COVID INQUIRY MODULE 2B

WRITTEN SUBMISSIONS FOR PRELIMINARY HEARING 16 NOVEMBER 2023

JOHN'S CAMPAIGN AND CARE RIGHTS UK

A. INTRODUCTION

1. These written submissions address the following topics on behalf of John's Campaign and the Care Rights UK (together, "**the CPs**"):
   1.1. Issues
   1.2. Evidence and emerging themes in disclosure
   1.3. Procedural matters

2. These written submissions will be supplemented by oral submissions on behalf of the CPs at the preliminary hearing on 16 November 2023, though it is not envisaged that each of the topics raised in this note will be addressed orally. The Inquiry is respectfully requested, therefore, to take account of these written submissions alongside the oral submissions made at the hearing.

B. ISSUES, THEMES & EVIDENCE

(a) List of Issues

3. The CPs welcome the changes made to the List of Issues following their opportunity to provide comments on the version dated 12 May 2023. In particular, the CPs are pleased that the Inquiry has included a new subsection on "*At-risk and vulnerable groups and those with protected characteristics*" (Q3(b)) and specific questions about the coordination between the Welsh Government and local authorities on the use and timing of NPIs (Q3(a)(v)).

4. The CPs would be grateful for confirmation from the Inquiry that the List of Issues will be kept under review to enable CPs to identify further themes or issues arising out of the disclosure, as they continue their review of the disclosure.

(b) Evidence and Emerging Themes from Disclosure

5. In the CPs' Written Submissions for the March 2023 preliminary hearing, they highlighted a concern that the focus of Rule 9 requests has been on service providers and that there has been insufficient engagement with service users (para 7). The CPs welcome the fact that the Inquiry has now obtained witness evidence from care agencies, care charities and NGOs and community groups. The CPs invite the Inquiry to continue to ensure that its investigation remains sufficiently focussed on service users.

6. In their March 2023 Submissions, the CPs invited the Inquiry to obtain evidence on a list of specified topics (para 8). Those questions remain important and relevant. The disclosure has included a range of evidence to support the submission that each of those questions are important topics for this module. It also indicates that more specific sub-issues, or other issues, ought to be examined. We briefly summarise below some of that evidence, and the additional issues or sub-issues which the CPs submit should be considered in this module.

Question 8.2: Indirect harm caused by covid restrictions/NPIs.

7. The full question 8.2 was: ***"****How was 'indirect harm' to individuals (such as harm caused by covid-related restrictions) evaluated and balanced against 'direct harm', in core decision-making?... For example, were particular individuals or bodies given responsibility for this, and if so, how did they implement the balance in practice in particular contexts? A context where the interests on either side of the balance were particularly sensitive is the care sector: what was done centrally to assist those responsible for the care sector to make policy and other judgments of this nature?"*

8. A number of concerns emerge from the disclosure that the '*indirect harm'* of covid restrictions was not adequately considered. That is, in many cases the harm caused by NPIs (such as restrictions on contact) was not properly evaluated or taken into account. For

example, there is evidence that the Welsh Government was aware of particular risks of NPIs to people with dementia (INQ000087134), but it is not clear how that impacted decision-making. John Watkins, a Consultant in Epidemiology, has criticised the Government's approach to NPIs and the failure to consider the adverse impacts of NPIs (INQ000183846).

9. There also appears to have been **insufficient consideration of those receiving care outside health and care settings**, which is a large proportion of people being cared for. Guidance was disproportionately focused on formal health and care settings. There was insufficient consideration of those providing care in a non-institutional environment (i.e. at home) and freelance (or "insecure") workers within institutions. This is emphasised in the Rule 9 statements of charities and NGOs with expertise in this area. Carers UK's Rule 9 statement describes the failure to consider the position of unpaid carers, who constitute the vast majority of carers in the UK (INQ000099707). Specific concerns include: (i) the adequacy of the provision of PPE, testing, and other necessary support to such workers; (ii) restrictions on those permitted to attend health or care settings failing to take into account the needs of unpaid carers, disabled, and older people,

10. Age UK's Rule 9 statement highlights concerns about ageism and the **failure to consider the rights of older people** and a lack of understanding as to the older population (INQ000099714). In particular, the older population appear to have been treated as a homogenous group, with little if any differentiation or consideration of actual need and impact.

