COVID INQUIRY MODULE 3

WRITTEN SUBMISSIONS FOR PRELIMINARY HEARING 27 SEPTEMBER 2023

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

A. INTRODUCTION

1. These written submissions address the following broad topics on behalf of John's Campaign, the Patients Association, and Care Rights UK (together, "**the CPs**"):
   1.1. The scope and focus of Module 3;
   1.2. The urgency of progressing with Module 6;
   1.3. Queries relating to the collection, disclosure, and use of evidence.

2. Oral submissions will also be made, with the Inquiry's permission, at the hearing on 27 September 2023 and together these two sets of submissions comprise the CPs observations for the second Module 3 preliminary hearing.

B. THE SCOPE AND FOCUS OF MODULE 3

3. The focus of Module 3 is described by the Inquiry as being "the impact of the Covid-19 pandemic on healthcare systems".[1] The CPs have a number of important observations on how the Inquiry appears to be, and ought to, approaching this Module to ensure that it effectively considers the important issues that arise in this context.

Healthcare provided outside hospital or the GP surgery

4. First, it is crucial that the Inquiry recognises that "healthcare systems" extend beyond acute hospital settings and community GP practices. Both of these are referred to in the "Module 3: Provisional List of Issues" ("LoI") document, but other equally important healthcare locations are not referenced. The delivery of healthcare in the UK is not limited to NHS premises, and the Inquiry's framing of some of the Issues identified as falling within Module 3 suggest a concerning narrowness of focus on those settings.

[1] Module 3 Provisional Outline of Scope document, p.1

5. Rather, for many people within the cohorts represented by the CPs, their experience of healthcare systems is through the provision of healthcare at home or in a residential care setting – so, in private homes, care homes, supported living facilities, and inpatient mental health units among others. The location in which healthcare is received does not alter that it is healthcare, and therefore firmly within the scope of Module 3; healthcare does not become social care because it is provided outside NHS premises.

6. The CPs respectfully encourage the Inquiry to have firmly in mind the breadth of locations in which healthcare is provided to ensure that Module 3 properly achieves its aim of understanding the impact of the pandemic on healthcare systems overall – and not just on healthcare delivery in acute hospital or GP settings.

7. For example, when considering issue 8a the Inquiry will need to consider the impact of infection prevention and control measures not just in hospitals but also in the delivery of healthcare at home services – what measures were introduced, how patients living at home were able to continue receiving their essential healthcare (or not) and what steps were taken to protect them, healthcare staff, and unpaid/family carers in the provision of healthcare?

8. Furthermore, when considering access to healthcare, it will be vital for the Inquiry to bear in mind that many patients receive some healthcare at home or in care settings, by community care or otherwise, and some in outpatient hospital or clinic settings. Patients in these circumstances experienced particular difficulties in accessing aspects of their care during the pandemic (particularly where, (i) certain community-based services were suspended and/or (ii) their ability to attend external appointments was severely restricted, including if they lived in a care home which then required isolation periods after any external healthcare appointment). This is a vital aspect of understanding how the pandemic affected healthcare systems and by its focus on acute hospitals and GP surgeries, the Provisional Scope document does not, at present, make clear that this will be considered.

9. There are also specific characteristics of the delivery of healthcare at home that differ from the delivery of healthcare in a hospital setting which the Inquiry will need to take account of to discharge the aims of Module 3. For example, healthcare staff delivering healthcare at home or in residential settings are much more likely to work in a number of settings (going between patients in their own homes, for example) than healthcare staff in hospital. In the context of a transmissible respiratory disease, this has obvious implications which

need to be taken into account to inform the Inquiry's understanding of impact on the functioning of healthcare systems – for example, on staffing issues (issue 3 in the list of issues), healthcare inequalities (issue 2 in the list of issues), people's experience of healthcare during the pandemic (issue 1 in the list of issues) and the effect of IPC measures (issue 8a).

The role of carers

10. Second, and relatedly, it is crucial for the Inquiry to examine the enormous contribution of unpaid and family carers in the delivery of healthcare and in the functioning of our healthcare systems. In terms of economic impact, unpaid carers in England and Wales contribute £162 billion to the economy every year – meaning that the value of unpaid care provision is broadly equivalent to the annual budget of the NHS itself (which received £164 billion in funding in 2020-21).[2] Put simply, our healthcare systems would not function without the extraordinary support provided by literally millions of unpaid carers.[3]

11. The Inquiry therefore cannot form accurate or useful conclusions about the impact of the pandemic on healthcare systems without considering the impact on unpaid carers and without taking account of them as a crucial part of the healthcare workforce. In particular where, for example, Module 3's provisional list of issues asks about the mental health impact on "*doctors, nurses and healthcare staff*" this (and every other equivalent reference) should be amended to include "*carers, including unpaid carers*".[4] Additionally, given that unpaid/family carers often provide crucial care not just at home but also during hospital admissions[5], consideration of issue 8c (visiting) must include how visiting restrictions affected the access of carers.

