COVID INQUIRY MODULE 3

WRITTEN CLOSING SUBMISSIONS ON BEHALF OF
JOHN'S CAMPAIGN, THE PATIENTS ASSOCIATION, AND CARE RIGHTS UK

I. INTRODUCTION

1. John's Campaign, The Patients Association and Care Rights UK (together "the CPs") have closely followed and participated in this Module. These submissions expand on the CPs' opening and oral closing submissions, as well as the issues identified in the CPs' witness statement and oral evidence, all of which we ask the Chair to take into account in reaching her conclusions and making recommendations for this Module.

2. In these submissions, the CPs refer repeatedly to "family carers." By this term, we mean a person close to a patient, who helps support them and provide care to them, who knows them intimately and is trusted by the patient to be their eyes, ears, and voice when necessary. Many family carers will be related to the patient, by consanguinity or partnership ties; but some may not. A particular special friend, and even in some cases a paid companion, may fulfil this role. Some will hold formal authority, for example a power of attorney for health and welfare. Others may advocate for the patient on a more informal basis. But although their precise relationships may vary, they will normally be easily identifiable – as many witnesses recognised – because of their importance to the patient and their expert knowledge in the patient's needs and wishes. One of our central recommendations is that every patient or service user should have the right to access for, and support from, someone special to them and, while we welcome debate about the terminology appropriate to this role (and recognise that they will have their own ways of describing themselves – spouse, parent, friend, companion), for the purposes of these submissions we use the phrase "family carer".

3. Through the 10 weeks of hearings, it has been obvious that the issues we highlighted in our opening submissions for Module 3 are key concerns for many witnesses, core participants and contributors to the listening exercise. We deal in Section II below with the evidence on those issues: (1) the lack of consultation with patients and patient representatives, (2) the exclusion of family carers and visitors from healthcare settings, (3) the failure to have proper regard to human rights and equality obligations in

decision-making, (4) difficulties accessing healthcare for non-Covid conditions, (5) the widespread use of virtual consultations, and (6) the inappropriate imposition of DNACPR decisions. In summary, the CPs' position is that:

a. High quality healthcare is patient-centred, and the system must ensure that a patient's voice is listened to.
b. Excluding family carers and visitors from healthcare settings harmed patients, their loved ones, and healthcare staff. The pandemic response relied on millions of unpaid family carers to step up to fill the gaps in the healthcare system but excluded them from care provided in healthcare settings. They were not (but should have been) treated as partners in care and given the recognition they deserve.
c. Statutory duties, including under the Human Rights Act 1998 and Equality Act 2010, were seemingly abandoned at a time when they were needed most. This appears to be at the root of many of the more specific problems identified above and below.
d. The pandemic response had a serious detrimental impact on access to healthcare for non-Covid conditions.
e. Virtual consultations do not work for everyone, particularly the digitally excluded and some older and disabled people. Increased reliance on NHS 111 was also problematic given its shortcomings.
f. DNACPR decisions should never be imposed without individualised assessments or the participation of patients and their family carers and loved ones in decision-making.

4. Overall, the evidence has provided a clear and compelling narrative of what went wrong. Several overarching themes have emerged which, in our view, provide a helpful framework (i) to understand what should be the priorities and focus of a high-functioning healthcare system, and (ii) to guide and inform the recommendations that the Inquiry makes.

5. The first theme is the foundational and central importance that people's loved ones often have in their lives. That has been clear from the moving evidence from members of the Covid bereaved groups, from impact films and from Every Story Matters, as well as from the measures voluntarily adopted by members of the Clinically Vulnerable Families group and many others to keep their loved ones safe. It may seem a trite

observation that we love our loved ones, but when those connections were put to the test – as they were by Covid and the Covid response – the strength of our attachments, the way that they order and shape our lives, and their impact on our well-being, became truly apparent. That realisation is a strength that must be built upon – and it must also heighten our concern for those without immediate family, whose challenges and suffering may otherwise go unnoticed.

6. The second theme is the diversity and variety of people and the uniqueness of their personal and medical needs. That has been clear in the evidence from witnesses speaking for older people, for disabled people, for people of colour, expectant and post-partum mothers and, indeed, whenever individual voices have been heard by the Inquiry.

