COVID INQUIRY MODULE 3

WRITTEN SUBMISSIONS FOR PRELIMINARY HEARING ON 10 APRIL 2024

JOHN'S CAMPAIGN, THE PATIENTS ASSOCIATION AND CARE RIGHTS UK

INTRODUCTION

1. These written submissions address the following topics on behalf of the CPs[1]:

   A. The Scope and Focus of Module 3
   B. Evidence
   C. Preparation for the Substantive Hearings

2. The CPs would like to supplement these written submissions by oral submissions at the preliminary hearing on 10 April 2024, with the Inquiry's permission. The Inquiry is respectfully requested to take account of these submissions alongside the oral submissions made at the hearing.

A. SCOPE AND FOCUS OF MODULE 3

3. The CPs made some preliminary submissions about the list of issues for the purpose of the last preliminary hearing. Since there has been no specific response to those submissions, and the List of Issues has not been updated, we reiterate them here.

The impact of Covid-19 on people

4. The CPs welcome the indications from the Inquiry that it will focus on the impact of Covid-19 and the response to it on people. Those indications include that the first issue in the Inquiry's list of issues for this module is the impact of Covid-19 on people's experience of healthcare; the 100 summary account requests (see CTI's note §16); and that the Module 3 hearings will begin with an impact film. It is only by focussing on

[1] "The CPs" are John's Campaign, the Patients Association, and Care Rights UK

the people that the healthcare system exists to serve (and the people the system employs to provide that service) that the Inquiry will be able to obtain a full and accurate understanding of the impact of the pandemic and the response to it. Doing this reflects the NHS Constitution for England[2], which begins by stating "The NHS belongs to the people." Similarly, the fourth principle is: "The patient will be at the heart of everything the NHS does". The first "NHS value" is: "Patients come first in everything we do." Similar values are expressed in relation to the NHS across the other three nations of the UK.

5. The CPs will of course be happy to try to assist the Inquiry as much as possible with providing impact evidence. However, as small organisations with limited staff and resources, who are involved in several Modules, and who have pressures of their ordinary workload which are not controllable, they would please ask for as much notice as possible in relation to requests for their input.

6. The CPs also welcome the fact that the Inquiry has issued s.21 notices. It is a real concern that the public bodies concerned had delayed so long in providing information to the Inquiry, given that the importance of engaging with the Inquiry is clear. The CPs hope that those bodies have now given a full and candid account of the relevant issues.

Further submissions on what issues should be investigated

7. Healthcare outside hospital. The CPs have previously highlighted a concern that the hospital setting should not be given disproportionate attention in this module. It is important to also investigate the impact of Covid-19 and the response to it on healthcare outside hospitals and to consider healthcare holistically across the range of relevant contexts. Healthcare is provided in GP surgeries, community care, at home, in residential care, in other care settings, in hospices, mental health facilities and in many other settings. As the NHS Constitution for England states:

> "**5. The NHS works across organisational boundaries**
>
> It works in partnership with other organisations in the interest of patients, local communities and the wider population. The NHS is an integrated system of

[2] https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

organisations and services bound together by the principles and values reflected in the Constitution. The NHS is committed to working jointly with other local authority services, other public sector organisations and a wide range of private and voluntary sector organisations to provide and deliver improvements in health and wellbeing." (Emphasis added)

8. An investigation which encompasses healthcare outside the hospital is important for two reasons. First, non-hospital healthcare involves very important services, which are provided to a large number of people. For example, the NHS provides some 95 million contacts in community services each year[3]. Restricted access to community services for many meant that non-Covid related health needs were left unidentified and untreated, which led to deaths and life-threatening illness and injury. We are aware, from other modules, such as M2B that mortality at home rose during this period. Secondly, healthcare outside hospital raises specific and different issues with respect to Covid-19 and the response. To take some basic examples, the risks of Covid-19 infection were different; effective infection prevention and control measures were different; and the dangers of not providing non-Covid-19 health care and treatment were different.

9. The need for a broad investigation is underlined by concerns raised in this and other modules about the lack of parity between NHS health care providers and health and social care in other settings (see in particular in this module the witness statement of Marie Curie INQ000353677). This raises considerations about accessing PPE, testing, capacity, staffing and funding for those providing healthcare who worked alongside the NHS.

10. Regulation and oversight. Issue 2 in the Inquiry's list of issues is 'core decision making and leadership'. It is unclear whether that will include the way in which systems for complaints, regulation and oversight operated during the pandemic. The CPs understand, from those they represent, that those systems were suspended or otherwise hugely disrupted. This is obviously a concern: if anything, regulation and oversight was more important during a pandemic. The CPs invite the Inquiry to examine this issue, and whether disruptions in oversight could and should have been avoided.

