

COVID INQUIRY MODULE 6

WRITTEN SUBMISSIONS FOR PRELIMINARY HEARING ON 5 FEBRUARY 2025

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

INTRODUCTION

1. John's Campaign, Care Rights UK, and the Patients Association (together, "**the CPs**") are pleased to participate in and assist the Inquiry with its Module 6 investigation. The CPs have deep and extensive (including personal) experience working with and responding to the needs of people who draw on care, along with their families, before, during and after the pandemic. They have witnessed first-hand the impact of the pandemic on the experience of people in the adult social care sector. The CPs will strive to ensure that the voices of those drawing on care, and the experiences they had during the pandemic, are central to the Inquiry's discharge of Module 6.
2. These written submissions address the following topics on behalf of the CPs:
 - a. Key areas of concern;
 - b. Rule 9 requests;
 - c. List of Issues; and
 - d. The Inquiry's procedure.
3. These written submissions will be supplemented by oral submissions on behalf of the CPs at the preliminary hearing on 5 February 2025. The Inquiry is respectfully requested to take account of these submissions alongside the oral submissions made at the hearing.

KEY AREAS OF CONCERN FOR MODULE 6

Overlap of Module 6 (social care) with Module 3 (healthcare)

4. During the pandemic, social care was too often neglected, deprioritised and considered in isolation. The CPs are concerned to ensure that those mistakes are not repeated and that social care is considered in the wider context of healthcare and combined health and social care support structures.

5. There is an important and unavoidable overlap between health and social care, as the CPs have repeatedly emphasised. This was reinforced in Module 3, where Amanda Pritchard, NHS England, highlighted the importance of social care in the context of healthcare: *‘I would say don't forget social care. I know this Inquiry won't, to be clear, but we can only do what we can do in the NHS if we've got an equally, you know, if we've got that strong partnership with social care, so the staffing, the resourcing, all of the questions you've rightly asked me, I would say that would be a crucial underpinning for our resilience in any future pandemic’* [29/149/16-23].

6. The same considerations will apply in Module 6. Lessons learned in this Module need to be considered alongside lessons emerging from Module 3, and in the context of the wider health and social care structures in order to effect real change and make holistic improvements. Without major structural change and proper alignment of health and social care, the same problems as arose in the pandemic will recur.

The diversity of care settings and the people in them

7. The CPs urge the Inquiry to consider the importance of the diversity of: (i) care settings; (ii) the people living and receiving care in those settings; and (iii) the manner in which (and by whom) care is given.

8. Government decision-making and rhetoric during the pandemic suggested that those in power considered people living in care settings and/or receiving care to be a homogenous group (often older people at the end of life). In fact, there is significant diversity regarding:

- a. The places in which people receive care: this includes individual homes, mental health units, residential care homes (which themselves vary widely, with some providing general or nursing care, and others being highly specialised, whether by age or needs), and supported or assisted living arrangements (where the level of independence and care input may also be very varied);
 - b. The people receiving social care: the needs of people receiving care range widely by age, disability, and other characteristics. They include people of all ages with a wide range of support needs. People requiring social care are also as individually diverse as any other group of people and should never be defined by or viewed solely by reference to their age, abilities or their need for additional support; and
 - c. The way in which social care is provided: for some recipients of care, their care is provided by employed staff in a residential care setting – including agency or sub-contracted staff; others receive care from unpaid family carers, either at home or alongside care from professional carers in residential care settings. The manner in which care was provided, and by whom, is another variable feature of the social care sector that gave rise to different needs and different risks during the pandemic, and that needed proper recognition in order for appropriate decisions to be made. For example, many people who were in contact with the CPs discovered that there is a broad and unhelpful division in that care at home falls almost exclusively on the unpaid family carer, often with very little professional help. However, if needs exacerbate, the unpaid carer's health fails and they can no longer cope, the person needing care is transferred to a residential setting from which the family carer is too often excluded. This unhelpful dichotomy was exponentially worsened by pandemic decisions.
9. It is important that the Inquiry keeps clearly in mind the range of needs and circumstances that fall within the adult social care sector because: (i) the pandemic had a distinct impact on people with different care needs and different care arrangements; (ii) the Government failed to take adequate account of the differences between people in the adult social care sector (for example, by imposing restrictive visiting rules on all residential care homes based in part on an understanding of the perceived vulnerability of older people, without any recognition that the risks of Covid-19 on people with care needs significantly varied; (iii) Government decisions did therefore have a differential impact on different parts of

the adult social care sector, and different people within it, and (iv) the Inquiry's recommendations will need to be tailored to address the variability of the sector as described above.

