

**BEFORE BARONESS HEATHER HALLETT IN THE PUBLIC INQUIRY TO EXAMINE
THE COVID-19 PANDEMIC IN THE UK
MODULE 3**

**SUBMISSIONS ON BEHALF OF JOHN'S CAMPAIGN, THE PATIENTS
ASSOCIATION AND RELATIVES AND RESIDENTS ASSOCIATION
FOR PRELIMINARY HEARING, 28 FEBRUARY 2023**

A. INTRODUCTION

1. John's Campaign, the Patients Association and the Relatives and Residents Association ('the organisations') are glad to have been jointly designated a Core Participant in Module 3 of the Inquiry. They look forward to engaging with the Inquiry to share their expertise of the individual experience of health provision during the pandemic, and to ensure that the voices of individuals and their families are fully heard in the Inquiry's investigation of the impact of the pandemic on healthcare systems in the UK.
2. These written submissions address the group's key areas of concern and interest at this preliminary hearing stage.

B. THE CORE PARTICIPANT'S PRIMARY CONCERNS AT THIS STAGE

Observations relating to the provisional scope of Module 3

3. John's Campaign, the Patients Association and the Relatives and Residents Association have considered the provisional scope of Module 3 and the information provided by the Inquiry thus far about the manner in which the work of Module 3 is to be undertaken. They are aware that they bring a particular focus and understanding to Module 3, as representative organisations of individuals deeply affected by the pandemic who, in many cases, remain healthcare users and continue to experience the ongoing effects of the pandemic on healthcare provision.
4. That particular constituency gives rise to the first key area of concern for John's Campaign, the Patients Association and the Relatives and Residents Association. The Inquiry is respectfully requested to include in the Module 3 investigation a line of

enquiry relating to the impact of **ongoing restrictions**. Although the Inquiry's terms of reference state that it "*will examine, consider and report on preparations and the response to the pandemic in England, Wales, Scotland and Northern Ireland, up to and including the Inquiry's formal setting-up date, 28 June 2022*", a comprehensive investigation of the response to the pandemic in the context of Module 3 must include an analysis of how that response has precipitated *enduring* changes to healthcare provision. Evidence relating to ongoing restrictions after 28 June 2022 is therefore relevant and consistent with the terms of reference, to provide a more informed understanding of the long-term impact of the pandemic response. In particular, the organisations are aware that there have been material changes to the way in which healthcare settings approach infection control, with restrictions on access to settings being much more readily adopted or maintained than was the case before the pandemic. The Inquiry is invited to collect evidence on the extent to which restrictions remain in place or are renewed in certain circumstances by healthcare settings, and how they may have impacted the responses and culture within healthcare settings in order to gain an understanding of the way in which healthcare provision has been affected in an enduring way by pandemic-response measures.

5. Alongside this, and expressing a similar concern to ensure that Module 3 take a sufficiently broad approach to properly understand the impact on healthcare provision, John's Campaign, the Patients Association and the Relatives and Residents Association wish to highlight the importance of considering the experience of individuals across the full **range of settings** and not just those settings traditionally associated with healthcare. In particular, John's Campaign, the Patients Association and the Relatives and Residents Association are concerned to ensure that the experience of people **at home and living in care settings** who had healthcare needs are taken into account. Restricted access to healthcare for non-Covid-related health needs was a key feature of the pandemic and ought to form part of the inquiry into the pandemic's effects on healthcare systems. It is important to highlight the number of individuals who were cared for at home and in a range of care settings and whose access to healthcare (including appointments, assessments, and treatment) was substantially affected by measures put in place to respond to the pandemic, as well as the effect of self-isolation measures in restricting access to healthcare. On this last point, the organisations are aware that individuals living in care settings (which

imposed draconian isolation rules after the initial period of the pandemic) chose not to attend medical appointments for fear of having to undergo a period of isolation after every appointment. Module 3 must consider these overlapping and interwoven aspects of the pandemic response in order to secure a holistic understanding of impact.

6. Next, John's Campaign, the Patients Association and the Relatives and Residents Association wish to ensure the Inquiry takes adequate account in Module 3 of **the experience of individuals**. This arises in a number of ways:

- 6.1. **The need for focus on the person rather than the setting:** The way in which the provisional scope of Module 3 is framed currently reveals a disproportionate focus on healthcare systems and the impact on systems and settings, rather than on individual impact. For instance, in the CTI Note for the Preliminary Hearing, at para 33(d) (part of a section detailing areas within the scope of Module 3), it is clarified that, in respect of processes for discharging patients from hospital, "*Module 3 will consider the impact on hospitals of an inability to discharge patients who have been deemed fit for discharge*". It is only the impact "*on hospitals*" which is referred to here. But, in the view of John's Campaign, the Patients Association and the Relatives and Residents Association, the impact on individuals of decisions relating to discharge must also form part of the Module 3 inquiry. Healthcare systems exist to provide healthcare to people and to protect and care for people. The impact not only on hospitals as institutions but also on individuals as service users must be at the heart of this module. In the context of discharge, this might be achieved by the Inquiry considering and obtaining evidence on, for example, how individuals were affected by discharge decisions; whether patients' physical or mental health was put at risk by discharge processes or difficulties discharging patients otherwise fit-for-discharge; how individuals were assessed and prioritised for discharge, and so on. A sole focus on the impact on hospitals in this context would provide an incomplete picture of the relevant effects of the inability to discharge patients and an inadequate investigation of matters within the scope of Module 3. The same would apply in respect of other lines of inquiry if focus is disproportionately on settings and sufficient attention is not given to the experience of individuals.