12. The CPs also suggest that an expert report is obtained on the role of carers in healthcare, and the impact of the pandemic and response on access to carers. The report ought to cover

[2] Figures taken from https://www.carersuk.org/policy-and-research/key-facts-and-figures/ citing research by Perillo and Bennett, 2023.
[3] Carers UK data suggests there are 5.7million unpaid carers across the UK: https://www.carersuk.org/policy-and-research/key-facts-and-figures/#:~:text=According%20to%20the%20Census%202021,%2C%20Juggling%20Work%20and%20Care).
[4] This applies to issue 1, issue 8cii and particularly to issue 7.
[5] This can occur where, for example, patients communicate unconventionally, or their symptom presentation is unusual, so that familiar carers play role in identifying and meeting healthcare needs even during a hospital admission. It also arises as an issue for patients whose first language is not English and who rely on family carers to interpret for them and ensure that their informed consent to medical treatment is properly given.

the way in which healthcare decisions taken during the pandemic affected carers and the care they provided, including the extent to which they were (or were not) considered in the making of those decisions. This bears directly on the Inquiry's stated focus that, "*throughout the Module will be consideration of whether the healthcare decisions to be examined disproportionately affected any particular group(s) in society; the measures put in place to reduce the unequal impact of the pandemic on minorities or vulnerable healthcare workers or patients and whether any unequal impact was foreseeable*".[6] Unpaid carers bore a heavily unequal burden in the relevant period (and ought to be considered as one category of "*vulnerable healthcare workers*") and their situation deserves considerable attention.

13. Third, the CPs wish to underscore the importance of the Inquiry recognising that references to "systems" should really be understood as references to people. It is only by focussing on the people that the 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 functioning of the healthcare system and, accordingly, of the impact that the Covid-19 pandemic had on it.

Issue 8c: visiting

14. Third, on Issue 8c (visiting), the CPs consider it crucial that the Inquiry investigate:

    14.1. The involvement of unpaid or family carers in the delivery of healthcare (see above);

    14.2. The extent to which the visiting guidance in force at various times recognised (or, more generally, failed to recognise) the role of unpaid/family carers/other external carers (such as personal assistants) in the provision of healthcare and granted them access to healthcare settings in accordance with their status as part of a patient's healthcare team;

    14.3. How guidelines were interpreted and understood by different settings;

    14.4. How and whether families were given visiting access at the end of life;

    14.5. The impact of exclusion of families at the end of life; and

[6] Module 3 Provisional Scope document, p.1

14.6. How different settings interpreted "end of life" (which in the CPs' experience varied from some settings which understood it to mean anyone anticipated to die in the next year, and others which interpreted it to mean the final days or even hours of life).

15. Given the extremely important role of carers in the healthcare system, the CPs invite the Inquiry to change the name of issue 8(c) to 'Visiting and access for carers'.

Integration of healthcare and social care

16. Fourth, although the Inquiry has decided to investigate social care and healthcare separately, it is essential that in each of the two Modules, the Inquiry recognises that the focus should be on the people relying on the healthcare and social care services rather than on the sectors in the abstract. While the CPs understand and appreciate the rationale for these two important sectors being the focus of independent Modules, there is substantial overlap between them and the investigations into them need to run alongside each other in substance and time to ensure that a holistic understanding, and a comprehensive review, of the relevant issues is achieved.

17. An example of the overlap is in respect of the impact of Covid-19, and the response to it, on those with dementia. The National Dementia Strategy[7] explains:

> *"This is a comprehensive strategy which requires us to transcend existing boundaries between health and social care and the third sector, between service providers and people with dementia and their carers… Success will require true joint planning and joint working between health and social care commissioners and providers, the third and independent sectors and people with dementia and their carers."* (Introduction, p7)
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> *"Two-thirds of all people with dementia live in their own homes in the community…. Apart from family members or friends, who provide the vast bulk of care and support, home care is probably the single most important service involved in supporting people with dementia in their own homes" (p47)*
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> *The Strategy identifies a number of examples of the overlap between healthcare, social care, and family care; and the importance of the input of family carers (for example to help the person with dementia to communicate). One such example is the management of pain:*

