COVID INQUIRY MODULE 2B

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

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1. These submissions focus on those needing care and their relatives and unpaid carers. There are two reasons why this group is relevant to this module. Firstly, this group perhaps suffered more severely as a result of the pandemic and the response than any other. It should in consequence have had a central place in decision making. It did not: it was overlooked or, when it was considered, it was treated less favourably than others. Secondly, this group of people is a useful lens through which the Inquiry can examine what went wrong with core decision making. The problems in this area are symptomatic of wider flaws: problems with core decisions which had particularly potent consequences for those needing care and their carers. The Chair is respectfully invited to read the CPs' (John's Campaign and Care Rights UK) opening and closing submissions together. These submissions will largely avoid repeating the evidence that was set out in the CPs' opening submissions ("OS"), but that evidence remains important.

2. In these submissions, the CPs argue:
    a. People needing care and their carers should have had a more central place in core decision-making.
    b. Covid-19 deaths in care homes were under-reported.
    c. Discharge without prior testing was wrong.
    d. The government failed to obtain sufficient input from stakeholders, and when it did so, that input was overlooked. There was an 'implementation gap'.
    e. Indirect harm was not given sufficient attention in core decision-making. Widespread evidence of severe indirect harm for those needing care was overlooked.
    f. People needing care were denied access to healthcare, often on a blanket basis; and there was widespread inappropriate use of DNACPR notices.
    g. Guidance was inadequate, conflicting and unclear.
    h. Restrictions caused more harm than good, and were imposed on an inappropriate, blanket basis.
    i. There were PPE shortages for those in care.

j. The NHS was prioritised over social care, there was a broader lack of support for those providing care, and unpaid carers were particularly neglected.

k. This evidence taken cumulatively suggests those in care were considered expendable.

l. Human Rights and Equality Duties were abandoned at a time when they were needed most. This appears to be at the root of many of the more specific problems identified above.

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

3. Those in need of care should have been a priority for core decision-makers from the very start of the pandemic because of their exceptional vulnerability both to Covid-19 and to the restrictions imposed in response. As Ms Herklots put it: "given what we knew about Covid-19 and the vulnerability, therefore, of older people living in care homes, I felt that that should be such a high priority for action": [2/129/6-8]. She explained they were not given a sufficiently high priority: [2/148/15-19].

4. The Welsh Government was made aware of this vulnerability and the need to urgently protect those needing care. For example, on 11 March 2020 PHW produced a paper [INQ000147246] which noted that Wales has a higher proportion of the adult population who have long-term illness, who are older, and who provide care:

> "the demographic characteristics of the Welsh population … are such that Wales may experience disproportionate levels of impact from Covid-19… 200,000 requiring hospital admission… 18,000 will require mechanical intervention at some point... 25,000 predicted deaths… Older people and those with comorbidities have higher estimated hospitalization and mortality proportions, so the estimates for Wales referred to above may be higher than the above under the [reasonable worst-case] scenario… given the demography and health status of the population of Wales, PHW strongly advocates early implementation of these three behavioural interventions and specifically commends urgent attention directed at the elderly population cared for in residential and nursing homes in Wales." Dr Sandifer [7/57-60].

5. Despite this clear and stark warning, the Welsh Government continued to look the other way. Many of the decisions over the next couple of months (such as the decision to discharge patients to care homes without testing) gave little (if any) attention to the highly vulnerable population in care homes. As with much of the government's response, our clients were left asking the same question that your ladyship had to repeatedly ask Mr Goodall, Mr Gething,

Mr Drakeford and other core decision-makers: But what did you do? All too often, no concrete or substantive action was identified in response.

6. Even ignoring the obvious vulnerabilities of those in care, the evidence emerging in March 2020 should have made clear to core decision makers that something was going badly wrong in the care sector. Those in care were among the most severely affected by the pandemic and its response (see OS/§5-9). Care home residents were such a large proportion of those dying that they should have been front and centre of core decisions.

7. Yet despite this, those needing care were overlooked and neglected by core decision-makers. There was a general lack of attention to them in core decision documents. Serious concerns raised about this group were either overlooked, or not translated into specific action. And when action was occasionally taken, this group was treated less favourably. A number of examples are given below.

8. This neglect concerned both those needing care and those providing it. Mr Llewelyn said:

> "there was a general sense that the needs of social care staff as a whole weren't being taken into account, that the -- you've already heard in some of the evidence sessions this week about testing arrangements and the provision of PPE, I think <u>there was a sense within the workforce that they were being neglected</u> and weren't taken into consideration and account in the same way as other service areas. And I think it was a feeling both within the workforce but within wider local government as well, that they weren't appreciated as fully as they should have done, that there was <u>an issue of parity of esteem with other healthcare workers</u>": (Emphasis added) [7/134/21-7/135]

Covid-19 deaths in care-homes under-reported

9. Ms Herklots said:

> "people who were dying in care homes from Covid-19, those deaths weren't even being counted, and I thought that was extraordinary… this issue of inadequate data covered a number of different areas throughout the pandemic, I would say, but was very stark at that time": [2/126/23-25].

