UK COVID-19 INQUIRY

MODULE 3

CLOSING SUBMISSIONS ON BEHALF OF THE DISABILITY CHARITIES CONSORTIUM

Introduction

1. These submissions are prepared on behalf of the Disability Charities Consortium (DCC) for the purposes of module 3 closing submissions. The DCC are grateful for the opportunity to make these submissions and they should be read alongside the oral closing submissions made by Mr Burton KC on 27 November 2024.[1] The DCC extend its thanks to the Chair for the opportunity to have been a core participant in module 3 and for the Inquiry's focus in module 3 on the experiences and needs of disabled people as they related to healthcare during the pandemic.

2. These closing submissions repeat what was said in DCC's written opening submissions: the needs of disabled groups were seriously overlooked. It is now clear, having heard 10 weeks of evidence in Module 3, that disabled people were either forgotten or considered much too late in the day and their needs and lives were considered to be less important and more expendable than the non-disabled. By way of reminder, around 16 million disabled people live in the UK, with disabled people constituting one in every five in the population.

3. In these closing submissions, the DCC urge the Inquiry to take concrete and practical steps to ensure that disabled people are considered and treated equally in any future pandemic.

4. The closing submissions will focus on four topics:

    a. **Accessible communications;**

    b. **Consultation with disabled people;**

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[1] [40/207/13 – 40/222/21].

c. **Clinical training and escalation of care in pandemic situations;**

d. **Mortality data.**

5. DCC would be grateful if the Inquiry could note that where examples are given relating to a particular impairment or condition, these are all illustrative of a wider concern faced by disabled people as a whole.

1. <u>Accessible Communications</u>

6. By virtue of paragraph 12(c) of the Inquiry Provisional List of Issues, the Inquiry has determined that it will consider the communication and advice for people shielding and those designated at CV/at highest risk. As we set out in our opening submissions, the information sent to disabled people during the shielding programme was a paradigm example of a failure to communicate crucial information to disabled people in an accessible format.

7. Section 20 of the Equality Act 2010 requires that reasonable adjustments are made for disabled persons which includes communicating information to disabled persons in a format accessible to them. Since 1 August 2016, all providers and commissioners in England have been required to follow the Accessible Information Standard ("the AIS"), published by NHS England (NHSE),[2] and yet, as Professor Powis admitted, "compliance with the AIS was generally managed on a sporadic basis".[3]

8. The Inquiry heard from Matt Stringer, that throughout the early stages of the pandemic, that RNIB raised repeated concerns with Government that the shielding letters were not provided in an accessible format to those who were visually impaired.[4] The Department of Health and Social Care (DHSC) faced legal action from a disabled individual who met the CEV criteria after becoming aware that she had been sent four letters about the shielding programme but due to being visually impaired, she could not read those letter and only became aware of their content some time after they were sent.[5]

9. The RNIB called for a "reliable system to be put in place to ensure blind and partially sighted people get letters in their preferred format across the country", and yet the letters

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[2] [INQ000485652/69] at para 268.
[3] [INQ000485652/73] at para 277.
[4] [INQ000239594/14] at paras 41-43.
[5] [INQ000412890/170] at para 647.

only included a paltry nod to those with visual impairments by providing the contact details of the RNIB who would provide the letters in an accessible format, rather than sending the letters in the format required.[6] As Matt Stringer stated in his evidence, there was a "real sense of despair and forlorn and abandon[ment]" because disabled people were not getting the communication in a format that they could access.[7]

10. The DCC welcomes the additional information provided by Professor Powis regarding the Reasonable Adjustment Digital Flag and that a review of the Accessible Information Standard (AIS) is underway and an updated version is to be published in due course with a self-assessment framework and e-learning resources.[8] The DCC welcomes the fact that the updated AIS is said to "create opportunities to promote greater awareness of the AIS at ICB and local level".[9]

11. However, the DCC is concerned about the repeated delays in publishing the updated AIS. The DCC is aware that the original date set for its publication was April 2023 and as of December 2024, it has still not been published. DCC are also not confident that the steps outlined by Professor Powis will ensure fundamentally that the AIS will be consistently adopted and applied by all NHS and social care organisations, and that it would ensure that disabled people are communicated with in way that meets their needs in a future pandemic. Professor Powis provides no assurance in that respect.

12. As such, the DCC urge the Inquiry to recommend that:

    a. <u>The updated AIS is published forthwith and the Inquiry sets a deadline for its publication.</u>

    b. <u>The AIS is implemented by all NHS and social care organisations, reporting to NHS England and to the Department of Health and Social Care (DHSC) once it has been implemented.</u>

    c. <u>That NHS England audit the adoption and implementation of the AIS.</u>

    d. <u>That NHS England and DHSC take steps to ensure that disabled people are communicated with through accessible formats in the event of a future pandemic.</u>

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[6] [INQ000239594/14] at paras 41-43.
[7] [20/94/3-13].
[8] [INQ000474664/5] at para 16-17.
[9] [INQ000474664/5] at para 17.

e. In each of the devolved nations, equivalent actions must be taken to ensure that disabled people can access healthcare information and communications in their preferred format, according to the standards and legislation in those nations.

2. Consultation with Disabled People

13. It was a distinct and recurring theme across many topics of the evidence in module 3 that time and again, Government departments, public bodies and independent organisations failed to take modest practical steps to consult with disabled people or took those steps once it was too late. As a result, messaging, decisions and policies failed to take account of the needs of disabled people and take account of the effect that the decisions would have disabled people's lives and experiences of the pandemic.