[7] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

"63% of family carers reported that the patient had been in pain either 'often' or 'all the time'. Yet people with dementia receive less analgesia than other older people for a given illness. Dementia may impair the ability of an individual to make themselves understood, and at least some of the agitated and aggressive behaviours seen in late-stage dementia may be an expression of pain. People with dementia admitted to hospital for hip fracture with the same surgical intervention received less than half the pain relief of those who were cognitively intact. The majority of those with dementia were in severe pain post- operatively and this pain was not actively managed. However, communication problems in dementia may lead staff to 'surmise that pain not expressed is pain not experienced', and that pain expressed as aggression or confusion may lead to labelling and management as 'difficult'" (p62)

18. As things stand, with Module 3 finalising its issues and beginning evidence collection, while Module 6 is yet to begin, key issues risk falling through the gaps. Indeed, one of the errors made by the Government in the core part of the pandemic was to treat the two sectors as distinct and siloed from each other – which led to harmful policy decisions - rather than recognising them as overlapping and collaborative systems playing different roles in meeting the same people's various needs. Unless Modules 3 and 6 are run more closely together, the Inquiry risks repeating this error.

19. The siloed approach between Modules 3 and 6 makes it very difficult for Core Participants to effectively assist the Inquiry in identifying all relevant issues which fall into Module 3. For example, the Inquiry has rejected the CPs' request that dementia be included as one of the focus non-Covid conditions investigated in the course of Module 3 (Issue 5c in the Provisional List of Issues) – and part of the Inquiry's justification for that refusal is that it is better suited to consideration in the course of Module 6. However:

    19.1. The issues forming Module 6 have not yet been determined. The CPs are therefore not yet reassured that this important issue – and the many other "crossover" issues which could be considered under the "healthcare" or "social care" headings - will receive the attention they deserve from the Inquiry.

    19.2. The impact of the pandemic and response, on the healthcare and other care of those with dementia should, *at some stage,* be specifically examined by the Inquiry.[8]

[8] The CPs have previously put forward reasons why this should be examined within Module 3, which are not repeated here. The additional reasons why dementia should be examined at some point – whether in Module 3 or Module 6, include the following.

Dementia affects a huge number of people (nearly 1 million in the UK[9]). It raises particular issues which will not be examined in respect of the conditions in 5(c)(i) of the LoI in Module 3. Those issues include the interaction of healthcare, social care and the third sector; and the particular difficulties those with dementia have in accessing healthcare (such as inability to communicate or access virtual appointments). Dementia appears as one of the six focus conditions in the Department for Health and Social Care's major conditions strategy.[10] The particular issues raised in respect of dementia are also relevant to a very large number of people with a disability who require treatment and/or who have similar conditions which involve cognitive impairment or communication difficulties (such as those with learning difficulties), which will otherwise be overlooked by this Inquiry. Consideration of it would therefore provide insight into a different and important aspect of pandemic healthcare provision (i.e. provision to people with chronic conditions whose healthcare needs are often met in considerable terms by unpaid or family carers).

19.3. Even if a focus on dementia is ultimately incorporated into the social care Module of the Inquiry, this being run as a totally discrete exercise, separate from the healthcare Module, means that important lessons about how the pandemic affected *healthcare* provision for those with dementia is likely to be missed. If, however, it formed a core part of the social care Module but that Module was conducted contemporaneously to the healthcare Module, evidence and findings in relation to it could inform the Inquiry's conclusions across both Modules. A dementia patient's health and social care needs (and how the pandemic affected their being met) cannot effectively be understood if approached in complete isolation from each other.

20. On the issue of including dementia as a focus condition for Module 3, another justification given by the Inquiry for *not* including dementia is that statistical data, comparable to that relied on in respect of the other focus conditions, is not available for dementia. The CPs are surprised by this since, in their experience, dementia is a well-documented condition with plenty of statistical data available – and there were more excess deaths from dementia during the relevant period than from any other chronic condition. If the Inquiry is able to

[9] https://www.nhs.uk/conditions/dementia/about-dementia/what-is-dementia/#:~:text=How%20common%20is%20dementia,because%20people%20are%20living%20longer.
[10] https://healthmedia.blog.gov.uk/2023/05/17/major-conditions-strategy-what-you-need-to-know/

identify what statistical data it considers is missing, the CPs would be glad to try to help fill any identified gaps.