10. This meant, as the Chair put it, that the figures would be skewed and that the pandemic response would be based on inaccurate data. The reasons for this appear to include that there were few tests available for Covid-19 in care homes during March and April 2020; that staff had less experience or understanding of Covid-19; and that Covid-19 was not recorded on death certificates for other reasons: see, e.g. [3/140/14-22]. Some other reasons why

deaths in care homes were underreported were explained in the Office for Statistics Regulation blog *Glimmers of Light for adult social care* (8 July 2021)[1] [3/131/10-3/132/19] which referred to a data "chasm" in social care[2].

11. This is reflective of a broader problem that emerged, of inadequate data about social care. Dr Cooper said data in the care home sector "was a significant challenge… there wasn't a system that really could be relied on for us to help inform action or look at the reality of what was happening in any sort of systematised data way": [6/153/5-12]. Similarly, Ms Howarth noted that the Knowledge and Analytical Services only became involved in data collection analysis after the early stage of the pandemic, and that if they had been asked to advise earlier on, they could have avoided various errors and misreporting [3/121/3-12].

12. This, like many of the issues set out below, is symptomatic of a wider problem in core decision-making. There were inadequacies in data about vulnerable groups in a number of other respects. Professor John highlighted the importance of "ensuring that we have timely, accurate data systems" [4/131/1]. Professor Diamond noted that statistics were not gathered to show differentials in mortality by disability. He said this "is a major gap for our country" but it could be made available very easily and quickly: [3/95/12-3/97/13]. It is unsurprising he considered this to be a "major gap". The dogmatic adherence to 'following the science' during the pandemic meant data and numbers were of great importance in shaping policy. The absence of data about vulnerable groups (including qualitative data rather than just statistics) and the care sector is likely to have had far-reaching impacts on core decisions that affected them.

Discharge from hospitals to care homes

13. The policy to discharge without prior testing was wrong. There were extremely high rates of Covid-19 in hospitals at the time: see Mr Poole's summary at [2/14/1-4]; and Dr Orford, §149 of [INQ000356177/38]. The care home population was highly vulnerable to Covid-19.

14. The risk of asymptomatic transmission, and the consequent importance of testing, were well-known by the time of the 17 March 2020 decision, and of subsequent decisions to maintain

[1] https://osr.statisticsauthority.gov.uk/blog/glimmers-of-light-for-adult-social-care-statistics/
[2] NB the ONS only began publishing deaths in care homes on 28 April 2020: https://www.ons.gov.uk/news/statementsandletters/publicationofstatisticsondeathsinvolvingcovid19incarehomesinenglandtransparencystatement

the policy. For example, on 22 January 2020 SAGE had concluded that asymptomatic transfer “is likely”: [INQ000309706/1], §12. On 3 February 2020 SPI-M-O acknowledged the prospect that a high proportion of asymptomatic cases are infectious: [INQ000074895/1], §7. A scientific paper of 15 March 2020 [INQ000312305] noted that infectiousness peaked on or before symptom onset, there was “probable substantial pre-symptomatic transmission - about 44% of transmission”.

15. There was ample other scientific evidence, by 18 March 2020, of asymptomatic transmission: Dr Orford’s 20 February 2020 email [5/14/20-22]; the 21 Feb 2020 NERVTAG meeting [4/46/2-9]; and *Gardner* §39, 43-45, 52, 60-65, 69, 70, 73, 78, 85-88 (see also §103 and 105). On 1 April 2020 Dr Williams summarised to a CDC study: “potentially a high proportion of those testing positive (and therefore likely shedding [i.e. infectious]) are asymptomatic”: [4/52/21-25]. The evidence was of asymptomatic transmission, not merely asymptomatic illness. The WHO was less sure of the risks until July 2020. But, applying the precautionary principle, given the great vulnerability of those in care homes, the extensive mounting evidence meant prior testing should have occurred.

16. There is no doubt that there was at some level a failure to obtain or pass on evidence of asymptomatic transmission. A Welsh Government Scientific Evidence Advice Report Nov 2022, concluded that the discharge policy: "overlooked the potential risk for asymptomatic transmission": [INQ000300217/103]. Dr Goodall appeared to accept that it would have been appropriate to put in place more safeguards: [6/68/19-6/69/5]. Mr Gething suggested there was insufficient sharing of information [9/122]. TAC and TAG were not asked to advise on discharges into care homes (Dr Orford at [5/123/1-2]).

Inadequate attention to stakeholders

17. The government’s approach to discharge is symptomatic of a wider problem: failure to properly consult stakeholders, or ignoring their concerns. Ministers were aware of serious concerns that had been raised by people involved in the care sector from an early stage, about discharge without prior testing. See, for example: local government leaders raised this concern repeatedly from an early stage with Ministers [7/140-141]; email from Dr Goodall on 18 March 2020: [INQ000262195/1] §1; email on 28 March 2020 passed to Ministers for Health and Social Services (‘**H&SS**’) [INQ000336344]; Ms Herklots’ letter to the Deputy Minister for H&SS on 14 April 2020: [2/124/24-2/125/9]; Care Forum Wales and Care

Inspectorate Wales at a meeting with the First Minister and Ms Morgan on 15 April 2020: [INQ000336415]. Those concerns were evidently overlooked.

