COVID INQUIRY MODULE 6

WRITTEN SUBMISSIONS FOR PRELIMINARY HEARING ON 19 MARCH 2024

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

INTRODUCTION

1. John's Campaign, the Patients Association and Care Rights UK (together, "**the CPs**") are pleased to have been jointly designated a Core Participant in Module 6 of the Inquiry. They look forward to engaging with the Inquiry to share their expertise of the individual experience of social care during the pandemic. They wish to ensure that the voices of people needing care and their families, as well as those providing care, are fully heard in the Inquiry's investigation into the impact of the pandemic and the response to it on the adult social care sector in the UK. They are representative organisations of individuals deeply affected by the pandemic who, in many cases, remain social care users and unpaid carers and continue to experience the ongoing effects of the pandemic on social care provision. Between them, their reach extends to hundreds of thousands of individuals along with a number of organisations and care providers.

2. These written submissions address the following topics on behalf of the CPs:
   A. Key preliminary areas of concern and lines of inquiry.
   B. Rule 9 requests.
   C. Expert evidence.
   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 19 March 2024, with the Inquiry's permission. As it is not envisaged that each of the topics in this note will be raised orally, the Inquiry is respectfully requested to take account of these submissions alongside the oral submissions made at the hearing.

A. KEY PRELIMINARY AREAS OF CONCERN AND LINES OF ENQUIRY

The provisional scope of Module 6

4. The CPs suggest that the amendments identified below are made to the Key Lines of Inquiry (the suggested additions are in red). These submissions also address the matters identified by the Counsel to the Inquiry's Note (para 43), namely:

    4.1. Specific areas that are particularly important for targeted research;
    4.2. Any further topics and why these are important; and
    4.3. Views on the target populations for the research.

Care homes and supported/assisted living services

1. *Experiences of people living in care homes and in supported living facilities, and their loved ones during the pandemic.*
2. *Experiences of those working in the care ~~home~~ sector across various different job roles.*
3. *The use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPRs) decisions and communication with people needing care, and their loved ones about these decisions, their condition and care plan, including the government's input and guidance.*
4. *Discharge of people from hospitals into care homes in the early stages of the pandemic and the impact of this.*
5. *Infection prevention and control measures in care homes/supported living facilities including:*
    a. *Access to PPE and Covid-19 tests and the adequacy of PPE for workers in the care home sector, unpaid carers, and essential care givers.*
    b. *The broader management of Covid-19 in care homes.*
    c. *Government policy relating to care settings and the interpretation of this guidance by care homes/ supported living facilities.*
6. *Whether legislative duties, including equality and human rights duties, were overlooked.*
7. *The indirect harm caused by NPIs to people living in care homes/ supported living facilities, particularly the management of outbreaks, restrictions on visits and movement.*
8. *Access to healthcare and other professionals, and the treatment of non-Covid conditions in care homes/supported living facilities.*

9. *Regulation/oversight and the experience of those who complained/wished to complain about care during the pandemic.*
10. *Bereavement experienced by people who lost loved ones living in care homes/supported living facilities and the long-term mental health effects on people who were denied the right to care for their loved ones due to visiting restrictions and saw them deteriorate or die.*
11. *End of life care and support.*
12. *Recording of deaths in care homes during the early part of the pandemic, including whether Covid-19 was under-reported.*

Care in the home

1. *Experiences of those who receive care in the home either from unpaid or paid carers.*
2. *Experiences of those providing care in the home whether paid or unpaid.*
3. *The impact of the pandemic on day care services, respite care and reablement care and community medical services.*
4. *Infection prevention and control measures in the context of home care, including:*
    a. *Access to PPE for those providing care in the home whether paid or unpaid; and*
    b. *Broader management of Covid-19 in the cared for individual's home.*
5. *Bereavement experienced by people who lost loved ones who received social care in the home during the pandemic.*
6. *End of life care and support.*
7. *Guidance and policy.*

5. Potential audience groups that it is proposed are included in the sampling for qualitative interviews include those categorised by:
    a. *Residents of adult care/nursing homes/supported living facilities and their loved ones, including young people with complex disabilities whether cared for at home or in a care home and their parents.*
    b. *Staff working in adult care/nursing homes/supported living facilities.*
    c. *Those providing care in the home (i.e. domestic home) whether providing paid or unpaid care.*
    d. *Those receiving care in the home (i.e. domestic home).*
    e. *Those receiving care and living with dementia (which includes Alzheimer's).*
    f. *Those providing care to people living with dementia.*

6. CTI has stated that the Inquiry does not intend to examine children in care in this module, since they will be considered in a later module. We invite the Inquiry to approach this issue with some flexibility. There are certain issues which will in any event fall within the scope of this module, which affect children in care. The way they affect children may be relevant to this module, or may help the Inquiry understand the particular problem at issue. It may be impossible to properly separate the impact on children from this module, and consider it in isolation later. For those reasons, we invite the Inquiry to take into account the experience of children in care, where it is appropriate to do so, and not exclude them entirely from this module.