21. The CPs respectfully invite the Chair or ILT to confirm that dementia will be examined as a focus condition, either in Module 6 or in this Module, and that the examination will encompass healthcare and social care. They also invite the Inquiry to confirm that it recognises that healthcare and social care are often inseparable, and the integration of those two sectors will be examined with a particular focus on the person and the support they need from both health and care services.

The list of issues / rule 9 requests

22. The CPs welcome the LoI, which is a very helpful document. The CPs are currently considering the detail of the list, and are also considering whether to suggest further rule 9 statements are sent to witnesses in addition to the 127 who have already been sent rule 9 requests. The CPs will produce any such response to the LoI/suggestions on rule 9 requests at the earliest opportunity.

C. THE URGENCY OF MODULE 6

23. Building on the points made above about the inevitable overlap between aspects of Module 3 (healthcare) and Module 6 (social care), and the need for those Modules to therefore run in tandem and in a symbiotic manner, the CPs wish to stress the urgency of commencing substantive work on Module 6 and invite the Inquiry to prioritise it. The CPs welcome the announcement that the care sector Module will proceed, but are very concerned that public hearings will not begin until Spring 2025. Reasons why this Module should be expedited were canvassed at the last hearing, and included that there is a pressing need to learn lessons, since onerous Covid-19 restrictions remain in place in the care sector.

24. To put the issue starkly, given the life expectancy of those receiving social care (and particularly those receiving residential care in care homes), if Module 6 does not commence urgently, most of those affected by the issues it will address will be dead.

25. This is not an issue that arises in respect of Modules 4 and 5 (vaccines and procurement) and, in the CPs view, urgent progress on Module 6 should be prioritised over those

Modules. While the content of Modules 4 and 5 is, of course, of the utmost importance, those Modules are much less susceptible to irreparable damage if delayed. For example:

25.1. The evidence in those Modules is much more likely to be documentary, or provided by witnesses giving evidence about events in their professional life, than in Module 6 – where the experiences of people needing care and family members will form a crucial part of the relevant evidence. The longer the Inquiry takes to receive evidence from those affected by Module 6 issues, the more likely it is that the quality and availability of evidence will have eroded, by death, failing memory, or an increasing unwillingness of affected individuals to relive traumatic personal memories.

25.2. Further, and unlike Modules 4 and 5, many of those with relevant evidence to give in Module 6 are involved in the social care sector on a voluntary basis. John's Campaign is an exemplar of this: an influential and highly involved player in the sector during the relevant time, but run entirely by volunteers. Their capacity to remain engaged and of assistance to the Inquiry is likely to erode as the time, energy and personal toll of continuing to work on these issues mounts.

26. For these reasons, and for the reason identified in paragraphs 8-9 above, the CPs strongly encourage the Inquiry to devote resources to Module 6, so that it can make real and imminent progress alongside the conduct of Module 3.

D. EVIDENCE

27. In respect of the evidence being obtained in Module 3:

27.1. The CPs would appreciate clarification from the Inquiry about how the information that is being gathered from the Every Story Matters programme is helping frame the Inquiry's approach and issues of focus. The CPs consider it crucial that the evidence obtained from this strand of the Inquiry's work is properly fed into the Inquiry's overall strategy and informs the way in which the Inquiry moves forwards. It would do a disservice to those sharing their stories if they were collected and then did not help frame the Inquiry's work.

27.2. The CPs request that, when the Inquiry shares expert reports and rule 9 responses, it includes with those a copy of the instructions given to experts and the questions asked of rule 9 witnesses. The CPs' experience from other Modules is that, without knowing what issues witnesses were asked to address, it is very difficult to understand why their evidence takes a particular approach and why, for example, some topics are addressed and others omitted. To be clear, the CPs do not consider they need advance input to the instructions or questions that are sent to witnesses, but they do need to know what those instructions or questions were in order properly to engage with the evidence that emerges (and, notably, the provision of instructions with an expert report is standard practice in litigation). The CPs ask that the Inquiry takes the same approach.

27.3. Additionally, the CPs request that the Inquiry is mindful of the demands on CPs – particularly those staffed entirely or in large part by volunteers – when imposing deadlines for responses to evidence or documents disclosed. Again, the CPs' experience from other Modules is that time frames for responses have occasionally been unduly short, putting untenable pressure on CPs and their legal teams, and it is hoped that this may be avoided in Module 3.

27.4. The CPs are grateful for the list provided by the Inquiry of the rule 9 requests that have been made. They are considering whether there are any other individuals or organisations to whom requests should be made and will correspond with the Inquiry on this as soon as possible.

E. CONCLUSION

28. 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.

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12 SEPTEMBER 2023