18. There were about 1,800 tests available a day in mid-March (Dr Goodall, [6/89/1]) and the number "dramatically increased" from the beginning of April: [INQ000349197]. There were only about 18 patients discharged per day without a prior test in March 2020 and about 11 per day in April 2020, in Wales: [INQ000271757][3]. The importance of not sending infectious patients into the tinderbox of a care home was so great that allocating a handful of the available tests to this context was plainly justified. The First Minister agreed with this. He described this as a fair point, accepting how vulnerable those in care were [11/216-219].

19. The decision to extend testing to all staff and residents in care homes was not taken until 16 May 2020, again several weeks slower than the other three nations. There remained limitations in supply of testing for the care sector for some time after that. In June 2020, Ms Herklots recorded that care "homes still experienced difficulties in accessing testing for residents and staff": [2/132/25–2/133/6]. There was statistical evidence that supported this: [2/143-144] and [INQ000271757/7]. The Cymru Covid-19 bereaved families said in their opening that: "The perception of the Cymru group is that the delay was akin to a death warrant for the elderly, and a stark message from the Welsh Government that they did not matter".

20. Alternatively, if the Chair considers there were insufficient tests, then it is important to ask why. It is clear that the supply of Covid-19 tests in the early stages was far from ideal. It was described as "rather chaotic", and it appears that tests that had been promised to Wales were diverted to England: Dr Orford [5/119-120] (referring to an email by Tracey Cooper on 22 March 2020).

21. Having enough tests and PPE is a fundamental basis for an effective response to a pandemic, and the need for the UK to ensure it always has access to enough tests and PPE for any future pandemic ought to be a key recommendation made by this Inquiry. It appears that emergency planning for a pandemic was cut as a result of austerity policies. For example, Mr Llewelyn explained that in 10 years prior to the Inquiry, the local government

[3] See Table 1, which contains the total number of monthly discharges in the relevant period in 2020, about 30% of which received a prior test.

budget was cut by £900 million, and the areas that were cut included emergency planning and capacity: [7/138/10-16] and [8/1/4-11]. The costs of not being properly prepared (additional deaths, chaos in public services) going into a pandemic would plainly massively outweigh the costs of having sufficient stockpiles and clear mechanisms for procurement of testing and PPE. It is notable that some core decisions resulted in vast wasted expenditure of public money (such as the building of Nightingale Hospitals: see Dr Salmon at [9/97/15-18]), and a fraction of that money could have been used to ensure the country was properly prepared.

22. The government assumed that care homes could effectively isolate new residents: On 22 March 2020 Mr Heaney told Mr Gething: "Isolation facilities in care homes would be in place to manage such discharges": Mr Gething's WS §494. It appears from that paragraph that this was one of the reasons the Minister relied on in favour of the discharge policy. Similarly, Dr Goodall indicated that the government expected care homes could isolate: [6/71/15-16]. The ability to isolate was obviously important: the Welsh government was aware that patients should either be tested or isolated: [INQ000349197/2].

23. In fact, up to 58% of care homes did not feel able to effectively isolate suspected Covid-19 residents (Amnesty report, p19, referring to research by the Alzheimer's Society 13 May 2020). There were available reports stating that care homes were likely to have a high degree of internal transfer of infection: 15 May 2020 TAG Consensus Statement, [INQ000066455], referring to evidence from 2018. Indeed, an email sent to Mr Gething and others on 7 April 2020 said: "Given the way Covid roared through [care] homes in Italy/Spain the idea that they are or can be made somehow secure places is clearly contestable" [INQ000349300]. The government both failed to inquire into whether care homes could effectively isolate residents, and ignored the evidence that they could not do so.

Purported justifications, and causation

24. Two other justifications have been put forward for discharge: hospitals might reach capacity, and the person may be at risk of getting Covid-19 in hospital. But neither is a justification for not testing asymptomatic patients prior to discharge. That is the key problem. Nor is either point a sufficient justification for discharging a patient to a care home which cannot isolate that person from the other highly vulnerable residents. It is in any event worth noting that hospitals were never near to reaching capacity in Wales in March-April 2020: [3/138/22-

3/139/6] referring to [INQ000412041/3-4]. One of the justifications given by Dr Atherton was that the care homes had PPE: [5/71/23]. That is plainly wrong: see below. Dr Atherton could not point to any steps he or PHW had taken to satisfy themselves that vulnerable people in care homes were protected [5/71/14-23].

25. As to causation, Mr Poole KC rightly said in his opening address, "There is no doubt that there was a massive failure of infection control, contributed at least in part to the influx of infected but untested patients.": [1/58/11-18]. This seems inevitable since large numbers of patients were discharged from a setting (hospitals) where Covid-19 was rampant; and there was a striking correspondence between that event and the subsequent massive increase in fatality in care homes due to Covid-19 [INQ000271757/16].