The dignity and quality of life of people in care

10. Standing alongside their diversity is one feature common to all residential care settings: they are their residents' homes. The CPs consider this to be another feature of the adult social care sector that was often overlooked by decision-makers during the pandemic. Decisions about residential care settings should have been made with the same care and caution as would be expected in relation to decisions affecting private homes, affording residents of care settings the same dignity and concern that we would all expect to receive in our own homes. Decision-makers often seemed to overlook the fact that these were people who were still loved, who were members of families and friendship groups even though their health or personal needs meant they could no longer live in the same domestic home or community. The Inquiry is asked to be cognisant of this as it undertakes Module 6.

11. Relatedly, the need to consider the quality of life (and death) of people drawing on care, and the indirect impacts of key decisions on their quality of life, often appeared to be overlooked in decision-making despite warnings from stakeholders. It is therefore crucial that this mistake is not repeated by the Inquiry. What this requires is a constant awareness that decisions about "care homes" or "the adult social care sector" are not (and should not have been approached as) depersonalised decisions about institutions and the rules or practices that should be imposed on them for infection control – they are decisions about the lives (and, too often, deaths) of the people who live in residential care settings, and who rely on those settings to provide a safe, comfortable, and happy home for them where their needs are met. Understanding the impact of the pandemic on the adult social care sector will require a probing investigation of the experiences of individuals living in these settings, including the quality of care available to them; whether they had access to the right type of care, including healthcare and end of life care when they needed it; what measures were in place to ensure oversight and safeguarding; and what was done to address concerns and complaints when they were raised.

“Spotlight” settings

12. The CPs welcome the Inquiry’s intention to obtain evidence from individual residential care or nursing homes. They are, however, concerned by the suggestion in CTI’s Note (§5) that the Inquiry intends to select these spotlight settings “*at random*”, ensuring only that the selection includes a geographical variety.
13. This concern is linked to the prior points made about the variability of provision in the adult social care sector. Selecting institutions “*at random*” risks the Inquiry *not* obtaining a representative cross-section of the sector and not, therefore, obtaining the evidence necessary to form an accurate understanding of the issues that were experienced by individual care homes and nursing homes.
14. The CPs suggest that, rather than a random selection, criteria should be drawn up to identify a number of care homes which capture a range of characteristics to produce a representative sample, from whom evidence can be obtained. The CPs suggest that these criteria should include (i) institutional specialism (e.g. autism, dementia, epilepsy, mental health, older adults); (ii) age range of residents; (iii) size; (iv) care or nursing needs of residents and level of care/support required; (v) geographical location within the UK; (vi) urban v rural location; (vii) private (both profit and not for profit) v public institution; (viii) regulatory rating; and (ix) proportion of self-funded v publicly-funded care.
15. The CPs would be glad to work with the Inquiry on producing an appropriate set of criteria to identify individual care or nursing homes to whom Rule 9 requests can be sent, to ensure there are no omissions in the type of institutions approached to provide “spotlight” evidence.

The position of those in privately-run care homes and/or self-funding care

16. It is important for the Inquiry to consider specifically the position of people whose care is self-funded and arranged, as contrasted with those whose care is arranged for / funded

by a qualifying authority under section 73 of the Care Act 2014¹. There are two key concerns arising from this.

17. First, as the duty under the Human Rights Act ('**HRA**') applies directly to private care providers only where the care is arranged or funded (in any part) by a local authority, this made it more difficult for some people (whose care was arranged or funded differently) to rely directly on the protections in the HRA.² In the context of the pandemic this posed a particular problem where such people sought to rely on their HRA rights to seek individualised risk assessments in the context of decision-making on whether they required access to their family carer. Even where people living in care homes were seeking to challenge (or correctly apply) guidance from the government or public bodies (who are of course bound by the HRA), they were unable to enforce their rights directly with the care provider and instead had to rely on other public bodies (such as the regulator) intervening, which in many cases did not happen.

18. Second, during the pandemic, self-funding individuals faced significant additional financial pressures as a result of IPC measures. For example, the CPs heard from people who had to pay extra for Covid-related costs such as care staff PPE and other IPC-related expenses. They had no control over the expenses that were added to their bills nor the measures being imposed. Whilst provision was gradually made for PPE to the social care sector, the Government should have arranged for the supply and payment of PPE as a basic principle of effective infection control from the outset of the pandemic. An increase in bills for care in circumstances where care was more important than ever, accompanied by limited protections, assistance, or ability to challenge the measures imposed (including because complaints raised were often met by threats of eviction from the complainant's setting) raises concerns that the CPs urge the Inquiry to carefully consider.