11. Similarly, there appears to have been **little consideration of disabled people**, their actual needs and the impact of measures upon them. They too were treated as a homogenous group with insufficient consideration of and tailoring for their support and advocacy needs both within and outside of health and care settings.

12. <u>The CPs invite the Inquiry to examine the issues in bold above, as well as the following more specific questions:</u>

12.1. Were the harmful effects of NPIs as compared to expected benefits appropriately considered and responded to as the situation developed? Was there sufficient input from appropriate experts?

12.2. What efforts were made to obtain and adequately consider information regarding the impact of NPIs on vulnerable groups to inform decisions around their imposition?

12.3. Did the Welsh Government recognise the importance of care outside the care home/healthcare settings, and of unpaid carers; and were core decisions regarding covid restrictions appropriate insofar as they affected those receiving and giving care outside institutionalised settings?

12.4. Was consideration given to the particular impact of travel bans (across counties) on older people/those requiring care?

12.5. How were older people represented in policy making and how much autonomy were they given, as compared to the rest of the population?

12.6. To what extent did Welsh organisations, such as Age Cymru or the Alzheimer's Society Cymru, rely on their national offices during the pandemic, rather than raising issues themselves (Welsh-specific or otherwise)?

Question 8.3: To what extent was core decision-making evidence based?

13. A key theme arising out of the disclosure is **evidence of restrictions being put in place without study of data or impact** (both positive and negative). For example, the notes from COBR and Cabinet meetings show there was an acknowledged need to analyse the implications of measures on those in care settings but there was an apparent failure to follow up on this or comprehensively collect and analyse data (see e.g. INQ000089005).

14. In particular, the **data collection appears to have been poorly coordinated**, particularly in relation to social care. Whatsapp discussions in tranche 24 of the disclosure indicate that data on care homes was misunderstood.

15. <u>The CPs invite the Inquiry to examine the issues in bold above, together with the following more specific questions:</u>

15.1. How was data collected and used in decision-making?

15.2. Was data collected from sufficiently representative sample groups?

15.3. What steps were taken to address the inability to obtain the appropriate data to inform decision-making?

15.4. Was the data considered by those with expertise in vulnerable groups?

Question 8.5: To what extent was the care-sector part of core decision-making?

16. A particular concern emerging from the disclosure is that there was **little consideration of the care sector overall**. Concerns were repeatedly raised about the care sector not "*co-producing*" in decision-making. This appears to have meant that:

16.1. The views of the care sector were not sought enough (i.e. there was limited engagement with stakeholders);

16.2. When their views were sought, they were not listened to and there was little evidence of recommendations being implemented (see e.g. the Rule 9 statement of the National Care Forum, INQ000099701);

16.3. Little regard was had to the impact on the care sector.

17. In meetings of COBR and the Cabinet Office there was a notable lack of consideration of the care sector and the impact of the pandemic on the people who rely on it, despite recognition that care home residents need to be supported (INQ000089093) and visits from family and friends were crucial (INQ000185087). There were repeated references to the need to assess the effectiveness of measures but little balancing of the impact of the effectiveness against the negative impact (INQ000083787). Outbreaks in care homes only seem to have been considered from an infection-control perspective (INQ000083778).

18. The care sector should have played an important part in core decision making. That is in part because of the significant number of people who rely on the care sector – both formal and informal settings, most of whom were highly vulnerable to covid and to the detrimental effects of covid restrictions. A substantial proportion of overall deaths from covid, were suffered by those in the care sector, including when in 2020 a large number of hospital patients were discharged into Welsh care homes without being tested or otherwise

protected. Likewise, a substantial proportion of non-covid deaths caused by the response to the pandemic were suffered by those in the care sector. In part for those reason, much greater consideration should have been given to the needs of individuals within this sector in core decision making.