[3] https://nhsproviders.org/topics/delivery-and-performance/the-nhs-provider-sector

11. End of life healthcare/care. Palliative care for patients with Covid-19 in acute hospitals is issue 5(b), but it is unclear whether other forms of end of life or palliative care are covered. These are important topics that were overlooked during the pandemic, and which ought to be covered at some stage by the Inquiry. The significant issues include[4] (i) the absence of any or adequate end of life care (including palliative care at home, where there were a significant number of deaths), leaving people to die alone and without support, (ii) the reasons for this, including systemic inadequacies for a group of people who 'fell between hospitals and care homes in respect of infection prevention control'[5]; (iii) whether people at the end of life were considered expendable, and (iv) restrictions on visits from carers and loved ones. Those delivering palliative care in hospices, through charities providing palliative care, or in other care settings, were not considered as frontline services, and faced similar barriers to social care workers in relation to PPE and other matters.

12. End of life care is an issue which overlaps with some of the issues raised in module 6 but it is a distinct healthcare related issue. The CPs invite the Inquiry to investigate it in both Module 3 and Module 6, as it raises distinct issues about end of life care in healthcare and care settings. For this module, we invite the Inquiry to obtain evidence on the above issues.

B. EVIDENCE

Spotlight hospitals

13. As noted above, the CPs consider that it is important to focus on the experiences of people in healthcare settings, and not the institutions alone. The CPs suggest that, in addition to the investigation into the Spotlight hospitals, the Inquiry obtains (and gives sufficient weight to) evidence of representative experiences – the voices of individuals relying on healthcare and staff - within those hospitals.

[4] This All-Party Parliamentary Group report contains detail of some of the issues specific to covid-19 and end of life care: https://hospiceuk-files-prod.s3.eu-west-2.amazonaws.com/s3fs-public/2023-02/Final%20APPG%20report.pdf
[5] APPG report, p14

Particular issues for further evidence, including expert evidence

14. The CPs welcome the Inquiry's decision to obtain expert evidence on a range of topics.

15. The CPs make the following suggestions for further evidence, whether from experts or from other witnesses who are able to help with these issues. We anticipate that we will be able to provide further suggestions and will do so in our oral submissions.

    a. Use of DNACPRs. The use of DNACPRs is issue 6(b) within the provisional list of issues[6]. There is a great deal of evidence[7] that these notices were issued on an inappropriate basis – without consulting the person and/or their representatives as appropriate - across a range of different healthcare settings. The widespread use of this approach suggests there were systemic issues behind it, such as age, disability or other discrimination; or at least inadequate local or national guidelines. The examination of this issue would benefit from an expert (or other appropriate witness) who can digest and summarise the complex evidence of how these notices were used inappropriately across a range of settings, and whether the use of them was linked in some way (whether through discrimination, flawed guidelines or otherwise). The witness could also help the Inquiry understand the ethical and medical issues involved in this relatively technical area.

    b. Access to healthcare outside NHS premises. CTI's note indicates that Professors Snooks and Edwards will examine 'a number of aspects of healthcare outside of hospitals'. The CPs invite the Inquiry, if it has not done so already, to instruct the Professors to include healthcare provision in people's homes, care settings, mental health units, and other community settings: the full range of care settings in which healthcare should have been delivered. As touched upon above, there

[6] The provisional scope for Module 6 also includes DNACPR at issue 5: https://covid19.public-inquiry.uk/wp-content/uploads/2023/12/12093450/Provisional-Outline-of-Scope-of-Module-6.pdf. The Inquiry may wish to clarify the division between the two modules in this respect. The CPs discourage the Inquiry from attempting to examine DNACPRs for those in care and those in healthcare separately. The issue cannot be effectively divided. The care and healthcare systems are inseparable, and it is necessary to examine DNACPRs in both contexts together in order to properly understand the wider systemic or discriminatory issues.

[7] See, for example, the evidence heard in Module 2B, and https://www.amnesty.org/en/documents/eur45/3152/2020/en/

are specific and different issues applicable to healthcare outside NHS premises, concerning how delivery of healthcare was affected by the pandemic and the response to it; and controlling the spread of Covid-19 in the course of that healthcare.

c. The clinically extremely vulnerable population. This population is covered by issue 11 in the Inquiry's list of issues. The Inquiry is invited to consider whether expert evidence would assist in respect of this issue, for example as to (i) whether the conditions which were considered to be 'extremely vulnerable' to Covid-19 were appropriately categorised as such, (ii) whether the restrictions on their access to healthcare and other matters which resulted from this categorisation were proportionate, and (iii) whether alternative but less onerous means of protecting these individuals from Covid-19 should have been adopted (depending on the circumstances).

d. Access to and impact on healthcare services for those with learning disabilities and cognitive impairments. The pandemic response had a particular and severe impact on people with learning disabilities and cognitive impairments (such as dementia) in accessing healthcare. That was particularly so when they did not have access to familiar caregivers. People with learning disabilities were around eight times more likely to die during the pandemic[8]. There are a number of specific and discrete issues of concern, which ought to be investigated, some of which are outlined in the footnoted report and the accompanying links[9]. For example, there is evidence of a widespread failure to make reasonable adjustments in relation to accessing healthcare in this context. It is not clear from the documents produced by the Inquiry whether appropriate evidence has been obtained about this.

