out (even for medical outpatient appointments).
    f. The 14 day isolation requirement was maintained until 1 May 2021: see INQ000222639.

38. Those restrictions caused very serious harm. Some of it has been described above at §13-20; as have the repeated efforts made by John's Campaign, Ms Herklots and others to draw the harm to the attention of government from March 2020. Further detail of the harm is explained in a postion paper by Ms Herklots : WS §4.6.3 and INQ000184909. She noted that the wider harm of not permitting visits "*in some cases may be irreversible or result in a resident sadly passing away*". She then explained what could be done to reduce restrictions on visits, including using PPE, holding visits outside, a case-by-case consideration of whether visits should be permitted in light of local risks, and balancing the risk of visiting against the wider harm. (See further her August 2022 report INQ000232394). Those concerns were reflected by many others. For example, Mencap INQ000099715 state that blanket restrictions on visiting caused huge anxiety and distress, and policy did not consider reasonable adjustments needed for people with learning disability. Indeed, on 11 November 2020 the First Minister commented on: "*care home visits… really heartbreaking set of restrictions there – if people had a negative lateral flow test in the hours before, could we liberalise things there?*" INQ000198980. But the restrictions were not liberalised.

39. Given the very serious harm that resulted from preventing contact between those needing care, and their carers and loved ones, the following changes should have been made by government:
    a. Testing prior to a visit and taking measures based on actual infection status rather than assumed infection status.
    b. Further testing after a visit, to reduce the need for isolation.
    c. The use of PPE during a visit by anyone at risk, and holding visits outdoors where appropriate.
    d. An essential caregiver. This is a person nominated to provide essential care to the person needing it, and who is provided with the same testing and PPE as an ordinary member of staff, so can visit a resident frequently under all circumstances.
    e. A more selective approach. Mobility of staff, whereby staff worked in several settings, was an important vector of transmission: Welsh Government / TAG,15 May 2020: INQ000066455. Risky mobility should have been limited, so that staff who had come into recent contact with someone who may be infectious, and had not been sufficiently tested / provided with PPE, should not have contact with a vulnerable person needing care. On the other hand, a loved-one who had not had that recent contact, may be permitted to visit.
    f. Similarly, specific individualised assessment for each individual, balancing the adverse impact of denying visits (for example if that would cause a dementia sufferer a serious deterioration and potentially death), against the risk from covid of a visit. The views of the individual should be taken into account.

40. The approach to visits is illustrative of a broader problem in core decision making. Blanket approaches were too often applied (including to those needing and providing care) without scope for individual variation in a context where the indirect harm of the approach outweighed its benefit. For example, in care homes, when there was a single positive test, it was assumed that everyone was positive (INQ000283277, Written Statement by Mr Gething, 2 May 2020). The circumstances in the particular care home, for example if the person testing positive was entirely isolated from many of the other residents, were ignored.

PPE shortages for the care sector

41. In the first few months of the pandemic sufficient PPE was not made available to those providing care across a range of settings, including in domiciliary care. The National Care Forum described how "*PPE supply for the social care sector was particularly chaotic during the first wave*" INQ000099701, p4. Similarly: "*Unpaid carers were unable to access PPE because of cost or shortages*": Carers UK, INQ000099707, p10. A report worked on by Dr Chris Williams noted that poor access to PPE was a challenge for care homes (INQ000224072).

42. On 26 March 2020: Simon Hart raised concern about shortage of PPE in care homes: INQ000113639. See also 30 March 2020, INQ000180891. On 3 April 2020, the Welsh government said PPE had been made available for distribution to those in social care settings: INQ000080917. But it did not reach them for some time. On 9 April 2020 the Secretary of State for Wales noted that care homes were unable to get PPE: INQ000113667. The same occurred on 15 April: INQ000113670. The day before, on 14 April 2020, the Department for Levelling Up, Housing and Communities announced the delivery of PPE to care settings: INQ000198991. On 18 April 2020, it was acknowledged that lack of, or incorrect use of PPE contributing to the spread of Covid by staff in care homes (INQ000224075; INQ000224073, p2). On 1 July 2020 Care Forum Wales said the lack of PPE continued to be a problem: INQ000183763.

43. The reasons for this failing appear to include:
    a. That "*very early on… PPE suppliers had all their stock commandeered for English providers and they would no longer supply Welsh customers*." Care Forum Wales INQ000183764, p4.
    b. That there was initially no agreement in place to ensure that supplies provided by the Welsh government to local authorities, would then be sent to care homes as had been intended.
    c. The application of a need-only policy, as raised by Care Forum Wales: "*At the start of the crisis PPE was being rationed "until it was needed" but that didn't understand the reality of, for example, a domiciliary care worker visiting someone who was symptomatic not then just being able to leave them until PPE was available before providing care*." June 2020 INQ000183763.

Conflicting and unclear guidance

44. The guidance and regulations produced for Wales were at times conflicting, confusing and/or lacking in clarity. The need for clear guidance was identified at an early stage. For example, on 10 February 2020 Care Forum Wales asked for guidance for the care home sector, in a meeting with Welsh National Commissioning Board: INQ000183764. On 26 February 2020 Care Forum Wales wrote to Frank Atherton at the Welsh government to ask for "*any specific advice for care providers, both care homes and domiciliary care agencies, in dealing with an outbreak of coronavirus… all involved and members are concerned that they have not received any specific up to date advice*": *ibid* and INQ000183760. A more specific set of queries was sent in on 2 March 2020.