7. The third theme arises from the unanimity of witnesses saying that high quality healthcare is person-centred, and the repeated concerns identified about the erosion of patient-centred care during the pandemic. This theme was clearly evidenced when witnesses spoke about the lack of consultation with patients, patient groups, and other stakeholders, the lack of individualised assessments and issues with blanket decision-making, and the exclusion of carers and visitors from healthcare settings and decision-making. A person-centred healthcare system must ensure that a patient's voice is listened to, along with the voice of their chosen representative, like a friend or family member, who will often be the "expert" in that person and is trusted by them to act as their eyes/ears/voice when needed.

8. The issues experienced in healthcare during the pandemic particularly arose when these three themes were ignored or overlooked. Many of the most damaging policies and decisions, including the exclusion of family carers from healthcare settings, provide stark examples of the harm that was caused when people's profound connections to their loved ones and their unique needs, values and desires were sidelined, and when the care provided to them was not person-centred.

9. The CPs propose specific recommendations for the Chair to consider at paragraphs 92-96 below. Our proposed recommendations focus on the right to a care supporter, the importance of patient-centred care, through feedback and consultation mechanisms, and the importance of training healthcare professionals on existing equality and human rights obligations. Each of the proposed recommendations, if

adopted, would prevent recurrence of some of the clearest issues experienced in the healthcare system during the pandemic; they also respond to and reflect the three themes identified above. The recommendations we propose, and the protection of person-centred care that they would achieve, is important not just in the event of a future pandemic but now, with the legacy of the pandemic response still deeply shaping patients' experience of healthcare.

II. THE EVIDENCE HEARD IN THIS MODULE

10. The evidence given in Module 3 demonstrates widespread agreement among witnesses on the following core points.

A. HEARING THE PATIENT'S VOICE

11. There was widespread agreement among witnesses in Module 3 that decisions without proper consultation with directly affected people were not good decisions. This applied to decisions about individual patients, and to higher-level policy decisions, including decisions on IPC measures.

12. Mr Hancock acknowledged that "*there's a vital need to consult people on the ground, both through organisations and directly*" **[36/199/8-10]**. This need stems from the underlying purpose of the NHS. Our healthcare system should serve people, not institutions, and the patient's rights must be at the heart of how the system operates, if that aim is to be achieved. This was highlighted throughout the evidence including by Ms Monroe KC in the closing submissions on behalf of the Covid-19 Bereaved Families for Justice UK, who pointed to the various witnesses who had spoken of '*the need to prioritise people over institutions and consider individual needs over wholesale edicts*' **[41/51/24 – 41/52/1]**. This requires proper patient involvement: through personal consultation where the decision being taken is one relating to an individual's treatment, or through the involvement of patient representative groups where the decision is at a strategic or policy level. As Mr Stringer stated on behalf of the Disability Charities Consortium, patients, including disabled people, must be seen as individuals and not as a collective or second-class collective **[20/92/1-25]**.

13. The requirement to involve patients in decision-making is already enshrined in the NHS Constitution and the NHS Act. Section 4 of the NHS Constitution (underpinned by the statutory duty in the Health Act 2009 to have regard to the constitution) requires the

patient to "*be at the heart of everything the NHS does*". It says "*It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers ... Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services*". Section 13H of the NHS Act 2006, the duty to promote involvement of each patient, provides that "*NHS England must, in the exercise of its functions, promote the involvement of patients, and their carers and representatives (if any) in decisions*". In terms of how this can be achieved, on an individual and wider level, the evidence in Module 3 was as follows.

(i) Involving individual patients in decisions relating to their care, and conducting individualised assessments to determine the most appropriate care

14. Caroline Abrahams of Age UK underscored: "... *the need for individualised assessments and an individualised approach. ... All the things I have talked about today, our biggest concerns for older people during the pandemic, were when blanket policies were imposed, or when sweeping assumptions were made about older people all being the same*" **[21/56/23]**. Paul Chrisp of NICE agreed that personalised assessments of patient needs were necessary even when there were broad guidelines in place: "*The guideline does not override the responsibility to make decisions that are appropriate to the circumstances of an individual or their families and carers*" **[23/66/1-4]**.