14. It is striking that in the "Every Story Matters" report dated June 2024 that it was reported by disabled people in the listening events that disabled people felt confused and unsure and lacked accessible information:[10]

> "The lack of clear and easy-to-understand guidelines about lockdowns, PPE and service changes or closures left many feeling confused and unsure. This lack of accessible information made it particularly difficult for them to understand the changing rules and regulations, leading to feelings of anxiety, isolation, and exclusion. They recommended that in the future, governments and health services should involve people with learning disabilities in creating accessible guidelines and contribute to decision-making.
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> "I would've had all people with learning disabilities involved in decision making and be able to think about what to do and do it better.""

15. The messaging "Save the NHS" helped form the impression that vulnerable people were seemingly expected to sacrifice themselves to protect the NHS from being overwhelmed. Scope research in May 2020 found that 63% of disabled adults were concerned that they wouldn't be able to access hospital treatment if they became ill with Covid-19.[11] Consideration should also be given to whether this messaging had any impact on the

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[10] [INQ000474233/137]

[11] [INQ000235594/10] at para 26.

misuse of DNACPRs (Do Not Attempt Cardio-Pulmonary Resuscitation notices) and wider negative impacts on the medical treatment disabled people received during the pandemic.

16. The move to online consultations for health services during the pandemic had negative consequences for disabled people where no alternative accessible format was provided for them to access the health service. As Professor Edwards explained, disabled people were very much in the group of the "digitally excluded".[12] For example, RNID research in September 2020 found nearly 60% of 384 respondents admitted they had been put off seeking medical advice from their GPs after the introduction of remote appointments during the pandemic.[13] Jackie O'Sullivan also explained the additional barriers facing learning disabled people in using remote technology because of issues such as communication barriers, information technology illiteracy and diagnostic overshadowing amongst this group of people.[14]

17. The Inquiry also heard the difficulties faced by Dr Sarah Powell, a BSL user, in communicating with the healthcare services and that she had, for the first time, to ask her hearing son to communicate with 999 call handlers and paramedics on her behalf, and that interpreters were not available in A&E.[15] It is unclear what thought was given to disabled people, if any, when the decisions were made to change the way people accessed healthcare services. Professor Banfield stated in his evidence that he did <u>not</u> think that consideration was given to inequalities caused by remote consultations.[16]

18. The national visiting guidance introduced on 16 March 2020, and then amended on 25 March 2020 failed to take account of the needs of disabled people.[17] It only permitted visiting to one immediate family member when a patient was either a child, or receiving end of life care or a woman in labour.[18] As Jackie O'Sullivan explained in her evidence: "family members and carers are absolutely vital for people with a learning disability and it was treated a little as if it was a nice-to-have".[19] Only on 8 April 2020 was the guidance amended to allow for a visitor who was "supporting someone with a mental health issue, such as dementia, a learning disability or autism where not being present would cause the patient to be distressed."[20] Professor Powis effectively conceded in his evidence that it

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[12] [9/30/2 – 9/31/8]
[13] [INQ000235594/10] at para 26
[14] [21/87/1-14]
[15] [21/14/14 – 21/18/4].
[16] [21/110/19 – 21/111/2]
[17] [IN000412890/179] at para 685; [INQ000330806]; [INQ000399381]
[18] [INQ000399381]
[19] [21/76/22 – 21/77/4]
[20] [INQ000000132/1]

was a mistake not to make an exception for those with dementia, a learning disability or autism at the outset,[21] and DCC would say the same for carers providing assistance for those with physical disabilities. The reason given as to why even that limited group of disabled people was not considered sooner was because it was "new territory" for NHSE.[22]

19. The visiting guidance published on 8 April 2020,[23] was, in the words of Matt Stringer, "blunt" and "high level".[24] It was the view of Matt Stringer that it clearly did not have the input of disabled people in order to shape the guidance "in a much more nuanced way".[25]

20. The guidance did not allow for all those disabled adults who would need someone to assist them, for example, those with Down's Syndrome, deaf and hearing-impaired people, blind and visually impaired people. There was too much left open for interpretation by the people on the ground trying to apply the guidance in stressful and pressurised circumstances.[26] It did not support those working in the NHS to be able to support disabled patients, and disabled patients were disadvantaged as a result.[27] Matt Stringer explained just one of many real-life examples of how this actually affected disabled people of which the DCC became aware:[28]

> "...there was a blind lady who was of full mental faculty who was going through a medical procedure which was nothing to do with Covid. She was denied her partner being there with her and her partner, husband, had to take out a sort of power of attorney to accompany his wife to that health visit or that health process, you know, because the hospital wouldn't allow him to accompany her which we would have said should have been allowed by this sort of advice."

21. Similarly, Jackie O'Sullivan described the experiences of learning disabled people: a 49-year-old adult with Down's Syndrome who had never been alone in their life who was admitted to hospital in March 2020 and denied visits from their family and died alone; and an individual with a chest infection who was admitted to hospital and had no one to support her, whose hospital team failed to realise that she was non-verbal until four days in.[29]

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[21] [28/114/11 – 28/114/24]
[22] [28/114/11 – 28/114/24]
[23] [INQ000000132]
[24] [21/69/5-17]
[25] [21/69/5-17]
[26] As explained by Matt Stringer [20/70/4 – 20/70/23]
[27] As explained by Matt Stringer [20/70/4 – 20/70/23]
[28] [21/71/4 – 21/71/16]
[29] [21/78/10 – 21/79/19]

22. The updated guidance published on 5 June 2020 gave local discretion to trusts and other NHS bodies but asked providers to consider a wider category of persons which a patient would need for support.[30] The guidance said:[31]

> "**Other people who are in attendance to support the needs of the patient**, for example a familiar carer/supporter/personal assistant, should not be counted as additional visitor. Patients may be accompanied where appropriate and necessary to assist with the patient's communication and/or to meet the patient's health or social care needs. Where possible patients should contact the ward or department in advance to discuss local considerations and make appropriate arrangements."