¹ According to Section 73 of the Care Act a care provider is to be taken for the purposes of section 6(3)(b) of the Human Rights Act 1998 (acts of public authorities) to be exercising a function of a public nature in providing the care or support, if the requirements of subsection (3) are met. The requirements are that—(a) the care or support is arranged by an authority listed in column 1 of the Table included in the provision, or paid for (directly or indirectly, and in whole or in part) by such an authority, and (b) the authority arranges or pays for the care or support under a provision listed in the corresponding entry in column 2 of the Table. The position of care provided outside this context is less clear.

² This was recently considered by the High Court in *Sammut and others v Next Steps Mental Healthcare Ltd and others* [2024] EWHC 2265, a case that concerned the death of a patient in a nursing care home run by a privately-owned company which considered the impact of section 73 of the Care Act and how it interacted with an earlier decision in *YL v Birmingham City Council* [2007] UKHL 27. The claim under the HRA was struck out because the Court found that the defendant was not a public authority and was not carrying out “*functions of a public nature*”.

19. The Inquiry is asked to take evidence on and consider the impact of these issues in the course of Module 6.

RULE 9 REQUESTS

20. As the Inquiry is aware, the CPs have made a Rule 9 request by letter dated 22 January 2025 identifying three witnesses able to provide evidence on key issues for Module 6. The CPs refer to and rely on the contents of that letter, which is summarised here for convenience.

Boris Johnson

21. The CPs strongly urge the Inquiry to ask Boris Johnson to provide evidence on the key decisions made by him, as Prime Minister, and the UK Government in respect of the adult social care sector, including the decisions relating to the discharge of people from hospitals into care settings. The CPs are particularly concerned about key decisions made and guidance issued by the Government at the start of the pandemic that had far reaching and damaging consequences. In particular, the CPs are concerned by the evidence to date, which suggests that there was a failure to consider the harm that these decisions ultimately caused. The severity of these decisions, and the Government's approach to them, underlines the need for proper and public accountability in respect of the Care Sector.

22. Comments made by Mr Johnson in the course of his premiership suggest there was significant disregard of the value of people in residential care settings, particularly older adults, and the CPs are concerned that this impacted on the decisions that were made regarding them and the care that was afforded to limiting negative impacts on them. The comments also caused distress and consternation among those with loved ones living in residential care. It is only by taking evidence from Mr Johnson himself that this issue can be addressed by the Inquiry, both in terms of ascertaining whether and, if so, how the needs of those in residential care were taken into account and the value afforded to them by decision-makers, as well as obtaining explanations for the disparaging and dismissive comments Mr Johnson made about them. These points were not covered in any detail by

Mr Johnson in his earlier evidence to the Inquiry and it would be a material omission if the opportunity were not now taken to obtain his account.

Diane Mayhew and Jenny Morrison, Co-Founders of Rights for Residents

23. The CPs invite the Inquiry to ask Diane Mayhew and Jenny Morrison, as Co-Founders of Rights for Residents, to provide evidence on the impact of the pandemic on recipients of care and their loved ones. Rights for Residents was founded in response to the traumatic experience of being separated from loved ones receiving care during the pandemic, and is now a unique grassroots community campaigning for the rights of people who draw on health and social care. Evidence from Ms Mayhew and Ms Morrison would play an important role in amplifying the voices of thousands of people with direct experience of the issues arising in Module 6.

Provision of oral evidence by CP group

24. As stated in their letter regarding the additional Rule 9 requests, the CPs note, for the avoidance of doubt, that they request that Rights for Residents be asked to provide evidence in addition to the evidence already provided by their CP group. The CPs themselves also stand ready to assist the Inquiry with oral evidence in Module 6 and respectfully ask the Inquiry to invite a representative of their CP group to provide oral evidence to supplement the written evidence they have already provided.

Impact witnesses

25. The CPs welcome the Inquiry's invitation for input on impact witnesses and will provide suggestions in writing in due course.

LIST OF ISSUES

26. The CP's comments and suggested amendments to the List of Issues are detailed in an Annex to these submissions. Three specific points are highlighted here.