[8] https://www.learningdisabilityservice-leeds.nhs.uk/wp-content/uploads/2022/03/bmj.n1701.full_.pd_.pdf

[9] https://www.england.nhs.uk/learning-disabilities/improving-health/learning-from-lives-and-deaths/action-from-learning/people-with-a-learning-disability-and-coronavirus/. Some but not all of the issues of concern are considered in this: https://www.england.nhs.uk/coronavirus/documents/supporting-patients-of-all-ages-who-are-unwell-with-coronavirus-covid-19-in-mental-health-learning-disability-autism/.

e. Relatives and carers in healthcare. Relatives and carers play an essential role in healthcare. The CPs made detailed submissions about this for the purpose of the last preliminary hearing in this module[10]. The importance of their role is reflected in the NHS Constitution for England. For example, it states that "NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers." (Emphasis added). The Chief Executive of NHS England recently stated "Unpaid carers are essential partners for the NHS, whose incredible contributions each and every day we should all recognise and value."[11] This module ought to examine the critical and inseparable role of relatives and carers in healthcare for all relatives and carers across all four UK nations. Given the specific and often overlooked role they played, this module may benefit from expert evidence about unpaid carers in the NHS.

f. Nosocomial transmission in hospitals. This falls within issue 8 in the Inquiry's list of issues (preventing the spread of Covid-19 within healthcare settings). The CPs invite the Inquiry to consider whether expert evidence would assist in respect of this issue, particularly in relation to: (i) the impact and extent of nosocomial transmission; (ii) what arrangements were in place to prevent it; and (iii) what could have been done better, including the use of Nightingale Hospital.

C. PREPARATION FOR SUBSTANTIVE HEARINGS

16. The CPs understand and endorse the need for this module to be heard promptly and efficiently. However, that needs to be balanced with ensuring that progress and timetables are feasible and enable all CPs to meaningfully participate. The CPs are small, largely voluntary, organisations which have other unavoidable commitments. The extremely tight timescales adopted in previous modules prevented the CPs from

[10] The Chair's Ruling of 9 October 2023 included a provisional conclusion that "the role of unpaid carers and healthcare provided at home" would be better analysed in Module 6. A provisional scope for Module 6 has since been published: https://covid19.public-inquiry.uk/wp-content/uploads/2023/12/12093450/Provisional-Outline-of-Scope-of-Module-6.pdf. That module does not appear to include the issue of the role of carers in healthcare, so the Chair is invited to include it within this module.

[11] https://www.carersweek.org/about-carers-week/latest-news/posts-folder/2023/june/top-nhs-leaders-in-england-offer-support-for-carers-week/

being able to fully or effectively participate, and to properly prepare, in various respects. The Module 3 hearings are due to begin on 9 September 2024. Due to childcare or other obligations it is unavoidable that key members of the legal team and clients will be unavailable during August. We invite the Inquiry to avoid any significant deadlines, whether for Rule 10 submissions or otherwise, during August.

17. With that in mind, the CPs suggest that the following timetable, or something equivalent to it, is adopted. This has been identified by working backwards from the hearing, using the shortest periods necessary to enable CPs to effectively participate and properly prepare:
    a. Witness statements and underlying material disclosed – insofar as possible – by the start of May.
    b. Inquiry to produce a list of proposed witnesses by the end of May (CTI's note states this will be provided "later in Spring"), and where possible an indication of the stage in the hearings at which they will give evidence.
    c. CPs have opportunity to make submissions on the list of witnesses 14 days thereafter.
    d. Final[12] witness list to be produced by end of June.
    e. Evidence proposals to be produced on a rolling basis beginning no later than 1 July, to enable CPs to make Rule 10 submissions on witness questions, at least for the first half of the hearings, during July.
    f. Deadline for written opening submissions during first week in September.

18. If the timetable above (or similar) is not possible, the CPs invite the Inquiry to consider pushing back the hearing dates.

[12] If all witness statements were not disclosed by this point, the witness list should be open to amendment.

CONCLUSION

19. The CPs are grateful to the Inquiry for the work that has so far been conducted on Module 3, and stand ready to assist the Inquiry in whatever way they can.

ADAM STRAW KC

EMMA FOUBISTER

LEIGH DAY

27 MARCH 2024