23. While the category was more widely applicable to anyone with health or social care needs, it was still not created with enough input from disabled groups and left even further room for interpretation and local discretion.[32]

24. Professor Powis has confirmed that NHSE did not consult with disabilities advocacy groups between issuing the guidance on 8 April 2020 and the updated version on 5 June 2020.[33] He has stated that, the guidance was in part changed because of correspondence sent to NHSE on behalf of disabled people in respect of the overly restrictive implications of the guidance.[34] And that NHSE relied on those letters alone to make the changes; he confirms that they did not consult with disabilities advocacy groups before the guidance was changed on 5 June 2020. [35] Professor Powis further admits that an equality impact assessment was not carried out until July 2020 and only then was it accepted that personal assistants and carers should be treated as a visiting staff member, rather than a visitor. [36]

25. Professor Powis' belated admissions demonstrate a disappointing failure by NHSE to properly engage with disability groups, even once NHSE was on notice that the guidance was disadvantageous to those vulnerable in society. The excuse that it was "new territory" does not explain why disabled people were disregarded, rather it mandates that steps should be taken to consult with disabled groups, to ensure that NHSE were complying with their duties under the Equality Act 2010. Professor Powis' evidence demonstrates a consistent theme in the evidence: that public bodies do not take their duties under the Equality Act seriously, they wait and rely on disabled individuals and advocates of those

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[30] [INQ000330865]
[31] [INQ000330865/2]
[32] [21/72/8 – 21/73/19]
[33] [INQ000474664] at para 13
[34] [INQ000474664/4] at para 13
[35] [INQ000474664/4] at para 13
[36] [INQ000474664/4] at para 13

with disabilities to raise a problem. The Equality Act 2010 requires proactivity, not reactivity and DCC urge the Inquiry to take steps to ensure that public bodies implement their duties before the harm is caused to disabled people.

26. The failure to consult with disabled groups is perhaps most starkly borne out by the publication of the Clinical Frailty Scale in the rapid guideline: critical care (NG159), published by NICE on 20 March 2020.[37] The Inquiry has good evidence, from the CQC (Care Quality Commission) and Mencap, that "the use of the tool was interpreted by some as meaning that disabled people who were not 'frail' but needed assistance would be denied access to critical care."[38] Although the guidance was amended on or around 25 March 2020, it was the conclusion of Jackie O'Sullivan of Mencap that the "genie was out of the bottle" because the original guidance published on 20 March 2020 had already been communicated quite widely, including in the media.[39] In Mencap's report "My Life, My Health", they concluded that:[40]

> "…the original NICE guidance had ongoing damaging consequences. By the time clarification to the Clinical Frailty Scale was sent out, it came to Mencap's attention that many perfectly healthy individuals received letters from their GPs recommending they think carefully about whether they would want resuscitation if they went into hospital or would even want to be treated in hospital at all, should they get Covid-19."

27. NICE did not consult disability groups on the guidance.[41] Dr Paul Chrisp accepted that they should have been consulted.[42] He explained that "speed" was the reason for the failure to conduct a thorough equalities impact assessment; only age was considered in the EIA.[43] It is both disappointing and unfathomable that the needs of disabled people could be overlooked in such a cursory way. The DCC do not accept that speed, or the exigencies of the pandemic situation, provides a good reason for the lack of consultation.

28. As Jackie O'Sullivan made clear in her evidence, even at the height of the pandemic, her organisation and others stood ready to constructively and quickly engage with those bodies drafting guidance and could provide comments overnight to ensure that the needs of disabled people were properly considered. As she explained in her oral evidence:[44]

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[37] [INQ000474301]
[38] [INQ000235491/10]
[39] [21/65/6 – 21/65/20]
[40] [INQ000216426/17]
[41] As confirmed by Dr Paul Chrisp in his evidence [23/81/1-25]
[42] As confirmed by Dr Paul Chrisp in his evidence [23/81/1-25]
[43] [INQ000228378]; [23/75:6 – 23/75:23] [23/81:1 –23/ 81/25]
[44] [21/66/14 – 21/67/3]

> "… if they had contacted us, we would have helped them and we would have pointed that out. At the same time, I was involved in a working group on the Care Act
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> easements. We turned that around in a week. There were a group of charities like myself and representatives and we were literally, you know, commenting on things overnight it didn't slow up the process, we even produced an Easy Read guide for officials to be able to share on the date of publication. **So we would have done everything we possibly could to help NICE get this right. But we weren't asked**." (our emphasis)

29. Therefore, it is the submission of the DCC that even if formal full blown EIAs and in-depth consultation with all stakeholders were not always considered practicable, or as Hamza Yousef said, potentially of limited use,[45] DCC does not accept that other forms of engagement would not have been possible.

30. Mr Yousef usefully explained that what really is needed is "far greater engagement and deeper engagement directly with those who are affected… deep, quick engagement is necessary as well as embedding human rights legislation in statute here in Scotland as best we possibly can."[46] While Mr Yousef was making this proposal in relation to Scotland, we consider that this should be something that each nation of the UK strives to implement as a matter of urgency. As Mr Stringer explained, there needs to be a mechanism within the policy making process for new policies to be sense checked with disabled people or the organisations representing them because groups, like the DCC "brings the insight… from those millions of people that we support".[47]

31. The DCC invite the Inquiry to recommend:

    a. <u>DHSC, and its counterparts in the devolved nations, establish a standing body, akin to a disabled person's panel, that can provide timely context-specific reflections on policy and measures that may affect disabled people. This should be established by the end of 2025.</u>

    b. <u>In planning for the next pandemic, the DHSC, and its counterparts in the devolved nations, engage with Disabled People's Organisations ("DPOs") and</u>

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[45] [34/170/25 – 34/172/24]
[46] [34/17/28 – 34/172/24]
[47] [20/94/17 – 20/95/20]