19. There appears to be evidence of a **lack of engagement with stakeholder groups or experts in this sector**. Any consultation was extremely limited and often too late to be of value. For example, in tranche 2 of the disclosure, Rule 9 responses from charities and NGOs (including Homecare Association, Disability Wales, Carers UK and Mencap) show that the views of those they represent were not adequately considered. In particular, Care England's Rule 9 statement reports a particular concern that the views of care sector representatives were not being afforded the same level of attention as the views of public health bodies, despite the fact that they were presenting lived experiences and real-time data on the reality on the frontline (INQ000099684).

20. <u>The CPs invite the Inquiry to examine the issues in bold above, together with the following more specific questions:</u>

    20.1. How and when were views of the care sector sought?
    20.2. What did "*engaging with stakeholders*" mean in practice?
    20.3. Is there evidence that the views of stakeholders were actually taken on board?

Inconsistent guidance

21. The disclosure gives rise to certain additional areas of concern within this module. It indicates **inconsistent or conflicting guidance or policy** was produced, causing confusion. The CPs are aware of a Care Home Compliance Director who was provided with different sets of guidance from Government, the local authority and Public Health Wales.

22. More specific questions are as follows:

    22.1. What sources of guidance or policy were produced by core decision makers, which care providers were expected to follow?
    22.2. What guidance was produced which hospitals were expected to follow?

22.3. What consideration was given to potential conflicts in guidance?

22.4. What consideration was given to the needs of specific settings?

22.5. What measures were in place to assist individuals or organisations with reconciling conflicting or unclear guidance?

Equality and human rights considerations in the health and care sector

23. The disclosure indicates that duties arising from equality and human rights legislation were overlooked or breached, in core decision making, including that which related to the care sector. The **role of regulatory bodies was hindered and diminished**, meaning that there was less oversight and monitoring. In particular:

23.1. Compliance with the existing legal framework was suspended (and in some cases remains so);

23.2. There was a lack of impact assessment, including monitoring of compliance with the Public Sector Equality Duty and Equality Impact Assessments;

23.3. There were in many cases failures to conduct individualised risk assessment rather than simply relying on blanket policies;

23.4. There were widespread failures to make reasonable adjustments (See, for example, DRUK's Rule 9 statement, at INQ000099696).

24. Further specific questions are:

24.1. Should equality and human rights legislative duties have been overlooked or breached?

24.2. What mechanisms were in place for safeguarding individuals and monitoring compliance with law and regulatory requirements while established measures were suspended?

24.3. What options did individuals have to complain or question the suspension of these measures?

Levels of hospital acquired infection

25. The disclosure indicates high levels of infections within health and care settings and notes high levels of hospital acquired infections. This emerging issue does not appear to have been considered in any detail or led to changes in approach.

26. Specific questions in relation to this are:
    26.1. When did decision-makers become aware of the high levels of hospital acquired infections and what steps were taken to address this?
    26.2. How many people may have been infected whilst suffering delayed discharge because appropriate community facilities were not available when needed?
    26.3. How were competing needs for infection control, individual patient well-being, and efficient discharge weighed and the impact of measures analysed?

Lack of record keeping

27. Finally, the CPs are concerned by the evidence that there was a lack of record keeping for official meetings in some contexts (see e.g. paragraph 57 of the witness statement of Glynn Jones, Director of Office of the Secretary of State for Wales). This is a concern, given the well-established recognition within government that record keeping is important, particularly in a context such as this where lives are at stake.