Submissions in support of the above

7. The suggested amendments are taken in turn.

8. The CPs respectfully invite the Inquiry to examine **supported or assisted living settings**. Those in supported living setting are important cross-section of people in care. A MenCap report found that 78% of people living in Specialist Supported Housing are people who have learning disabilities and/or autism as their primary support need[1]. The needs of and particular obstacles faced by those receiving and providing care in supported living facilities are different to other care settings and equally worthy of investigation. For example, the UK Government produced different guidance for supported living facilities and for care homes (i.e. see supported living guidance[2]).

9. **DNACPR government input and guidance**: Other modules have heard evidence of very widespread use of DNACPR letters. The excellent Amnesty Report '*as if expendable'* sets out some evidence to this effect at p24 onwards. The fact that this was so widespread indicates that the government did not do enough to prevent it. In module 2B, the Older People's Commissioner, Helena Herklotts, described how the use of DNACPR letters made older people feel "that their lives weren't valued, that they weren't important" [Day 2, p128, lines 1-11].

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[1] https://www.mencap.org.uk/sites/default/files/2018-04/2018.052%20Housing%20report_FINAL_WEB.pdf .

[2] [Withdrawn] [Withdrawn] COVID-19: guidance for supported living - GOV.UK (www.gov.uk))

10. Incidentally, the CPs invite this module to read the Amnesty report[3] in detail. It contains a range of important evidence – including a number of interviews of people affected by the pandemic and its response. The CPs invite the Inquiry to carefully investigate within this module each of the issues raised in that report, and to either adduce the report as evidence or seek to obtain the underlying evidence for itself.

11. **The impact of discharge from hospitals into care homes.** This particularly concerns the policy in March and April 2020 to discharge patients from hospital into care homes without comprehensive prior testing. The additional topics are both the number of Covid-19 cases/deaths the policy caused, and also the impact in terms of how it affected future decision making. The CPs invite the Inquiry to consider obtaining expert evidence about how many Covid-19 cases/deaths the policy caused. In module 2B there were some suggestions that 'the size of the care home was more important than the policy to discharge' (see e.g. papers by Dr Williams and Professor Gravenor, such as INQ000224072), and therefore that the discharge policy did not cause much harm or that it was necessary due to the anticipated pressures on the NHS (which it is not clear materialised). Those suggestions were problematic for various reasons. For example, they were made in papers/testimony produced by authors/witnesses who arguably bore some responsibility for the discharge policy, so were not sufficiently independent. In addition, the findings were difficult to understand: the size of a care home and the discharge of patients into it, are not mutually exclusive. The CPs consider that the way the care home was managed was more important than its size. In consequence, if the inquiry considers that the impact of the discharge policy should be investigated at all, it would be better to instruct an independent expert who can digest and summarise all of the relevant evidence on this topic, rather than relying on a couple of apparently biased, limited and unclear reports.

12. **Government policy and guidance relating to care settings, and the interpretation of this guidance by care homes/ supported living facilities/ local authorities**. The core decision-making modules touched on this, but did not look into it in any detail. It is crucial to properly test assertions regarding actions said to have been taken to consider the impact of these restrictions and minimise them. It is important because it affected large numbers of people and caused significant suffering. This is set out in more detail in the CPs' module 2B