45. Together with a very general UK Action Plan, the only guidance produced at that time was the 9 March 2020 '*Guidance for Social or Community Care and Residential Settings on Coronavirus*' INQ000080847. This was extremely limited. Further guidance dated 18 March 2020 '*Covid-19 preparedness and response: framework for the health and social care system in Wales'* INQ000183668 also contained no substantive or helpful advice. An action plan for care homes was only published on 15 April 2020 INQ000338296 – a month after schools were closed (see report by Nuffield Trust). Thus, Care Forum Wales and the Older People's Commissioner considered that at an early stage, the Welsh government was "*slower to respond to the concerns of the care sector*": INQ000183764.

46. After the slow start, a large range of guidance and regulations were produced, which at times was confusing, contradictory and/or unclear both for those providing and those needing care. For example, Ms Herklots states that advice and information about what action older people should take was unclear from the beginning: WS §3.9. She, together with Age Cymru, drew attention to the importance of clear and consistent guidance from the government: §3.9, 3.11. "*Care Home Voices: A snapshot of life in care homes in Wales during Covid-19'* INQ000181725 noted rapidly changing guidance *"was often confusing or contradictory*" §10.4.4.1.6. She notes how it was "*a challenge for older people to keep up with all the changing information*": WS §3.16. This was made worse by the fact that it was unclear who could provide clarification or deal with complaints.

47. Care Forum Wales produced a report in June 2020 INQ000183763 which identified as a weakness: "*Perpetually changing guidance and lack of clarity on implementation*. "*Guidance was impossible to follow and effectively inform staff…*"" (p6). To give a specific example, Carers UK explain INQ000099707, at p9, that unpaid carers were not one of the vaccination priority groups identified on 2 December 2020, were a priority group in the 31 December 2020 announcement, were then not a priority group in each iteration of the interim Joint Committee on Vaccination and Immunisation advice, but were included as a priority in the final guidance. The National Care Forum considered that "*Particularly chaotic changes were linked to PPE, IPC, isolation and visiting*": INQ000099701, (p5). A further example is PHW guidance stating visits were permitted at the end of life, but did not define 'end of life'. John's Campaign wrote to PHW to explain that a wide range of approaches was being taken to what this meant, and inviting PHW to define it more clearly. PHW did not do so despite multiple efforts by John's Campaign: INQ0000283957 §103-104, and the documents exhibited there.

Lack of support, including financial support, for the sector

48. The government provided inadequate support, including financial support, for the care sector and those working in it. Examples are as follows.

49. First, essential care workers were not recognized as key workers until 13 October 2020. Even when they were, that did not go far enough, because essential caregivers and unpaid carers remained excluded. Yet they played just as important a role as care staff. The lack of key worker status deprived them of "*the associated support and prioritisation for services such as access to childcare, schooling etc, and access to financial assistance to implement the necessary absences for isolation and enhanced sick pay*" (INQ000099701 p5). Second, social care support and respite should not have been withdrawn. Ms Herklots' Report of 18 August

2020 explained that fear that health workers would bring Covid-19 into homes, led many to rely on family or friends to provide care instead, with a huge increase in the number of unpaid carers (see also §10 above). She said: "*Given the vital role that domiciliary care and respite plays in supporting older people's health, well-being and independence… social care support and respite should be reinstated as a matter of urgency*": INQ000184908, p11.

50. This appears to have been belatedly recognized by the government: On 30 Dec 2020, a Ministerial Advice noted that many carers have been coping alone without the usual support, leading to deteriorating mental health of carers: INQ000144976. Third, care home staff should have been, but were not, given equivalent testing to acute trust staff (see INQ000224075). Fourth, additional financial support should have been provided. Care Forum Wales explained some of the additional costs incurred by the care sector as a result of the pandemic response, such as the costs of self-isolation by staff. They noted these costs were unsustainable for providers: INQ000183754 and INQ000183764. National Care Forum described difficulties in "*access to financial assistance to implement the necessary absences for isolation and enhanced sick pay*" (INQ000099701, p5).

51. The role of unpaid carers was overlooked even further. Carers UK said: "*The general lack of awareness of unpaid carers and the key role they play which led, at times, to them being left out, or not considered*" INQ000099707, p13. Carers UK provide examples of how unpaid carers were left out, including the provision of vaccinations and PPE. Unpaid carers were never given key worker status, but should have been given their important role.

52. These particular problems again reflect broader concerns about core decision-making. They again indicate that the care sector was not given the attention it required, in light of the great and obvious vulnerability of those within it. Care England expressed the view that "*Decisions were made during the pandemic, particularly…during the first wave, with the ambition of throwing a protective ring around the NHS, with little to no regard for the adult social care sector*" (INQ000099684, §8.2). National Care Forum described "*the lack of understanding of the care and support sector…compared to the absolute primacy given to NHS in all aspects of the government's response to the pandemic*" (INQ000099701, p4).

53. Looking to the future, social care has not received sufficient funding in recent years. This has led to a lack of capacity in the sector and other problems. The Homecare Association have explained that the lack of capacity means that hospitals struggle to discharge people into care: INQ000232402. Dr Salmon is of the view that a clear lesson to be learned is the need for "*spare capacity*" in the care sector if it is to be a "*resilient system*": INQ000224354 §§29, 22. This was a major theme in the Amnesty report (p12-14).

54. The Core Participants look forward to the opportunity to explore these important issues in oral evidence with the witnesses to this module, and to supplement what is set out here with closing submissions.

ADAM STRAW KC
EMMA FOUBISTER

LEIGH DAY

20 FEBRUARY 2024