15. Dr Bryden emphasised the importance of patients coming into hospital having discussions about their treatment "*at the earliest stage possible*" to give them "*an understanding of what was involved and an ability to express their views whilst they were still able to do so*" **[18/142/12-25]**. She described the need to involve patients and their families in the decision-making process **[18/144/7-10]**.

16. Sir Andrew Goddard also emphasised the importance of involving patients and carers in decision-making: "*Decisions in ITU should involve the multidisciplinary team where appropriate, particularly if a decision is taken to withdraw treatment from existing patients in critical care, and must be made with the patient, and, if appropriate, their carers*" (INQ000346095 at para 61c). However, during the pandemic, families were

often not involved in any decision-making processes and decisions were not even communicated to them effectively (see witness statement of Margaret Waterton INQ000425385 at para 57).

17. This poor practice reduced the quality of the service being delivered to patients, and failed to treat them and their families as important partners in care. Caroline Lamb underscored the importance of ensuring that people are "*equal partners in terms of some of the decisions that are being made, that we are giving people advice and guidance that helps them to make an assessment about what it is that they feel comfortable doing and what they don't feel comfortable doing, and that that is accompanied by appropriate support*" **[32/188/15-25]**.

18. Professor Michael McBride (CMO NI) highlighted some "*crucially important*" work following the pandemic around "*advanced care planning*": "*a systemic and structured way about people identifying when they are well, about things that matter to them, and having structured conversations with the individuals that matter to them about things that they wish in terms of their personal wishes, their financial wishes, medical wishes in terms of treatment and care at the end of life etc*" **[10/30/12-22]**.

(ii) Consultation with patient representative groups, and taking account of patient experience in the formulation of guidance

19. On the broader policy decisions, there was too often a failure to seek patient feedback on important questions about the delivery of and/or quality of care. Andrew Goodall (Welsh Government and NHS Wales) admitted that concerns reported in a Healthcare Inspectorate Wales 19 March 2021 report about a lack of individualised end of life care did not get back to him **[31/43/1-20]**. There was no way of obtaining or analysing patient feedback on quality of care. Professor Fong underscored the need for direct consultation with those on the frontline to get an accurate picture of what was actually occurring: "*I felt that there was a gap between what we could understand by seeing number on screens and what was actually happening when you spoke to people on the ground*" **[12/5/2-5]**. Matt Stringer agreed that better insight into what is happening and what needs to happen "*comes from lived experience… our sense would be that we were always slightly playing catch up on whichever aspect of Covid we were engaged with*" **[20/87/11-17]**.

20. Sir Stephen Powis was unsure if disability groups had been consulted on the NHSE visiting guidance, but said that "*the principle of consulting is something that we hold dear at NHS England and it would be a principle that I think would serve us well in this area, as in many other areas*" **[29/28/14-18]**. This should have been done in respect of the various pieces of guidance that NHSE was promulgating (and indeed that Government departments and other official bodies were promulgating). Sir Stephen's evidence was that taking more time over formulating guidance would provide more scope for proper consultation with affected groups, and the need to produce guidance quickly during the pandemic was one reason that proper consultation was not undertaken **[28/84/1 – 28/85/25]**; this underscores the need for effective guidance to be put in place *now*, when there is time for it to properly reflect the views and experiences of those it will affect. As Professor Gould observed in her evidence, patients and families should be, and should have been, consulted on IPC guidance "*because they're going to have the guidelines used on them, and they deserve a voice*" **[8/89/11]**. Amanda Pritchard (NHSE) said, "*It is absolutely my personal experience from having worked in the NHS for now many, many years that that partnership with patients is invaluable when you're designing and delivering services*" **[29/156/4-7]**. She admitted that there was variation in the extent to which patient experience teams were engaged during the pandemic **[29/156/8-25]**. In a future pandemic, her view is that all providers and trusts should be encouraged to follow the better practice of involving patient teams **[29/157/2-6]**.