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[3] https://www.amnesty.org.uk/files/2020-10/Care%20Homes%20Report.pdf

submissions. In summary, there was a delay in producing guidance at the start of the pandemic. Thereafter, guidance was confusing and contradictory, and not understood by a number of people providing and needing care. The distinction between guidance and law was also often unclear. There were a number of specific problems with care sector guidance, such as how it defined important terms (including "the end of life") which had serious adverse impacts. The interpretation of this guidance by staff was also a concern. Guidance was interpreted very differently between different care homes/settings. This raises the question of how the guidance could have been better framed to avoid serious inconsistencies in approach. It is also clear that government did not listen to concerns raised by both those needing and providing care in formulating and updating the guidance. For example, concerns detailed in the Older People's Commissioner's report "*Care Home Voices: A snapshot of life in care homes in Wales during Covid-19'* dated June 2020 at p23-24 did not lead to concrete action to address concerns. Similarly, amendments to visiting guidance for care homes suggested by Care Rights UK supported by 5 other members of the Department for Health and Social Care's Adult Social Care Working Group of Stakeholders (the National Care Forum, National Care Association, Association for Real Change, Care England, and Alzheimer's Society) in February 2022 were rejected less than an hour after they were submitted, having been given short shrift by a DHSC official. Many concerns were ignored (often until legal proceedings were initiated) and changes were only belatedly made with little evidence of ongoing consideration of impact as guidance was formulated/lessons being learned over time.

13. **Whether legislative duties were overlooked.** The CPs' closing submissions for module 2B set out a number of ways in which people needing care were neglected. Further detail is contained in the Amnesty report: as indicated by its title "As if Expendable". The evidence, taken cumulatively, indicates that those in care were valued less than others: their lives were considered to be worth less than those of other people. This is an issue of serious public concern which should be examined. As those closing submissions explain in more detail, there has been broad evidence that duties in the Equality Act 2020 – whether the equality duty in s.149, or the reasonable adjustment duty, or otherwise - were ignored.

14. Similarly, there is considerable evidence that the human rights, and autonomy, of those needing care were abandoned. The need to seek consent was often ignored – whether in making DNACPR decisions, and the deprivation of liberty. Duties in the Mental Capacity Act and Deprivation of Liberty Safeguards were overlooked. Other similar issues of concern are:

14.1. The increased use of sedation and anti-psychotic drugs to manage distressed behaviour and the deterioration in quality of care, without consent.

14.2. Investigation into the use of restraints and enforced isolation, without consent.

14.3. The abandonment of the legal responsibilities of people with guardianship duties or powers of attorney, particularly in relation to consent of the person requiring care.

14.4. Blanket approaches to restrictions on access to family and friends, without taking into account the harm this may cause.

15. There is an important more general issue of principle: while it may be easy to dispense with those duties at a time of crisis, they are even more important than normal (particularly when oversight and regulation is reduced) and should be fiercely protected. Properly used, those duties could have helped government to ensure a balance between different fundamental rights and to manage the crisis unfolding in social care.

16. **The indirect harm caused by NPIs to people living in care homes/ supported living facilities, particularly the management of outbreaks, restrictions on visits and movement.** Indirect harm is harm other than that caused by Covid-19 itself. Again, the CPs' opening and closing submissions in module 2B explain in some detail the very severe indirect harm suffered by those needing care. It was in many ways considerably worse than the harm caused by Covid-19. It includes the huge number of excess deaths from causes other than Covid-19 during the first wave of the pandemic (later waves were subject to 'mortality displacement'); or the number of additional physical and mental illnesses; the 9 fold increase in people waiting for medical treatment including for serious conditions such as cancer; the severe deteriorations in physical or mental health (sometimes so severe they led people to 'give up on life'); the number of people who died alone, and the ongoing distress and trauma this caused to bereaved loved ones.

17. In some ways, Covid-19 had disproportionate attention. Huge efforts were made to obtain data on it, and on the extent to which restrictions would tackle it. Covid-19 was often the overriding consideration in decisions as to whether to impose restrictions. It was initially perhaps understandable that the focus was on Covid-19 itself. But that does not mean that ignoring other harms was appropriate. It was not. A death caused by dementia was just as important as a death caused by Covid-19. There was a widespread failure to:

17.1. Measure indirect harms, for example to obtain data (including qualitative data) on what indirect harm would be caused by a restriction.

17.2. Understand and take into account indirect harms.

17.3. Make decisions by balancing the benefit of a particular measure (in terms of what Covid-19 harm it would prevent) against the indirect harm it would cause.

17.4. Achieve an appropriate balance between protecting people from the harm of Covid-19 and protecting wider health and wellbeing.

18. To take a specific example, restrictions on visits in care homes were, for a long time, imposed solely because they would prevent the spread of Covid-19. It was never properly examined what the indirect harm was (it included, for some people, huge increase in risk of death or serious physical and mental health problems – a much greater risk than the risk from Covid-19) or what the benefit of strict restrictions were on infection control (particularly where carers and staff were moving between care settings). People needing care were often not asked whether they preferred to spend their last months of life alone and isolated from their loved ones or essential carers (i.e. people nominated to provide essential care to the person needing it, who were often family members), having regard to the balance of risks from indirect harm as compared to Covid-19.