<u>those with lived experience and obtain qualitative and quantitative data to help to improve interventions.</u>

c. <u>DHSC, and its counterparts in the devolved nations, consider making co-design of policies with DPOs the default principles, not the exception.</u>

3.<u>**Clinical training and escalation of care in pandemic situations**</u>

<u>DNACPRs</u>

32. It is an obvious statement of fact, repeated by many in this Inquiry, that the blanket use of DNACPRs should never been countenanced and a person's disability should never be used as reason alone for imposing a DNACPR. And yet, it is clear from the evidence produced and heard in module 3 that there was a flagrant misuse of DNACPRs that affected disabled people adversely during the pandemic.[48] For example, the interim CQC report reported that they saw an increase in the number of submissions (from 9 to 40) which related to DNACPRs, the majority of which concerned orders that had been put in place without consulting the person or the family, and sometimes on numerous people routinely.[49] The CQC also reported examples from feedback of care not being provided to a person with a DNACPR in place, for example delay in calling a doctor, or a care home not calling an ambulance straight away.[50] The CQC inspectors also noted a conflation between DNACPR decisions and advance care directives.[51] The blanket use of DNACPRs was reported by the Joint Committee on Human Rights, Amnesty, the Queen's Nursing Institute and a survey by Learning Disability England.[52]

33. In addition, this Inquiry heard the evidence of Professor Wylie where he became aware that one Trust applied a blanket policy based on age, disability and condition.[53] Further, Jackie O'Sullivan explained that she was aware through Mencap that GP surgeries were sending letters to groups of individuals with learning disabilities that they may want to consider a DNACPR.[54]

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[48] :

[49] [INQ000235491/7-8]

[50] [INQ000235491/7-8]

[51] [INQ000235491/7-8]

[52] See [INQ000235491/9-10].

[53] [20/22/14 – 20/22/25]

[54] [21/67/11 – 21/70/20]. Also see the [21/67/11 – 21/70/20]

34. The ‘Every Story Matters’ report reported numerous and distressing stories of bereaved family members being unaware of DNACPR notices being put in place, DNACPRs being recommended without discussions with loved ones, and how bereaved families believe that old age or an existing health condition led to healthcare professionals putting in place a DNACPR notice.[55]

35. The misuse of DNACPRs affected the way in which some GP’s dealt with patients with a learning disability. For example, the fact that people with a learning disability in some Mencap homes were contacted in March 2020 stating that it would be better to keep people who fell ill with Covid-19 supported at home and to provide them with end-of-life care.[56]

36. However, there was a peculiar dichotomy in the evidence: all those in senior positions stated that, except for what was reported in the media, they were not aware of any specific details regarding the misuse of DNACPRs during the pandemic, and yet the repeated experiences of patients, and families of loved ones is that DNACPRs were misused for disabled people on the basis of their disability alone, and/or inappropriately applied because family members and patients were not consulted or in some cases simply informed that one has been applied.[57]

37. It is also apparent that DNACPRs were confused with do not treat notices.[58] As stated in the expert repot of Professor Summers and Dr Suntharalingam:[59]

> “A DNACPR notice is not meant as a proxy for broader treatment decisions. However, in the absence of a clearly documented discussion and decisions about other forms of treatment, there is a potential for inappropriate over-interpretation of DNACPRs as a generalized treatment limitation option.”

38. Dr Suntharalingam confirmed in evidence that the confusion arose not only in respect of medical professionals but also potentially families and patients.[60]

39. The DCC had hoped that the evidence in module 3 would reveal *why* DNACPRs were used in a blanket fashion for disabled people, *why* they were applied inappropriately and without proper consultation, the *extent* of the problem during the pandemic, and the *steps taken* by each nation to ensure it would not happen again. Unfortunately, even after

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[55] [INQ000474233/168-173]
[56] [INQ000505520]
[57] For example, see the evidence of Professor McBride, Professor Smith, Jeanne Freeman, Sir Frank Atherton, and Professor Powis.
[58] As confirmed by Professor Wylie: [20/18/17 – 20/19/12]
[59] [INQ000474255/24] at para 40
[60] [19/89/5 – 19/90/1]

hearing all the evidence, the Inquiry has little by way of answers to these important questions.

40. In England, the CQC reports go some way in understanding the problem with the misuse of DNACPRs during the pandemic but even the CQC reports do not set out the reason why these practices happened or were allowed to happen. Without knowing the cause of the practice, it is difficult for the Inquiry to be sure that the same problem will not happen again.

41. In Wales, the DNACPR reviews have been very limited. The "Review of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Decisions for Adults in Wales"[61] conducted by the Healthcare Inspectorate Wales during 2023 did not make clear whether DNACPR forms used during the pandemic were considered and Judith Paget could not confirm if the practices in the pandemic were considered.[62] The response rate to the surveys conducted for the review were poor, receiving 97 responses in total.[63] The further review: "An All-Wales Thematic Review Learning Report: Mortality Review – Do Not Attempt Cardiopulmonary Resuscitation",[64] belatedly disclosed to the Inquiry, reveals that a total of 4 cases from January 2022 to January 2023 were reviewed.[65] Judith Paget confirmed in her evidence that the review did not consider whether DNACPRs were used inappropriately during the pandemic for disabled people by reason of their disability, and it was limited to a review of documentation.[66] Judith Paget pointed to the review by the Nocosomial Transmission Group,[67] as reviewing the DNACPR practices during the pandemic, but the document does not give any indication of how extensive the review was, and there is no indication as to whether the specific issue of whether blanket DNACPRs were applied to disabled people because of their disability was a problem in Wales. It almost goes without saying, that these reviews have been far too limited in their methodology and scope to understand the heart of the issues facing disabled people in respect of DNACPR practices during the pandemic in Wales. DCC invites the Inquiry to recommend that NHS Wales carries out a thorough systematic review of the DNACPR practices during the pandemic, with a particular emphasis on the effect on disadvantaged groups, especially disabled people.