26. Dr Williams' and Professor Gravenor's papers as to the contribution discharge made to Covid-19 in care homes. They accepted that discharge had – or may have had - a "significant effect," causing Covid-19 in care homes and therefore deaths: e.g. [INQ000224072/4]; and [INQ000224074/6], §4.1 and §5. See also Dr Williams: [4/48/3-11].

27. The conclusions in the articles were based on the number of reported deaths or Covid-19 cases. But it is clear that in March and April 2020 those numbers were substantially under-reported: §9-12 above. Caution should be exercised when assessing the conclusions, since some of the authors are arguably open to criticism for not passing on adequate information about the risk of asymptomatic transmission, to those in government (such as Dr Williams and Professor Gravenor).

Stakeholder involvement / the implementation gap

28. There was limited stakeholder engagement by the government. For example, the government consulted with the Older People's Commissioner, Professor Foster and the Disability Equality Forum and Care Forum Wales. This was a good start, and contrasts to the lack of any significant engagement by the UK government. But it did not go far enough. Unfortunately and importantly, the evidence suggests that even this limited consultation did not lead to concrete action.

29. There remained two serious deficiencies. Firstly, the involvement of stakeholders was too limited. Ms Herklots does not have a formal structure which ensures the government

understands the concerns of all of those in care, or of younger or disabled people. Professor Foster considered that disabled people were not adequately represented in political decision-making: [2/92/1-11]. She explained a number of substantive problems which may have been avoided had there been better representation or better evidence, including failing to think about the consequences of restrictions; and removal of the human rights of those in residential institutions. [2/92/12-20] and [2/112/23-2/113/2]. She suggested the creation of a post of Minister or Commissioner for Disabled People: [2/110-111]. Dr Cooper said "we should have set up settings based meetings earlier so that we could really understand … what was materialising on the ground within care homes…" [6/216/1-6/217/5].

30. The importance of the need for input of people with lived experience was emphasised by several witnesses. Dr Hoyle noted that the TAG members "didn't have the same lived experiences as other parts of the population. So from that respect there was a degree of unconscious bias". He considered that the best way to have addressed that would have been: "to invite other people from other walks of life to the TAG activity.": [3/187/15-3/188/1]. Similarly, Professor John described the lack of diversity in TAG, highlighting that "having a diverse range of voices round the table is really important" [4/117/1-23].

31. Chris Llewelyn explained that there was a failure to properly engage with local authorities from an early stage. He said that in respect of the many matters which local authorities would have to deliver, there should have been engagement before strategic decisions were made, in part because this would have led to better policy making. There was not that engagement. Consultation was inadequate and often a step behind throughout the pandemic [7/110-119], [7/128-130]. The Welsh Local Government Association's key lesson learned from the pandemic was "we need collective and inclusive planning, led by Welsh Government, with a whole-systems approach engaging all partners who have a role to play.": [7/136/6-15].

32. Secondly, there was an "implementation gap". Professor Foster explained this was "the area we're really worried about": [2/107/4-16]. Core decision makers were not ensuring that the input of stakeholders was being implemented. This was echoed by Ms Herklots who said that: "there was a significant disconnect between what was being promised at policy level and what was being delivered on the ground.": [2/136/6-8]. She was given a voice, but it was often not translated into action.

33. The First Minister "certainly agreed" there was an implementation gap, and indicated there were 'many contributory reasons' for it; lessons that should be learned. They included that the ownership pattern of care homes in Wales was disparate and problematic, which meant (a) the views of the disparate audience are not sufficiently represented; and (b) the 'complex pattern of intermediaries' made it difficult to distribute, say, PPE to those on the ground. He made suggestions for improvements, including a central register of care homes and care councils [11/210/12-11/213/5]. In fact, Care Inspectorate Wales had a central register of care homes, from which they could obtain relevant data.

34. The CPs very much agree there is a need for improvements. They suggest the most effective improvements would be to implement proper mechanisms for liaising with stakeholders and actually listening to and acting on the views of those with relevant expertise (such as the Older People's Commissioner, Care Forum Wales and others). One option is for there to be a duty to have due regard to the needs of those requiring care, akin to s.149 of the Equality Act 2010. Another option is for there to be more formal requirements for involvement in key decisions for those people or bodies. Further, any pandemic response plan should make clear that human rights and equality duties (which themselves may entail inquiring into the equality impacts) cannot be suspended in a pandemic. These matters should have been in place well before the Covid-19 pandemic.

Wider problems in organisation of relevant government bodies

35. The above deficiencies may have been linked to a wider lack of co-ordination across the Welsh Government and with local authorities. The responsibility for delivery of care lies with local authorities (Dr Goodall at [7/14/16-18]) but they were not sufficiently involved in the Covid-19 response (Chris Llewelyn at [7/133/15-25] and [7/137/13-20]). Dame Morgan accepted that it would have been a very good idea to invite the Chief Executive of the Welsh Local Government Association to be a member of ExCovid, and she could and should have done more to establish regular contact with them: [5/198/8-17]. She recognised a broader lack of co-ordination: [5/170/1-6]). A *Review of the Health and Social Services Group Response Structure to COVID-19* (25 Sept 2020) [INQ000083255/5] identified a number of problems with internal co-ordination in the government's response structure, including lack of clear accountability as to the roles of 'cells', which at times created confusion and duplication of work: §1.1-1.4. The lack of clarity remained in October 2021: [6/31/22-6/32/9].