19. A key focus of the pandemic response was, for understandable reasons, infection control. However, this focus came at a significant cost to the physical health, mental health and wellbeing of individuals and to important issues such as consent and safeguarding. Much of the campaigning and support work that the CPs 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 the impact on social care systems during the pandemic on individuals in a holistic sense.

20. **Access to healthcare and other professionals and the treatment of non-Covid conditions in care homes/supported living facilities.** This is linked to the above issue. Many in care were, in practice, unable to access medical care or treatment. For example, the Patient Association survey recorded that 67% of respondents had appointments cancelled as a result of the pandemic (INQ000273424, p22). The follow up survey recorded that 66% struggled to

access at least one form of care, and 56% delayed access to treatment (INQ000273425, p3). The February 2021 survey (INQ000273426) made the obvious point that patients with greater care needs were impacted the most.

21. This was either because people needing care were prevented – prevented in fact, or prevented in practice due to excessive isolation requirements on return – from going out of the care setting to access that care or treatment. Or it was because professionals stopped going to care settings. There is concerning evidence that active decisions were made that medical care or treatment would not be provided to those in care homes. Critically ill people living in care homes were not admitted to hospitals, and GPs or other medical professionals would simply not visit the care home. There were many reports to the effect of care homes calling an ambulance and being told: "Well he's end of life anyway so we're not going to send an ambulance". There were "multiple reports… throughout the country of doctors refusing to enter care homes and only being available for consultations by phone or via video calls, no matter what the residents' symptoms were and even in regard to end of life support" (Amnesty report *Denial of access to hospitals and other medical services* at pages 21-24 and the evidence set out there). These issues should be examined by this module.

22. **Regulation and oversight.** There is evidence that regulatory functions were suspended at the start of the pandemic. For example, on 16 March 2020, the CQC announced that it would be ceasing its routine inspections of care homes. The CQC observed a sharp fall in notifications by providers about the outcomes of any applications to deprive a person of their liberty[4]. The Local Government and Social Care Ombudsman "suspended all casework activity that demands information from, or action by, local authorities and care providers, in light of the current Coronavirus outbreak" from 26 March to 29 June 2020. The same was true of a number of other regulators and complaints mechanisms relating to those needing care. This was not appropriate: this was the time when regulators and complaints mechanisms were needed most, particularly as loved ones were also shut out and unable to observe any issues. There is considerable evidence of a substantial increase in the abuse of vulnerable people in need of care during the pandemic, which proper oversight was in place to prevent. These matters ought to be investigated.

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[4] The impact of COVID-19 on the use of Deprivation of Liberty Safeguards - Care Quality Commission (cqc.org.uk).

23. **End of life care and support.** Many people needing care were at the end of life during the pandemic, and many faced this difficult time without adequate support. Care workers were left to care for dying people without adequate support, equipment, or training. Many people at the end of their lives, when at their most vulnerable, were left alone. Contact with families and loved ones was either prohibited, or only allowed in the most restricted circumstances such as right at the end of life when it was often too late as the person was already unconscious. There are also serious concerns about the timing of the prescription and use of anticipatory (end of life) medications. These issues ought to be examined.

24. **Recording of deaths in care homes during the early part of the pandemic, including whether covid-19 was under-reported**. This particularly arose at the beginning of the pandemic, when it appears that deaths were underreported, whether because few tests were available, there was little understanding of the symptoms of Covid-19, or otherwise.

Potential audience groups:

25. **Those receiving care in the home (i.e. domestic home).** The Inquiry has included as potential audience groups those providing care in the domestic home, and those receiving care in care homes. Those receiving care in a domestic home are no less important and should be added. Very often the failure of community services to support families caring at home led either to deterioration in the condition of the person cared for or to carer burnout and the necessity for the person to be admitted to a care home.

26. **Dementia (including Alzheimer's)** should be a focus group for the Inquiry. That is because:

    26.1. Dementia is the leading cause of death in the UK. Around 1 million people live with it. Dementia and Alzheimer's remained the leading cause of death in the UK in care homes throughout the pandemic, higher than Covid-19[5].