6.2. The need to consider individual experience as well as infection control: A

key focus of the pandemic response in healthcare settings was, for understandable reasons, infection control. However, this focus came at a significant cost to the mental health and wellbeing of individuals and to important issues such as consent and safeguarding. Much of the campaigning and support work that John's Campaign, the Patients Association and the Relatives and Residents Association undertook during the relevant period sought a rebalancing of focus to ensure that individual needs were not overlooked and infection control did not operate as a trump card to all other considerations. They are concerned to ensure that the Inquiry does not repeat the mistake of an excessive focus on infection control, and considers as well the impact in healthcare systems during the pandemic on individual experience in a holistic sense.

6.3. End of life healthcare: John's Campaign, the Patients Association and the

Relatives and Residents Association note that 'end of life' is not featured in the provisional outline of scope for Module 3 (whereas for example 'palliative care' is). They invite the Inquiry to consider 'end of life' healthcare as a distinct and important line of inquiry. There should be real concern about the quality of healthcare and support that was provided at the 'end of life', including how that term was defined and how it was decided whether an individual (generally in the absence of family and known carers) was to be moved onto an 'end of life' care pathway, and how they and their loved ones would be adequately supported.

6.4. Impact on staff and carers: John's Campaign, the Patients Association and the

Relatives and Residents Association wish to highlight the impact on healthcare systems of the exclusion of unpaid essential carers / family carers. The toll the pandemic took on healthcare workers was enormous and, while other organisations will be better placed to provide evidence of that impact on provision of healthcare generally, and on the burnout and wellbeing difficulties faced by healthcare staff, John's Campaign, the Patients Association and the Relatives and Residents Association consider that the exclusion of essential /family carers from healthcare settings (in the name of infection control) materially contributed to the exhaustion of staff and the negative impacts on provision of healthcare

which arose from that. This is an area that should fall for consideration within the scope of Module 3.

The listening exercise

7. Alongside the observations above about Module 3's provisional scope, John's Campaign, the Patients Association and the Relatives and Residents Association are concerned that the listening exercise as currently described may not be accessible to the most vulnerable and marginalised individuals. There has been no consultation with representative organisations such as these Core Participants to design a listening exercise that will reach and engage a proper cross-section of affected individuals to ensure that "broad and representative" information is obtained.
8. In particular, John's Campaign, the Patients Association and the Relatives and Residents Association are concerned to highlight the need to consider how to foster participation in the listening exercise by those who may not be able to communicate via conventional means (e.g. those who are non-verbal) so that their experiences are taken into account. It is not currently clear how, if at all, alternative means of participation are being catered for, and the Inquiry is encouraged to undertake further consultation on this.
9. The organisations would also be grateful for further information about how the personal accounts provided through the listening exercise will be used by the Inquiry. It is not clear whether the experiences collated will be considered in the context of the scope of each module. For example, will all of the experiences given relating to the topic "The NHS (and any other health services)" be considered alongside evidence disclosed as part of Module 3? John's Campaign, the Patients Association and the Relatives and Residents Association consider that further explanation and clarification on how the information provided by individuals will be used will encourage members of the public to engage with the process.

Rule 9 requests

10. As raised by John's Campaign and the Relatives and Residents Association in respect of Module 2B (and noting the Chair's rejection of the submission in that module), John's Campaign, the Patients Association and the Relatives and Residents

Association repeat the request that Rule 9 letters are provided to Core Participants to aid their understanding of the Rule 9 evidence provided pursuant to each letter; or that Rule 9 evidence summarises the questions which have been asked. We invite the Chair to ask those responding to Rule 9 requests to include the relevant questions in their witness statement, to allow for meaningful engagement by Core Participants with the evidence which is provided.

Expert evidence

11. On an analogous point, and as also raised in respect of Module 2B, John's Campaign, the Patients Association and the Relatives and Residents Association invite the Chair to disclose letters of instruction of experts to Core Participants while in draft, so that Core Participants can provide comments or suggested lines of questioning to CTI to consider before the final letter of instruction is sent. This would ensure efficiency and avoid delay in procuring the expert evidence necessary to progress Module 3's investigation.

Preparation for the hearing

12. John's Campaign, the Patients Association and the Relatives and Residents Association note the short timescales for provision of written submissions for the preliminary hearing. They are each small, busy organisations and respectfully ask the Inquiry team to provide for longer, more reasonable timescales for responses to and engagement with the Inquiry to ensure it is possible to take full instructions and engage in a meaningful way with any issues arising.

**ADAM STRAW KC
DOUGHTY STREET CHAMBERS**

**JESSICA JONES
MATRIX**

LEIGH DAY

21 FEBRUARY 2023