Indirect harm was not given sufficient attention

36. Core decision-makers failed to properly investigate indirect harm, failed to pay sufficient attention to it, and consistently made decisions which were ignorant of, ignored or devalued that harm. Decisions (particularly for those in care settings, but also for those receiving care at home from vital community services), were made solely or largely on the basis of whether they would reduce Covid-19 and whether they would stop the NHS from being overwhelmed. Other harms – for example dementia or cancer, or overwhelming the care sector – were ignored initially and later given insufficient weight. While this may have been understandable to begin with, given the challenge Covid-19 posed, that does not mean it was right. It is also particularly concerning that approaches remained solely or primarily focused on infection-control despite the increasingly substantial body of evidence pointing to the severe impact of indirect harms. A death due to dementia is no less important than a death from Covid-19, and it should not have been devalued. The CPs were disappointed that so much of the questioning in this module focussed on the early stages of the pandemic, rather than exploring more how decision-making failed to improve and respond to emerging evidence.

37. The pandemic response led to devastating indirect harm, including for many of those in need of care: OS/§14-21 and 38. In addition, the section below: "Lack of access to health care" explains in more detail the evidence that the restrictions stopped those needing care accessing health care and treatment. Care home mortality in Wales from non-Covid-19 causes more than doubled in April 2020: [INQ000350133/5]. Deaths from dementia and Alzheimer's increased by 221%: TAG July 2020, [INQ000252526/15]. The largest number of excess deaths occurred in care homes: [INQ000252526/17], figs 19 and 20.

38. Stakeholders repeatedly warned the government about these indirect harms, particularly in respect of those who relied heavily on carers, such as those with dementia and cognitive impairment: OS/§22-24. In addition:
    a. Ms Herklots said initial decisions did not take into account the harm that lack of visits cased: [2/148/22-2/149/1] and [2/135/7-25].
    b. The Wales TUC Equality Forum on 20 April 2020 stated: "For those who have dementia or who are supporting a loved one with dementia whilst in lockdown, this can be a confusing and especially awful time. The support that they may have relied upon, or the respite that they may have received may no longer be available and

union reps have asked us to raise the issue of dementia support with the Welsh Government." [INQ000068460/6]. There is no evidence that this concern was properly addressed by the government.

c. The ExCovid 'Deep Dives' into social care did not mention any of the types of indirect harm set out above: [INQ000215294], 21 April 2020; and [INQ000350133], 6 July 2020.

d. Professor Gravenor noted that a model was set up in September 2020 to build in indirect effects, so that these could be weighed against the benefits. But "I don't think the numbers to bring into the model were ever – ever provided, were ever made available… there was nothing to bring in. So we were, I think frustrated by that… I felt there was no information being provided to us at all that would allow us to bring that into the model." [4/187/12-4/188/2].

e. On 10 March 2021 PHW, in a briefing note to the Minister for H&SS, identified the need for a "*much more sophisticated understanding of the benefits and harms*" of Covid-19 measures: [INQ000056334]. There was a need for better measurement; a "centrally held point that was tracking the broader harms, be they about well-being, be they about impact on health services, be they about morbidity… we weren't aware of anything that was actually measuring the specific harms around health and well-being": Dr Cooper [6/213/11-13].

f. The *Second Review of the Health and Social Services Group Response Structure to COVID-19* (11 Oct 2021) [INQ000083257] concluded: "There is concern about the wider impacts and unintended consequences of this short-term decision making."

g. Mr Kilpatrick recognised that "none of us had really given that detailed discussion for the impact of social isolation measures on our most vulnerable": [7/191/11-13].

h. There was substantial anecdotal evidence (much of which was communicated to MPs) that restrictions in care homes were having a severe impact but decisions on restrictions continued to be made without weighing those considerations against the need for infection control.

39. The Inquiry is invited to consider making a recommendation to the following effect: Restrictions should not be imposed and certainly not maintained for extended periods unless all reasonable efforts had been made to identify the harms that would arise (Covid-19 and indirect harms). Secondly, there should be a balance between the benefit in reducing Covid-19, against the indirect harm that would be caused by restriction. This balance should also

take into account individual needs and personal wishes, given the fundamental importance of, and right to, autonomy.

40. The importance of this is well illustrated by the care home context. The decision whether a care home resident will spend their last months isolated, in severe decline, with an increased risk of death from non-Covid-19 causes; or face an increased risk of covid is a fundamental decision, and that person should have a say in it. This approach is supported by *Public Health Wales advice to the Chief Medical Officer for Wales* (24 October 2020) [INQ000147260].