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[61] [INQ000485929]
[62] [31/127/23 – 31/128/6]
[63] [INQ000485929]
[64] [INQ000514009]
[65] [INQ000514009/4]
[66] [31/187/10 – 188/14]
[67] DCC assumes it is the one identified at [INQ000413883/10-11]

42. In respect of Northern Ireland, Robin Swann confirmed that no in-depth assessment equivalent to the CQC review of DNACPR practices in Northern Ireland during the pandemic has been conducted.[68] Mr Swann also confirmed that he would be supportive of recommendation for a systematic review of all DNACPR notices put in place from 2020 to date, although he was not in a position to take it back to the Department.[69] DCC invite the Inquiry to recommend the same.

43. In respect of Scotland, the evidence of Professor Smith and Jeanne Freeman confirmed that the Scottish Government has not carried out a systematic review of the DNACPR practices during the pandemic in Scotland to identify whether blanket DNACPRs were being issued and whether they were being applied appropriately and why.[70] Jeanne Freeman stated that there was no more than a "look at" where the DNACPRs were said to be imposed because the Government was in the middle of the pandemic at the time.[71] Professor Smith agreed that a review of DNACPRs should be undertaken if the data was available and that the review should also examine the wider advanced care planning production at the time.[72] It is the DCC's view that a full, thorough systematic review of DNACPRs practices is called for and urges the Inquiry to recommend the same. The DCC would recommend that if there are concerns about there being 'sufficient data', that the Inquiry invites the Scottish Government to carry out a review in a similar way to the CQC, who conducted interviews with stakeholders, thereby obviating the need for well-recorded data.[73]

44. It has become apparent from the evidence in module 3 that there is still confusion about DNACPRs, do not treat notices, the clinical frailty scale and ceilings of care, and, as Jackie O'Sullivan explained, there is confusion on those areas even after the pandemic and resources are factored into decision-making.[74] Professor Wylie, in his evidence, also recognised that more training was needed about DNACPR notices and advanced care planning. Further, he explained that he thought there needed to be a public health information drive.[75] The DCC urges the Inquiry to address that confusion by requiring training for clinical staff and the implementation of a public awareness campaign.

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[68] [33/94/15 – 33/94/25]
[69] [34/170/12 – 34/170/22]
[70] Professor Smith [11/151/19 – 11/152/15]; Jeanne Freeman [34/68/15 – 34/69/5]
[71] [34/68/15 – 34/69/5]
[72] [11/151/19 – 11/153/5]
[73] See [INQ000235491/10-11]
[74] [21/89/22 – 21/90/7]
[75] [20/26/6 – 20/27/6]

45. As flagged in our opening submissions, DCC remain concerned that inappropriate DNACPRs still exist on the records of disabled individuals as a hangover from the pandemic, as was also highlighted by the Equality and Human Rights Commission and Amnesty in the CQC's Interim Report.[76] None of the evidence heard during module 3 assuages DCC's concerns that any governmental body in any of the four nations has taken the appropriate steps to check the records of disabled people to find out if inappropriate DNACPRs are still in place. Given the grave nature of the potential misuse of DNACPRs, the DCC invites the Inquiry to recommend that public bodies across the four nations take action to rectify this issue. Work must also be undertaken to repair the bonds of trust that may have been broken between patients and doctors who were impacted by the misuse of DNACPRs. An honest discussion on why the misapplication of DNACPRs occurred would go some way towards repairing the important bonds of trust between patient and doctor.

46. Looking forward, the DCC considers that it would be advantageous to have a national standardised process for DNACPRs in place and invites the Inquiry to recommend the same. There is not currently a standardised process across the four nations.[77] As explained by Professor Wylie, the ReSPECT form has been adopted in only 5 out of 7 English health regions, only 4 out of 14 Scottish Health Boards have adopted it, and it is not used in Wales.[78] Professor Chris Whitty confirmed that there should be a systemised framework in place, such as the ReSPECT form, and that there were advantages to having a national system which was widely accepted within medical nursing and other areas.[79] As Dr Suntharalingam explained, the advantages of the ReSPECT form, over DNACPR forms which are specific to institutions, is that "it is transportable, it stays with the patient. They themselves would have a copy. Where there are electronic systems across regions, it would be part of that, such as an electronic care plan."[80] The benefit of having a standardised process across all four nations is, as explained by Dr Suntharalingam, for the practical and obvious reasons, that the ReSPECT form can travel with people across borders, but that it also establishes shared best practice.[81]

47. The DCC invite the Inquiry to recommend:

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[76] [INQ000235491/10]
[77] As CTI, Ms Carey, put to Dr Suntharalingam: T 9/10/24 [19/12/5 – 19/12/9] and [19/17/9 – 19/17/21]
[78] [20/20/2 – 20/20/16]
[79] [12/204/23 – 12/205/16]
[80] [19/16/14 – 19/16/23]
[81] [19/18/1 – 19/18/12]

a. Full implementation of the CQC's recommendations;

b. Implementation of a systematic review of DNACPR practices during the pandemic in Scotland, Wales and Northern Ireland;

c. A full review in all nations as to whether DNACPRs created during the pandemic still exist on disabled people's records and the review should consider whether the DNACPR remains appropriate;

d. Creation of a single methodology for recording a DNACPR decision-making process, either through the ReSPECT document or equivalent;

e. Training for clinical staff and a public awareness campaign on DNACPRs, do not treat notices, the clinical frailty scale, ceilings of care and around the misconceptions around disability and quality of life.