    26.2. People with dementia suffered particularly badly from indirect harms arising from the restrictions. The evidence to support that is set out in more detail in the CPs' closing and opening submissions in module 2B. In brief outline, people with dementia depended very heavily on essential and family carers for their physical and mental wellbeing. They

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[5] Deaths of care home residents, England and Wales - Office for National Statistics (ons.gov.uk) "Dementia and Alzheimer disease was the leading cause of death in both male and female care home residents in England (accounting for 26.4% and 34.0% of deaths respectively) and Wales (28.3% and 36.2% respectively) in 2021; coronavirus (COVID-19) was the second highest leading cause of death"

were in many cases separated from that critical source of care, by the NPIs. This caused very serious harm. This is explained in detail in the reports by Ms Herklots (e.g. INQ000232394) and the witness statement by John’s Campaign, Care Rights UK and the Patients’ Association (INQ000283957). For example, they referred to the Alzheimer’s Society report (INQ000273455), which concluded “*Lockdown isolation caused shocking levels of decline for people with dementia”.* Person-centred care is the only treatment known to improve dementia, and by removing family or familiar carers, this form of treatment was denied (INQ000273460, §42). An Equality Impact Assessment on 27 August 2020 identified, in respect of those with dementia, a worsening of functional independence and cognitive symptoms during the first month of lockdown (31% of people surveyed), exacerbated agitation, apathy and depression (54%) and deterioration of health status (40%): INQ000087134. Dementia UK stated that there was a 52% increase in deaths amongst people with dementia during lockdown outside of the coronavirus figures – showing starkly that the restrictions put in place ‘have taken a grave toll, alongside that of the virus’ (INQ000176375 p.1).

26.3. There are particular issues as to the response to the pandemic in care homes which concern people living with dementia. An obvious example is how to balance the need to limit the spread of covid, with the need for a person with dementia to have sustained contact with their essential carer. Too often family members were treated as visitors rather than an essential part of the care team. These issues are also relevant to people with similar cognitive impairments.

27. **People with highly complex disabilities** (for example, severe global developmental delay and profound and multiple learning difficulties (PMLD)) should also be a focus group for the Inquiry. This may cover a range of disabilities, and often involves people living with a combination of different conditions. It is important for the Inquiry to consider the most vulnerable people in need of care, who are most dependent on their closest and most familiar carers. This group was particularly badly affected by the restrictions on visiting and their separation from family members and essential caregivers.

<u>Other points:</u>

28. The CPs ask the Inquiry to ensure full account is given in Module 6 of the experience of individuals. The CPs warmly welcomed the fact that module 2B began with a video of the

experiences of a number of those affected by the pandemic. They hope this approach will continue in this module. It is important to focus on the person rather than the setting, because that engenders better decisions by ensuring that the varied and individual experiences of people in different care settings are considered.

29. It is important for this module to take into account **unpaid carers** across the range of care settings. 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).[6] There were specific obstacles faced by unpaid carers, including not being recognised as 'carers' in the same way as a paid carer, a significant increase in caring responsibilities during the pandemic where the person they cared for lived in the community,[7] and restrictions preventing them carrying out their caring responsibilities where the person they cared for lived in a care setting. Those obstacles are important, far reaching, and should not be overlooked by this module.

30. The CPs wish to stress the urgency of collecting evidence from those in social care settings as soon as possible, due to the sad likelihood that many affected people will die before the conclusion of Module 6.

31. The CPs also raise a concern about the Inquiry's use of terminology such as "bed capacity" and care home "residents" in the provisional outline scope. The reference to beds is NHS/ health terminology and is not suitable for social care. Capacity in care homes is about space in people's homes (recognising that it concerns people living in care homes), rather than simply "beds" to be filled.

B. RULE 9 PROPOSALS

32. The CPs intend to write to the Inquiry with Rule 9 suggestions to ensure that all relevant areas of interest and concern are covered. Their suggestions are likely to be informed by the Rule 9 requests already made by the Inquiry, so they welcome provision of the existing list of Rule 9 requests.

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[6] Figures taken from https://www.carersuk.org/policy-and-research/key-facts-and-figures/ citing research by Perillo and Bennett, 2023.

[7] What We Do - Impact of Covid-19 Young Carers | Carers Trust

33. The CPs have already provided a detailed witness statement and exhibits in Module 3, including surveys carried out during the pandemic. They would very much welcome a Rule 9 request to provide a further statement relevant to Module 6.

C. <u>EXPERT EVIDENCE</u>

34. The CPs welcome the Chair's decision to provide topics and questions put to experts to Core Participants. This will allow for more meaningful engagement with draft expert reports.