Lack of access to health care

41. There was deeply worrying evidence that healthcare was not provided for reasons other than the risk of Covid-19: evidence that indicated that those needing care were considered to be expendable. Ms Herklots said:

> "what we knew is that health professionals had stopped visiting care homes, so GPs, for example, had largely stopped visiting care homes, so that was leaving care homes without that medical support that they needed, it meant that residents weren't seeing health professionals… there were also some concerns that I was hearing about access to hospital treatment, so, for example, if someone fell ill in a care home whether they would be getting access to hospital treatment, and I was concerned whether there was any blanket policy in place." [2/125/17-2/126/2].

42. Ms Provis recorded that no attempts were made to transfer her grandmother, or any of the other residents of her care home who caught Covid, to a hospital: [2/35/18-21]. There was a note not to transfer Ms Grant's mother to an acute hospital: [2/8/24-25]. The Amnesty report contains extensive evidence of multiple reports of blanket denial of health care to those in care (*Denial of access to hospitals and other medical services* at pages 21-24). The Locked Out report concluded "disabled people's access to ongoing medical treatment and health services were severely disrupted" [INQ000227530/10].

DNACPR

43. There is evidence of widespread use by medical professionals of documents which would state that a person needing care should not be provided with medical treatment if they fall ill, including 'do not attempt CPR' forms. See, for example, Ms Herklots [2/128/3-11]; and [2/139-140]. She described how the use of DNACPR letters made older people feel "that their lives weren't valued, that they weren't important" [2/128/1-11]. The Wales TUC Equality Forum on 20 April 2020 noted "DNRs have become a frightening part of the conversation around

coronavirus…" [INQ000068460/6]. This is again symptomatic of those in care being considered to be expendable. It is arguable that, given the very widespread nature of and blanket approach to this practice, the Welsh Government should have done more to prevent it.

Inadequate, conflicting and unclear guidance

44. There were many calls for clear and consistent guidelines for those needing care from an early stage – including in March 2020. For example, on 14 April 2020 Ms Herklots called on the Minister for an action plan for care homes, because of the need to inform the people affected, and for urgency and focus, which was lacking at that time: [2/129/11-10]. She considered the Minister's response (which was to decline) was inadequate: [2/130/25-2/131/5]. Despite further calls, not least from Ms Herklots, an action plan was not published until 30 July 2020: [2/137]. The Welsh Local Government Association considered that regulations were often not easy to understand. They offered to provide their expertise to help prepare and draft the legislation but stated that this was overlooked by the Government: [7/129-130] and [INQ000228421] (5 Aug 2020). Even Sir Frank Atherton accepted that in "settings such as care homes… the nature of the settings required more tailored situational advice and guidance": statement [INQ000391115/6], §22.

45. After the slow start, a large range of guidance and regulations was produced. At times this was confusing and contradictory, both for those providing and those needing care: OS/§46-47. Ms Grant stated that the rules on Covid-19 were "tantamount to chaos": [2/19/16]. Dr Cooper accepted that the guidance "was very confusing for care homes insofar as the guidance was changing very, very quickly… I think there were areas with care homes that I think we could have been clearer" [6/215-216]. One of the reasons for this appears to be that the UK Government produced guidance which was not applicable in Wales, but publicised it in Wales, indicated it was applicable to Wales, and/or failed to make it sufficiently clear it was not applicable to Wales: Mr Gething at §443 and Toby Mason [8/77-81].

46. There was no individual who clearly had specific responsibility for ensuring that communications about Covid-19 rules or guidance to those who may have needed support to understand (such as people with learning disabilities, visual or hearing disabilities, older people or those needing care), were clear and consistent (see, e.g. Mr Mason: [8/107-108]).

Remarkably, the Welsh Government's Head of Communications, Mr Mason, did not know who was responsible for producing guidance for or communicating with people in care (despite acknowledging the need for proper tailored communication with groups disproportionately affected by the pandemic) [8/105-107]). Dr Cooper agreed it would be better if there was a single member of the team who was responsible for producing guidance who fully understood the needs of people in care: [6/215-216].

Restrictions, including limits on visits

47. There were stringent restrictions which applied to those needing care and their relatives, representatives and carers, including in respect of visits. There were blanket bans on visits for much of the time until 1 May 2021. Despite the clear emerging evidence that those restrictions caused very serious harm: OS/§37-40, decision-makers failed to change their approach over time. This specific point is again symptomatic of wider core problems. It indicates the Welsh Government was not taking into account the views of stakeholders; and/or was neglecting those in care.

48. Given the very serious harm that resulted from preventing contact between those needing care, and their carers and loved ones, the government was invited to make several changes. They included that an essential caregiver (i.e. a person nominated to provide essential care to the person needing it) should have the right to visit a resident frequently under all circumstances. They would be provided with the same testing and PPE as an ordinary member of staff. This was something which the Welsh government was invited to implement from as early as March 2020 [INQ000283957] §160. Stakeholders repeated this request many times: see, for example, the letter from Ms Davies on 28 September 2020, which drew attention to John's Campaign's plan that one family care giver should be recognised as a key worker and have the right to visit (and be provided PPE) as such.