Prioritisation Tool and CRITCON 4

48. In March 2020 the four CMOs commissioned work on a rationing tool. The expert group was tasked to consider and develop a putative Covid-19 clinical prioritisation model to be used in the event of saturation of NHS critical care resources, drawing on insights and professional networks from primary care, critical care, ethics and law. It had an explicitly United Kingdom-wide remit and answered to the 'Quintet' of all four national Chief Medical Officers and the Medical Director of NHS England (Professor Sir Stephen Powis). The working group had an advisory and developmental role only, and implementation of any recommendations would have been by the decision of the Quintet, the CMO Office and Ministers.

49. The Inquiry experts Drs Summers and Suntharalingam (the latter of whom was part of the commissioned expert group) explained that the tool would be deployed "only in the event of a centrally declared national resource emergency (CRITCON 4 in one or more regions/nations, with a high-level Governmental or NHS-wide declaration), and only after exhausting all possible sources of mutual aid between all hospital".[82] They described the tool as follows:[83]

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[82] [INQ000474255/46]
[83] [INQ000474255/47]

> "if critical care resources became exhausted nationally, any declared clinical prioritisation would operate on a ranking basis in the event of needing to prioritise one patient over another when competing for the same resource (in effect, "the last ICU bed"). Such a ranking would be based on the best available evidence regarding the probability that patients could be reasonably expected to survive and benefit".

50. Ultimately, on 28 March 2020 it was no longer anticipated that there would be insufficient critical care capacity such that no prioritisation guidance would be necessary. A version of it was ultimately published into by The Intensive Care Society, following an unauthorised leak to the media of an incomplete draft.[84]

51. The question for the Inquiry is whether to recommend that rationing tool of the kind devised in March 2020 ought to be prepared in anticipation of a future pandemic causing NHS saturation.

52. This is obviously a hugely emotive topic that is laden with controversy. Some witnesses such as Professor Chris Whitty[85] and Professor Powis[86] reluctantly understood and accepted the theoretical imperative for such tool or policy. Others such as Caroline Abrahams of Age UK spoke vehemently against it.[87] Mr Hancock gave different evidence, but with respect, it was not entirely clear he understood the issue being put to him, and may indeed have been elided the rationing tool with the Clinical Frailty Scale in the rapid guideline: critical care (NG159) (which served a very different purpose).[88]

53. The DCC does not positively submit that the Inquiry ought to recommend a rationing tool for use in the case of a national emergency reaching CRITCON 4 should be prepared. Its primary position is that all reasonable steps must always be deployed in order to prevent there ever being a need to deploy such a tool. This of course includes all proper steps preparing for a future pandemic, including in terms of building residual and surge capacity in healthcare systems. However, it must be acknowledged that even when such steps have been taken, there will be a risk of a national emergency resulting in CRITCON 4. The DCC submits that if there is to be such a tool it ought to be devised and agreed upon *to the maximum extent possible* during non-pandemic times.

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[84] [INQ000474255/48].
[85] [10/170/18 – 10/172/19]
[86] [28/87/3 – 28/87/1]; [28/95/17 – 28/93/24]
[87] [21/43/11 – 21/45/11]
[88] [36/55/19 – 36/62/9]

54. Should the Inquiry recommend that a rationing tool should be prepared, DCC say that there must be the following associated recommendations:

   a. There must be a genuine public debate in the form of a widely drawn deliberative process that engages conscientiously with all relevant stakeholders, free of political influence, with a view to identifying the broadest possible consensus about the criteria to be deployed.

   b. There must be absolute clarity about <u>when</u> the tool can and must not be used. As the experts stated (emphasis in the original):[89]

      "The working group was tasked to only look at the question of what to do and how to rank (not exclude) patients **when and if the ICU beds ran** out in the context of a **national declaration of a state of emergency**. It did not look at the possibility of turning patients away while beds were still available to keep space available for others deemed more deserving, nor at the question of 'taking someone off a ventilator' to make room for others. That question was deemed too complex to be addressed in the heat of the moment."

   It is not difficult to see how easily those two scenarios or criteria could become confused in practice. Indeed, there is evidence before the Inquiry that suggests considerations surrounding this piece of work may have leached into the rapid clinical guidance published by NICE at the end of March. Indeed, it was hard not to notice that Mr Hancock[90] and other witnesses appeared to find the distinction difficult to grasp. It is obvious that the scope for confusion of this kind would pose serious risks to disabled people who often experience prejudice arising from misconceptions about their relative quality of life.

   c. There must be total commitment to ensuring that people living with disabilities are not disadvantaged inadvertently or otherwise by such a tool, and that any potentially demeaning or discriminatory content or criteria is left out.

   d. There must be unrelenting vigilance in ensuring that the tool is never misused or mishandled. Sadly, well-meaning rules are not always followed, often with tragic consequences for disabled people. The tool must only be used on the

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[89] [INQ000474255/47]

[90] [36/55/19 – 36/62/9]

premise that there are sufficient and robust institutional and legal safeguards in place to accompany it.

4. Mortality data: disabled people at much greater risk of death than non-disabled people

55. Based on data from the Office of National Statistics (ONS), in October 2020 the Disability Unit highlighted that Disabled People made up 6 in 10 deaths involving Covid-19 between March and July 2020, and that "even after accounting for residence type, geography, socio-economic and demographic factors, health characteristics, and vaccination status, a significantly greater risk of Covid-19 death remained for all disabled people compared with non-disabled people".[91]

56. The ONS identified this disparity by reference to self-reported disability status included in the 2011 Census using the question "Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? - Include problems related to old age" (Possible responses: "Yes, limited a lot"; "Yes, limited a little"; and "No"). Those who said that their day-to-day activities were "limited a little" or "limited a lot" are referred to as "less-disabled" and "more-disabled" respectively, whereas people reporting no limitation to their activities are referred to as "non-disabled". At the time of the 2011 Census, 9% of the population in England said their day-to-day activities were limited a little because of a health problem or disability which had lasted, or was expected to last, at least 12 months, while 8% said their activities were limited a lot.[92]

57. The disparity rate in mortality remained "largely unchanged across the waves of the pandemic."[93] Specifically, over the period 24 January 2020 and 28 February 2022, the majority of Covid-19 deaths occurred among disabled people (38,671, 52.5% of the total, for males; and 39,271, 63.6% of the total, for females). For both sexes, the age-standardised rate of Covid-19 mortality was statistically significantly highest among more-disabled people, while less-disabled people had a statistically significantly higher mortality rate than non-disabled people. These differences in risk by disability status were consistent throughout the waves of the pandemic.