35. In addition to the three proposed topics to be addressed by expert evidence, and the expert identified above regarding the impact of discharge from hospital, the CPs invite the Inquiry to obtain expert evidence on:

    35.1. <u>Indirect harms</u>. As detailed above, this was broadly neglected during the pandemic, yet was for a number of people considerably worse than Covid-19 itself. It is critical to understand what the harm was, so that the Inquiry can consider issues such as (a) whether that harm was overlooked; (b) whether restrictions were inappropriate in light of that harm; and (c) what could have been done to measure and take into account that harm.

    35.2. <u>Dementia</u> (see above).

    35.3. <u>Whether NPIs were appropriate, weighing up their effectiveness in tackling Covid-19 against the indirect harms they caused.</u>

    35.4. <u>Employment arrangements and staffing in care homes</u>. An important issue is the impact of staffing arrangements on the safe and proper operation of care homes during the pandemic. In particular, that includes low wages, zero hours contracts, the lack of statutory sick pay, staff shortages, agency workers being used across multiple settings. All of these issues are relevant to the ability of care homes to properly protect people living in them and made it difficult for care staff to isolate where necessary. Also relevant to this is the impact of care home insurance – and high premiums - on the decisions made by care homes relating to restrictions. In contrast to hospitals, which were given an indemnity against liability for infection transmitted on their premises, care homes were faced with the additional concern about employer/ employee liability which made it even more difficult for them to facilitate family member or essential care giver visits. As care home insurance is only provided by a limited number of companies, providers had very little option.

36. The CPs propose the following experts:

36.1. Dr Aida Suarez Gonzalez is an expert in Dementia and provided evidence in judicial review proceedings brought by John's Campaign during the pandemic.: Dr Aida Suarez Gonzalez | Dementia Research Centre - UCL – University College London.

36.2. Dr Tarun Solanki is a Consultant Geriatrician who is National Council Chair in England of the British Geriatrics Society: Dr Tarun Solanki | British Geriatrics Society (bgs.org.uk).

36.3. Dr Mark Zuckerman is a Consultant Virologist who has conducted studies on the transmission of covid-19 in care homes: A study of universal SARS-CoV-2 RNA testing of residents and staff in a large group of care homes in South London - PMC (nih.gov).

36.4. Jules Storr is an expert on infection prevention and control: Jules STORR | Consultant | World Health Organization WHO, Genève | who | Infection prevention & control | Research profile (researchgate.net).

36.5. Adelina Comas-Herrera is an expert at the Care Policy and Evaluation Centre, who specialises in the economics of social care and the treatment and support of people with Dementia **:**Adelina Comas Herrera (lse.ac.uk).

36.6. Deborah Ivanova is a CQC expert who wrote a report on enforced isolation among young people: Debbie Ivanova | Open Forum Events.

36.7. Andrea Sutcliffe CBE, the CQC's former Chief Inspector of Adult Social Care, who has expertise in the structure of the social care sector and the range of care settings: CQC's Andrea Sutcliffe CBE, Chief Inspector of Adult Social Care, announces departure - Care Quality Commission.

36.8. Alexander Ruck-Keene KC is an expert in mental capacity law and deprivation of liberty safeguards: https://www.39essex.com/profile/alexander-ruck-keene-kc-hon.

36.9. Dr Emma Wolverson is an expert in Ageing and Dementia. She is the research lead for Dementia UK and a Clinical Psychologist with substantial dementia research experience: https://www.hull.ac.uk/staff-directory/emma-wolverson.

37. CTI invited CPs to make submissions about which specific conditions should be examined. Dementia has already been covered, above. We support CTI's suggestion at §33(c) that those

with learning difficulties and dementia should be included. We suggest in addition that people with autism are also included.

D. THE INQUIRY'S PROCEDURE

38. The CPs of course understand the huge and difficult task placed on this Inquiry; and the way that has to be balanced against the need for speed. But they were not able to effectively participate in module 2B. They had to make submissions on witnesses, before being disclosed many of the witness statements. Huge amounts of disclosure were produced shortly before the hearings, and it was impossible to digest it in time to then produce witness questions and submissions. The CPs are each small, busy organisations involved in multiple modules of the Inquiry 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.

CONCLUSION

39. As previously noted in respect of Module 3: the CPs wish to re-emphasise that 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.

ADAM STRAW KC
EMMA FOUBISTER

LEIGH DAY

13 MARCH 2024