49. Yet nearly two years later, on 23 May 2022, the issue had not been properly remedied. A coalition of over 60 MPs, signed a letter coordinated by MPs (with support from Care Rights UK, John's Campaign and the Rights For Residents campaign) which yet again drew attention to the "devastating harm" of restrictions, and calling for a new right to a Care Supporter. This has not been implemented, and no good reason has been given for declining to do so.

PPE shortages for the care sector

50. 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: Ms Herklots, [2/124/10-18]. That was despite repeated and serious warnings to the government that this was lacking, such on 14 March 2020 from TUC Wales to the First Minister: [INQ000068458]; on 20 March 2020 from ADSS Cymru and the WLGA, who noted "Social care staff are undertaking a critical role at this time...": [INQ000082951]; on 22 March 2020 from the BME: [INQ000118526]; and on 31 March 2020 from the Workforce Partnership Council of health trade unions: [INQ000068472].

51. On 12 April 2020 a joint statement was issued on PPE in health and social care by the Wales TUC and the BMA Cymru: [INQ000180916]. This noted "Our affiliated trades unions in the health and social care sector have been contacted by hundreds of workers with concerns about inadequate levels of PPE to enable them to do their jobs safely. This includes cases where no PPE is provided at all, insufficient or unsafe PPE is given…". ExCovid noted, on 21 April 2020, that "PPE supply currently lags demand" [INQ000215294/4]. By June 2020, access to PPE remained "patchy": [2/132/4-15].

52. The reasons why inadequate PPE was provided are significant to core decision-making. They appear to include "woefully inadequate" stockpile: Mr Gething [9/41/24]; problems in distribution due to unclear supply chains in social care: e.g. First Minister [11/210/12-11/213/5]; and the stock was distributed to England first: Care Forum Wales [INQ000183764/4].

53. This is one area, among others, where the NHS was prioritized over those in care. Some of the reasons why it was wrong to prioritise the NHS over care homes were explained in an email sent to Mr Gething and others on 7 April 2020. As noted above, it explained: "Given the way Covid roared through [care] homes in Italy/Spain the idea that they are or can be made somehow secure places is clearly contestable." It went on to explain that these are not closed or low risk settings; that "staff clean, bathe, dress, feed, change dressings and all manner of close up activity, and the idea that district nurses will enter the same premises fully equipped (as it is often observed) and they do not, continues to simply jar": [INQ000349300]. Yet care homes were left in second place. The effect of this cannot be overstated and had a direct

impact on those in need of care. Without PPE, care staff were either expected to risk transmission, or vulnerable people were left alone or with inadequate care.

Parity with NHS

54. Ms Herklots considered that, in many other ways, there was a lack of parity between social care and the health service. For example, social workers were not recognised as key workers in the same way as NHS workers: "I felt that social care was definitely seen as secondary to the health service in a number of different ways.": [2/121/23-25] and [2/152/15-25]. A number of examples of lack of parity are given in OS/§35 and 52.

55. In 2021, the Welsh Government produced 'A Healthier Wales: our Plan for Health and Social Care'. It appeared to acknowledge the lack of parity between these sectors. It concluded that a separate system for social care was not fit for the future (p3); and recommended that there should be a whole system approach which is equitable and will "achieve more equal health outcomes" (p4). The Inquiry did not hear any evidence of specific action taken to address these issues.

Lack of support, including financial support, for those providing care

56. This persistent less favourable treatment of those needing or providing care was manifest in a number of other ways. Five examples are OS/§49-51.

57. Staff and visitors to those in care should have been, but were not, given equivalent testing to visitors and staff in acute trusts. It was recognized from an early stage that a "Major way infection introduced to care homes was from staff": [INQ000224075] (report from PHE on care homes, 18 April 2020). It was, as a consequence: "Pressed that staff in care home settings should be given, at least, equivalence with acute trust staff re testing" (*ibid*). But, as noted above, this did not occur for several months thereafter.

58. The need for testing of visitors – particularly staff visitors - continued to be recognized over subsequent months. For example, on 18 August 2020 Sir Frank Atherton told the First Minister that "there should be guidance and additional mitigation measures in some settings, such as requiring visitors to have a negative test before entering care homes.": statement [INQ000391115/41], §165. But it appears that a full roll-out of testing for visitors to care homes did not occur until mid-December 2020. The Scientific Evidence Advice Report at

[INQ000300217/104] notes: “From 30 November 2020, there was Covid-19 LFD screening for visitors to a small number of care homes, with a wider roll-out from the week commencing 14 December 2020”.