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[91] [INQ000083956/2]
[92] [INQ000271436/31]
[93] [INQ000271436/32]

58. The disproportionate number of deaths among disabled people was compounded for particular groups. Compared to people of the same age without such impairments, working-age people with both a hearing and visual impairment in England were nearly 12 times more likely to die due to Covid during the pandemic (24 January 2020 and 20 July 2022).[94] People aged 30-69 with a visual but no hearing impairment were more than eight times more likely to die, and those with just a hearing impairment were still four times more likely to die a Covid-related death.[95] Even after taking into account a wide range of other characteristics, the risk of a Covid-related death for people with a hearing, visual and dual-sensory impairment was still 1.30, 1.38 and 1.42 times higher than those without. The Health and Social Care Committee reported in its Sixth Report that the impact of the pandemic was disproportionately severe for individuals with learning disabilities, with the death rate for people with learning disabilities over six times higher than the general population when adjusted for age.[96]

59. The disparate impacts were known from early in the pandemic. On 19 June 2020 the ONS published its data demonstrating that between 2 March and 16 May 2020 and after adjusting for region, population density, socio-demographic and household characteristics, disabled people were twice as likely to die from Covid-19.[97] When looking at those under 65 years of age the rate of disparity increased exponentially; the relative gaps between those disabled and not disabled were largest among those aged 9 to 64 years. Males whose activities were limited a lot in 2011 had a rate of death involving COVID-19 6.5 times greater than those not disabled, while for females it was 11.3 times.[98]

60. As he explained in paragraph 173 of his statement, Mr Hancock, commissioned Public Health England (PHE) to report on disparities in outcomes and risks from COVID-19."[99] Disability was not identified as a relevant disparity in the PHE Review "Disparities in the risks and outcomes of Covid 19" dated June 4, 2020.[100] However, in August 2020 PHE published its 'Updated Review',[101] at which point in time the 19 June 2020 ONS data demonstrating the disparate impact set out above had long since been published and was known to Government. And yet, disability was <u>not included</u> in the Updated Review or in any PHE outputs thereafter.

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[94] [INQ000090541]
[95] [INQ000090541]
[96] [INQ000090541/108] at para 314
[97] [INQ000308703/8]
[98] [INQ000308703/8]
[99] [INQ000421858/42]
[100] [INQ000399820]
[101] [INQ000101218]

61. The DCC maintains that the failure by PHE to include disability as a relevant disparity in its ongoing disparities review represented a significant and costly omission. The PHE Review formed the basis of most Government interventions designed to mitigate disparities and as such nothing was done in relation to the extraordinarily high disparate impacts on disabled people (particularly working age disabled people).

62. Disability charities were rightly concerned at this data, and Jackie O'Sullivan of Mencap asked for more information on what lay behind the increased mortality rates, firstly in a stakeholder meeting held with the Chief Medical Officer and Deputy Chief Medical Officer, and then twice asking again in an email to Jenny Harries through a DHSC official, sent on 24 September 2020 and 9 November, but never receiving more than a holding a response.

63. Eventually, in in October 2020 the Chancellor of the Duchy of Lancaster, Rt Hon Michael Gove MP, wrote to Matt Hancock and other Secretaries of State requiring them to show "greater ambition" in tackling the "terrible disparities highlighted" by the PHE Review.[102] In that letter Michael Gove also said this:[103]

> "In addition to his headline ask for more ambition, I want to draw your attention to his request to departments to consider options for improving outcomes for those with disabilities, ahead of a future COVID-O discussion. This is also extremely important work. I expect Secretaries of State to work with their departments to bring much more ambitious and far-reaching proposals to that discussion, as per the Prime Minister's steer. The Prime Minister has clearly directed his Ministers to engage with this issue fully, and develop a strong package of interventions. If we do, then I have complete confidence that this committee and our Government can move the dial and prevent a replication of disproportionate impacts in the second wave."

64. Subsequently, the Director of the Equality Hub made a presentation to multiple government departments on 30 October 2020 in which the disproportionate impact on disabled people in terms of deaths, accessing healthcare, wellbeing and other matters was set out.[104] The purpose was to discuss (i) data HMG has on disability and COVID-19, and then to (ii) consider interventions that HMG could seek to implement across Government to tackle the disproportionate impacts COVID-19 has on disabled people. This followed "a steer from the Prime Minister for much greater ambition from this work".[105]

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[102] [INQ000083956/8]
[103] [INQ000083956/9]
[104] [INQ000083956]
[105] [INQ000083956]

65. The Equality Hub developed several policy proposals.[106] These were designed to improve: data regarding the drivers of the impact; government interventions by setting up a 'National Panel' of disabled people, improving the accessibility of communications with disabled people and digital accessibility. After discussion at a Covid-O meeting on 8 December 2020, very few of these proposals were adopted by HMG.[107] In particular, the National Panel was not set up and, as set out above, only inadequate improvements were made to the accessibility of communications. Nothing was done to increase or overcome digital accessibility issues.