(c) Expert evidence

28. An important emerging theme from the disclosure is the **lack of understanding of care structures** and the resultant failure to tailor core decision-making accordingly. Key decisions (such as the early decision to discharge a large number of hospital patients into care homes, without testing or protection, resulting in many deaths) were made without appropriate understanding of the care sector. For example, it appears core decision-makers did not understand the difficulty in isolating patients who are entirely dependent on others for their care and survival. This would be a helpful case study, to assist the Inquiry's analysis of issues such as the use of evidence and experts in core decision-making and given the importance that the care sector should have had in core decision-making. The CPs

submit that it would be very helpful to ask an expert to report on this topic, in particular to explain:

28.1. How the care sector operates, and relevant care structures;

28.2. That core decision-makers did not fully understand that;

28.3. What difference to core decisions a proper understanding of the care sector would have made; and

28.4. Identify differences between the way in which the care sector operates in Wales (including whether there are structural differences).

29. The CPs are in the process of considering possible experts to provide evidence on this topic and will provide suggestions of suitable experts in due course.

C. PROCEDURAL MATTERS

30. The CPs raise the following procedural concerns:

30.1. Lack of expert instructions

30.2. Lack of context for some disclosure

30.3. Expert reports on other modules

30.4. Missing Rule 9 statements

(a) Expert instructions

31. The CPs have previously asked to see instructions given to experts. We reiterate that request now. The lack of instructions has led to a number of difficulties in fully understanding or responding to recent expert reports. For example, the report by Professors Shakespeare and Watson on structural inequalities relating to disability does not consider the intersection between disability and age. Without access to the instructions provided, it is not possible for the CPs to know whether this is a failing in the report or whether the Inquiry has not asked relevant questions. Another example is the report of Dr Roland Salmon, who discusses NPIs and whether they were justified, but whose report is difficult to follow

without knowing its scope or why it was commissioned[1]. The CPs would therefore be most grateful if the instructions can be provided at the same time as the reports.

(b) Lack of disclosure context

32. The CPs have experienced some difficulties with the way the disclosure has been provided. We respectfully invite the Inquiry to obtain and disclose further information, in order to assist with the matters described below.

33. First, at various places in the disclosure reviewed to date, no context is provided for evidence that plainly requires it. For example, Whatsapp messages are disclosed without any explanation as to the reason for the creation of the group or information about the identities of the members of the group. In tranches 33 and 34 (disclosure from DHSC of Matt Hancock's Whatsapps in the group for the North Wales and DHSC Health Group), it is unclear what the purpose of the group is and there are repeated references to external materials that are not provided and that make it difficult to follow.

34. Second, there are several places where there are links within documents that are not accessible. For example, in tranche 9 document INQ000198989, there is a link to notes from an official call via a google document. However, it is not possible to know whether this document (i.e. the notes from the call) have been provided to the Inquiry.

35. This renders it difficult for CPs to understand the significance of some of the disclosure, which limits their ability to meaningfully comment on it or engage with the Inquiry.

(c) Missing Rule 9 statements

36. The CPs understand that certain organisations that have been asked to provide evidence have said that they are unable to provide statements from individuals in certain senior

[1] Other examples are the witness statements of Dr Chris Williams, consultant epidemiologist, and Ruth Marks, from the Welsh Council for Voluntary Action.

positions because they are no longer with the organisation (e.g. Carers Wales). The CPs would be grateful if the Inquiry could please explain:

36.1. Whether it will ask the relevant individual to provide a statement in any event?

36.2. If not, why not? We ask this to see if we can make suggestions to get around the problem. For example, depending on the importance of the individual, we may suggest the Inquiry considers compensating them for their time spent producing a statement.

D. CONCLUSION

37. Finally, the CPs are concerned about the impact of the Inquiry's short timescales for providing submissions on their ability to effectively participate. The CPs were only provided with the CTI Note on 30 October 2023 and asked to provide written submissions within 6 working days. It is imperative that the CPs have time to consider materials and provide instructions to their legal representatives. The short timescales make it extremely difficult for that to happen in an effective and meaningful way.

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LEIGH DAY

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