59. Further, unlike NHS workers, social care staff were not paid for sickness absence associated with Covid-19. The GMB repeatedly asked the Welsh Government, since March 2020, to ensure that social care workers receive their wage if they are forced to take sick leave or to self-isolate as a result of coronavirus. TUC Wales wrote on 19 May 2020 to the Deputy Minister for H&SS, to support that request: [INQ000180894]. They noted “The fact that many social care staff, who are already typically low paid, continue to face a financial penalty for taking sickness absence is contributing to the spread of the virus, particularly within care homes…”. Ms Taj explained that there was a long delay in the Welsh Government implementing this, and there was no explanation as to the reason for the delay: [7/98/1-18]

60. The role of unpaid carers was overlooked even further. On 30 Dec 2020, Mr Gething was sent a Ministerial Advice [INQ000144976], which noted that:

> “6. Since the start of the pandemic many carers in Wales have been coping alone without the support of statutory services… 7… increasing numbers of unpaid carers were experiencing deteriorating mental health and negative effects on their own well-being, as well as that of those they care for. Financial pressure has left some unable to afford food or facing difficulties in paying heating bills.”

61. It explained that concerns had been raised about this from an early stage in March 2020. There is no evidence that attention was given to unpaid carers by core decision makers, despite the huge number of them (see OS/§11-12), the particular vulnerabilities of those giving and receiving care, and the problems which had been brought to the government’s attention. Insufficient attention was given to this important group of people by core decision-makers.

62. Similarly, Professor Foster said there was a concern “that people were being neglected, particularly people receiving social care in their house on an individual basis, that there was a risk of abuse, and that Disability Wales had raised this with the Welsh Government, and we were concerned that there had been a very slow response.”: [2/96/11-17].

Were people needing care considered expendable?

63. As has been seen above, there were a large number of respects in which those in care were treated less favourably in respect of core decision-making. An important question for this Inquiry is why? One answer is that, taken cumulatively, those numerous examples indicate discrimination against those who needed care and older people (ageism and ableism). Professor Foster said "disabled people were generally seen throughout Covid as dispensable." [2/97/20-22]. The Locked Out report "details evidence of disabled people experiencing medical discrimination, restricted access to public services and social support… and an erosion of basic human rights as a consequence of the pandemic." [INQ000227530/6, 23].

64. Ms Herklots said: "some were feeling that their lives weren't valued, that they weren't important… those feelings were compounded by things like the issuing of the letter from a GP surgery in Bridgend about DNACPR, which caused huge distress. So there was a number of different things which happened cumulatively…" [2/128/3-11].

Equality Duties and Human Rights

65. Another, linked, answer, is that core decision-makers abandoned duties in the Equality Act and Human Rights Act: there is little evidence of those duties being considered in the Covid response. For example, there is no recognition of the right to respect for family life; that restrictions must be the least onerous necessary; or of the important principle within that right of personal autonomy. Ms Herklots had serious concerns that older people's rights were not being sufficiently protected [INQ000181725/22]. The Locked Out report concluded: "Disabled people's human rights, including the basic right to independent living, have been discarded during the pandemic." [INQ000142176/22]. As noted above, it considered there was "an erosion of basic human rights as a consequence of the pandemic."

66. Similarly, the equality duty in s.149 EA 2010 was repeatedly not complied with. The Locked Out Report concluded: "The use of [Equality Impact Assessments] … during the pandemic have been conspicuously absent… I think that had they been undertaken, some of the issues that we raised in the report would have been discovered..." [2/100/3-10]. As late as November 2020, Ms Herklots, together with the EHRC, considered there was "an absence of [EIAs] as legally required by the Public Sector Equality Duty": [2/145/19-25]. No EIAs were carried out for the first four 21 day reviews, which was for nearly 3 months after the initial lockdown: [5/193/14-21]. Mr Miles frankly admitted, that on 7 May 2020 "none of us thought that we'd

got to the stage where the level of impact assessment was adequate"; and he accepted that in future they should establish an earlier pattern of each type of formal impact assessment [10/167/9-14 and 174]. Dame Morgan accepted that EIAs could and should have been undertaken for the second to fourth 21 day reviews: [5/195/1-4]. No EIA was completed in relation to the discharge decision [6/62/6-15]. The explanations advanced for these failures were unconvincing: [5/195/1-17].

67. Similarly, Professor Foster's Locked Out report concluded that "politicians, policy makers and professionals" reverted to using a medical model of disability, whereas they ought to have continued to use the social model of disability: [2/91/5-17]. The Wales TUC Equality Forum on 20 April 2020 noted "There has been a very defined move away from social model to medical model…" [INQ000068460/6].

68. While abandoning human rights and equality duties must have been the easy option, if anything those duties were even more critical in a time of crisis. Protected groups are at greater risk, and decision makers are most in need of a framework to help them draw these difficult balances. It has often been said that the true test of a civilisation is the way that it cares for those in the most vulnerable positions. The response of the Welsh Government to Covid-19 in respect of those needing care cannot be said to have passed that test. We invite the Chair to consider recommending that equality and human rights considerations (including completing EIAs) are put at the centre of decision-making from the outset of any future pandemic response.

69. Finally, as Baroness Morgan said, "the pandemic isn't over": [10/4/3]. That is especially true for people in care who remain subject to restrictions. We invite the Chair to carefully consider making recommendations not just for a future pandemic, but also for those who are still suffering because of this one. The CPs will write separately about ensuring that there is an effective mechanism for monitoring the Chair's recommendations.

ADAM STRAW KC
EMMA FOUBISTER

LEIGH DAY

4 April 2024