21. Eluned Morgan admitted that "*in retrospect I'd have liked to have other views, and that's one of the things that I developed since, was to get to set up a system where we have a ministerial advisory group made up of people who are outside the system*" **[35/126/18-25]**. Similarly, Humza Yousaf said, "*We know that policy is far better formulated at the conception stage with those who it impacts as opposed to being done to them*" **[34/177/1-19]**. He said, "*those who have a disability themselves, they communicated to me that they often felt afraid that decisions that were made didn't fully understand the impact on them, particularly when we were opening back up, when we were removing NPI, for example, non-pharmaceutical interventions, and while that was welcomed by a lot of people, I know that a lot of people with disabilities and their carers felt that that situation could make them even more vulnerable*" **[34/108/13-21]**.

22. Matt Stringer observed that "*there's a general gap in thinking about disabled people in the round and in a full way*" **[20/102/22-24]** – a gap that could be overcome by involving disabled people, or appropriate representative groups, in the decision-making process.

As Jackie O'Sullivan of Mencap underscored, relevant groups were willing and able to provide such input but "*were not contacted by NICE or anyone else… 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 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*" **[21/66/14 – 21/67/1-3].** As Julia Jones observed, "*it's not rocket science*" to involve representative groups to make sure that guidance is "*going to relate to people's actual life experiences… that's a fundamental and structural thing… Putting themselves in the shoes of the patients who were at the heart of their services. The services are there for the patients*" **[21/25/1-24]**.

23. Reflecting back on the three overarching themes identified in Section I, the repeated failures during the pandemic to (i) have important conversations about care and treatment decisions with patients and their families, and prioritise good and clear communication with them and (ii) consult and involve expert representative groups in the promulgation of policies affecting their constituents, resulted in major deviations from person-centred care and failed to respect the variety of patients in the healthcare system, as well as their individual needs and wishes and relationships with their loved ones. To help avoid such failures in future, guidance making clear how patients and their representatives should be involved in decision-making should be drawn up now, with proper consultation, in readiness for a future pandemic.

B. EXCLUSION OF FAMILY CARERS AND LOVED ONES

24. A further, core example of this deviation from patient-centred care came in the exclusion of family carers from healthcare settings. This policy decision seriously harmed patients, their loved ones, and healthcare staff, and is a predominant issue of concern to the CPs, exemplifying as it does so much of what went wrong in healthcare during the pandemic.

25. This section addresses (i) the terrible impact of excluding family carers from healthcare settings, (ii) the failure to distinguish between family carers, who should have been treated as an integral part of a patient's care team, and visitors, (iii) the inconsistent approach taken by different healthcare settings to access for visitors and family carers,

(iv) the particular problems of excluding family carers and loved ones from end-of-life care, and (v) the impact of this policy on patients' loved ones and healthcare workers. In terms of the consensus that has emerged among witnesses, it is particularly notable that nearly all witnesses when questioned agreed that the negative impact of 'visiting' restrictions had not been adequately considered and/or addressed, that clear exceptions should have been in place at the start and that, once exceptions and necessary reasonable adjustments were belatedly introduced, they ought to have been much better communicated to protect the rights of patients and their loved ones. The effect of the initial total exclusion of 'visitors' (including family carers) was to raise a drawbridge which later alterations to the guidance seriously struggled to bring back down. The die had been cast, and the impact on patients was in many cases devastating.

(i) Impact of excluding family carers and loved ones

26. The Inquiry heard of the terrible impact that excluding both family carers and loved ones had on patients and their loved ones, particularly at the key moments of birth and death but also in many cases jeopardising the success of the very treatment for which a person had been admitted. For those living with dementia, other cognitive impairments or communication difficulties, exclusion of a family carer meant that their safety as well as the quality of their care and treatment was put at risk and they were denied a key reasonable adjustment. Even the legality of treatment interventions was called into question when proper consent was not obtained.

27. Caroline Abrahams described how patients living with dementia experienced a "*rapid deterioration*" in cognitive functions; those in hospitals were left "*alone without visitors, with no understanding of where they were or where their families were*" (INQ000319639 at para 38). Dame Jenny Harries explained that "*It is well evidenced that for some [older patients, those recovering from clinical states of confusion or infection, and those with dementia], physical and mental stress and deterioration can follow any reduction in their time spent with trusted, recognised carers*" (INQ000489907, para 5.12).