66. The 8 December 2020 Covid-O meeting did agree however that:[108]

> "a. departments should move at speed to roll out the measures agreed, and they should engage swiftly with HMT where additional funding is required.
>
> b. departments should work together to use improved data to better understand the disproportionate impacts of COVID-19 on people living with disabilities, including conducting a data audit of disabled people's travel patterns and preferences
>
> c. departments should support measures to address the negative effects of COVID-19 restrictions on the wellbeing of disabled people."

67. Very little if anything was done in by DHSC, NHSE or the CMOs in response to these instructions. Asked directly about his response, Mr Hancock said in evidence that the shielding program was expanded to cover disabled people.[109]

68. Whilst those living with Down's Syndrome were added to the Shielded Persons List (SPL), shielding was entirely focussed on clinical vulnerability. A policy predicated <u>only</u> on medical conditions rather than a wider social model of vulnerability or disability, always risked overlooking entire categories of disabled people, leaving them without a mechanism to ameliorate risks effectively and quickly.

69. Sadly, in the face of almost complete inaction, and despite the Prime Minister's call for much greater ambition to tackle it, the vastly disparate impact on disabled people in terms of mortality remained unchanged during the pandemic.[110]

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[106] [INQ000083956]
[107] [INQ000436880/82]; [INQ000091234]
[108] [INQ000091234/1]
[109] [37/26/10 – 37/27/22]. Mr Hancock also mentioned prioritisation for vaccines (the subject of Module 4).
[110] [INQ000271436/32]

70. DCC is hard pressed to submit what more should have been done (or might be done in the event of a future pandemic) because even now, some 4 years later, it is not known what caused the disparities in mortality rates for disabled people. This is of significant concern to the DCC and doubtless many disabled people. Unfortunately, the lack of any concerted effort hitherto to identify why disabled people were at such higher risk is consistent with the general disregard for their interests and welfare during the pandemic.

71. In their evidence to the Inquiry, Professor Whitty and Christopher Wormald[111] accepted further research must be done to better understand the mortality rate for disabled people. DCC is very pleased that Ms Gray KC suggested on behalf of NHSE that the Inquiry may wish to formally recommend that this research is undertaken. The DCC would obviously endorse this. The data and the lessons learnt from it must be published and acted upon.

72. The need for this to be done is obvious and requires no further elaboration here. But it must be said that the evidence given by the former Secretary of State for Health on this issue has caused significant alarm to the DCC. Mr Matt Hancock told the Inquiry that "*the virus itself was more aggressive against people living with disabilities*" and that "*the disparities were a result of the nature of the virus*." When asked to clarify whether he was contending that disabled people where "*clinically more likely to die from Covid-19 than non- disabled people*", Mr Hancock answered "*that is the clear evidence from the data, yes*."[112]

73. The Inquiry has not followed up Mr Hancock's offer to provide it with this evidence. Doubtless there is good reason for that, but in the event of any doubt, the DCC is not aware of any evidence to support his contention that C-19 was intrinsically more aggressive against people living with disabilities. It considers that the prospect of this being correct is fanciful in the extreme and the Inquiry ought to confirm as much.

74. If Mr Hancock (and/or the Government generally) really was of this view, it is not surprising that that under his leadership little was done to address the disparate impact on disabled people's mortality.

75. The DCC invite the Inquiry to recommend that:

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[111] Professor Chris Whitty: [12/176/25 – 12/178/9]; Sir Christopher Wormald: [30/99/20 – 30/100/17]

[112] [37/28/9 – 37/29/2]

a. DHSC and NHSE commission independent research into the possible causes of the disparate impact of Covid-19 on disabled people, including for those living with particular disabilities.

b. Work is done across Government to improve data collection and dissemination in relation to the prevalence and impact of disability amongst the general population with a view to reducing the impact of health inequalities on disabled people and improving access and responsiveness to healthcare services.

Conclusion

76. DCC hope that the learnings of the Inquiry can be implemented imminently in forthcoming policy opportunities, such as the upcoming NHSE ten-year plan, being developed in spring 2025 and due to be published in May 2025.

77. Whenever it comes, a report highlighting the lessons learnt that offers meaningful and bold recommendations would go some way to ameliorating the collective trauma of disabled people and limit the scope for the same or other mistakes to be made in the future; hopefully leading to better overall outcomes for disabled people.

78. Ultimately, we say that the overarching lesson is cultural and systemic: disabled people continue to get the rough end of the stick time and time again.

79. A systemic problem requires a systemic solution. The best solution the international community has settled upon is incorporation of the UN Convention on the Rights of People with Disabilities into UK law. Acknowledging that disabled people are at particular risk because of pre-existing and “entrenched discrimination”, the UN Committee on the Rights of People with Disabilities has called for “Critical and urgent action” to ensure that disabled people are explicitly included in public emergency planning and health response and recovery efforts. The statement concludes that “a human rights approach is critical to response and recovery efforts not only in relation to the COVID-19 pandemic, but also to ensure that States take action now to build equitable, sustainable and resilient societies that have the mechanisms”.

80. The DCC urges the Inquiry to make a recommendation to the UK Government to ensure that the rights of DP as set out in UNCRPD are better respected, protected and fulfilled and that this should be enforceable through systems of direct accountability. This would be consistent with the recommendation made by the Welsh Government’s Disability

Equality Forum following its evidence-based enquiry into disabled people's experiences during the pandemic:[113]

> "We strongly recommend that Ministers incorporate the UN Convention on the Rights of Disabled People (UNCRPD) into Welsh law, as a priority. This "sets out the rights of disabled people and provides a framework for action on how these rights are protected and enforced."

81. Both the Scottish and Welsh Governments are now progressing towards full incorporation of UNCRPD into Scottish and Welsh law. The DCC urges the Inquiry to recommend to HMG that incorporation is implemented across the four nations.

82. An embedded rights-based approach would at last elevate disabled people to the status of individual right holders; an important upgrade of their current position as de facto second-class citizens.

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20 December 2024

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[113] [INQ000227530/25]