27. Linked to the submissions made above, the first point the CPs wish to highlight is that the List of Issues must be wide enough to ensure the full range of people, needs, care settings and funding models are considered in the course of Module 6 (see above at paragraphs 7-9). In this regard, the CPs repeat the point made in their written submissions for the previous preliminary hearing, that issue 1 ought to be expanded expressly to include consideration of those in supported or assisted living facilities, as well as in residential, nursing or individual homes. It should also include people living in mental health units.
28. Individuals in supported living settings are an important cross-section of people drawing on adult social care, many of whom have learning disabilities and/or autism as their primary support need³ - the former being one of the Inquiry's chosen focuses for Module 6. The needs of and particular obstacles faced by those receiving and providing care in supported living facilities are different from other care settings and equally worthy of investigation; and the impact of the pandemic on them also had its own features which the Inquiry should investigate. The CPs seek clarification that the inquiry will also consider the situation of people, for example with advanced dementia, living in mental health units either permanently or temporarily under the Mental Health Act. A failure to include assisted living settings and mental health units providing care within Module 6's remit would result in a real lacuna in the Inquiry's understanding of the impact of the pandemic on the adult social care sector and on those drawing on care.
29. The second point which the CPs wish to highlight, for the Inquiry to consider incorporating into the List of Issues and obtaining evidence on, is the role played by insurers in the adult social care sector. In the CPs' experience, care homes often cited issues with their insurers as a basis for taking a risk-averse approach, for example to permit people living in the home to have visitors and taking the most restrictive approach where some leeway was provided by Government guidance. The extent to which insurance was indeed a factor, or the appropriateness of insurers taking this stance and limiting the rights of people living in care homes, is not clear, and the CPs would urge the Inquiry to investigate this to establish how terms imposed by insurance schemes impacted decision-making in the adult social care sector during the pandemic.

³ 2018 Mencap report available at: https://www.mencap.org.uk/sites/default/files/2018-04/2018.052%20Housing%20report_FINAL_WEB.pdf

30. The third point is that, given the huge number of people receiving care at home (including from unpaid family carers – the number of whom increased by an estimated 4.5 million in the first 4 months of the pandemic⁴) the CPs consider that the List of Issues needs to have a closer focus on care at home. This includes, for example, the Inquiry obtaining evidence on the significant impact of additional demands being placed on family carers on their own health and wellbeing, the dilemma faced by families who found the separation imposed by care homes intolerable and decided to care for their loved ones at home at great personal cost, the impact of provision of end of life care at home (often without adequate support), the impact on the quality of care provided to those drawing on adult social care in their own homes when health and care professionals were prevented by lockdowns from visiting them to provide necessary care, people deciding to stay at home without their care needs being properly met in order to avoid isolation requirements and visiting restrictions in care homes; and issues arising in respect of infection control when professional carers moved from home to home providing care. The List of Issues does not currently squarely address these points, and it ought to.
31. The identification of and provision of support for those providing care at home is an issue that must be considered as part of this Module. As far as the CP group is aware none of the four UK nations operates a comprehensive register of carers. In addition, many people, even while acting as carers to someone who depends crucially on their support, will prefer to speak of themselves as ‘just’ a husband, or daughter or partner and will not necessarily self-identify as an “unpaid carer.” The additional difficulty during the pandemic was the large number of people who found themselves unexpectedly taking on a caring role when official health and care services were withdrawn (as we highlighted in Module 3) whose contribution was vital but whose support was not recognised (and to whom support was not, in turn, provided). Recommendations from the Inquiry about how the situation of the thousands of “invisible” unpaid carers could be improved, both now and for a future pandemic, would be a very valuable output of Module 6.
32. Additional key themes arising from the List of Issues, on which the CPs’ suggested amendments are set out in the Annex to these submissions, are:

⁴ INQ000239459_0004 (State of Caring report by Carers UK, 2021)

- a. The extent to which statutory duties and basic human rights, including under the HRA, the Equality Act 2010 (including Equality Impact Assessments and the Public Sector Equality Duty) and mental capacity legislation were complied with.
- b. The adequacy of communication and consultation with individuals receiving care and their loved ones and chosen representatives (including the impact of the use of technology and virtual contact).
- c. The extent to which the restrictions placed on care homes were out of step with those placed on the rest of the population.
- d. The gaps in the provision of care and support and who was relied on to fill the gaps.
- e. The importance of considering the experiences of people drawing on care and their loved ones at the end of life, including the level of support available to them in different settings and their quality of life as they approached the end of their lives.

INQUIRY PROCEDURE

33. The CPs note that the Module 6 hearings conclude at the end of July and are immediately followed by the summer break in August. The CPs respectfully request that the summer break is considered when setting the deadline for the written closing submissions. In circumstances where the Module 6 report will not be published for some time, the CPs request until around the end of September to provide their written submissions following the oral hearings.

**JESSICA JONES
EMMA FOUBISTER
MATRIX**

LEIGH DAY

24 JANUARY 2025