28. Patricia Temple (Nurse) described the impact of visiting restrictions on those who relied on family carers: "*I found it really, really sad. I remember well one patient that we heard talking to his mum on the phone, a learning disabled man who couldn't understand why she couldn't come and see him and he was dying and you could hear him speaking*

on the phone to his mum and asking her to come and that was devastating for all of us because we have an obligation as nurses to care for our patients, to empathise with them and to be there with them and it was very, very difficult to see them suffering without their loved ones there. It was difficult for us as well to see them dying alone" **[25/11/6-22]**. She felt she did not have the flexibility to adjust the rules to individual circumstances **[25/11/23-25]**.

29. There are numerous practical benefits of family carers being able to support patients, particularly where they have a unique understanding of the patient's needs. The Inquiry has heard from many witnesses who feared the consequences of not being able to rely on their expertise to meet the patient's needs.

    a. Leslie Moore described "*the constant concern of not being allowed to accompany PD into hospital, as his primary care giver who knows and understands his needs like no other, if he were admitted to hospital, was a constant worry and concern*" (witness statement INQ000485656 at para 14).
    b. Martina Ferguson described the benefits of being able to support her mother's care, including providing practical assistance with her personal care and hygiene (INQ000360941 at paras 15-19).
    c. Dr Saleyha Ahsan, who was allowed to visit her father as a carer in hospital, said that it was "*frightening*" to think about how his care would have been impacted if she had not been present **[39/86/7-15]**. She said "*The hospital had a policy that if a patient had a carer at home, they would allow a carer to remain with a patient in hospital at this time. Due to the immense pressure the staff were under, it appeared obvious to me, from what I witnessed, that they would have not been able to provide care to those with care needs*" (INQ000474260, para 13).

30. Professor Kloer recognised the practical support family carers provide, saying "*we knew very early, at the start of the pandemic, in our gold meeting in early March that we were worried about the sort of moral support that visitors provide for patients but also physical support around feeding and so we knew that was an issue because it's very much part of healthcare*" **[30/169/5-10]**. It was also known, very early, that excluding family carers and visitors would be devastating for some patients: as Julia Jones highlighted in her evidence, "*My co-founder, Nicci Gerrard, went on television on March 13, 2020, and said, for people living with dementia, separation and isolation*

will be a worse risk than Covid" **[21/6/4-8]**. Tragically, these concerns proved well-founded.

31. At times in his evidence, Matt Hancock failed to acknowledge the real practical need for family carers to be able to be present, rather than simply the "*emotional*" benefit. For example, he juxtaposed "*protecting lives*" with the "*deep emotional considerations*" of allowing visitors **[36/4/12-19]**. He did, however, agree that those who needed support should have been allowed access to family carers from the outset, and emphasised that guidance providing for this should be drawn up now in readiness for a future pandemic **[37/54/1-13]**.

32. Family carers also play a crucial role in advocating for their loved ones. This important piece is missing if they are not able to be in the room or to pick up on any issues. Sir Stephen Powis said that it can be more difficult to provide compassionate one-to-one care and detect signs of deterioration in the condition of a patient when there are no family members around (see witness statement INQ000232195 at para 240). The presence of family carers can thus have a material beneficial impact on the quality and success of healthcare given to patients. Dr Guy Northover (CYPMH expert) said that visits from "*family and carers are absolutely crucial*" **[24/164/1-9]**, "*…the treatment needs to involve those systems and not just an individual. So delaying or not enabling that to happen has a negative impact on the therapeutic delivery of care*" **[24/164/12-15]**. Professor Michael McBride (CMO NI) explained the impact of isolation on the health of those needing care: "*it is important that we recognise that the sense of isolation and loneliness has detrimental impacts on them from a physical health point of view as well, as well as the impact on family*" **[10/147/13-16]**.

33. In Jackie O'Sullivan's evidence, she underscored that "*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 in some instances and people were denied access. But it is absolutely important. People can help with communication. We see a lot of diagnostic overshadowing, people not displaying pain in the same way that perhaps you might expect from a member of the general public. And also family members have a lot of information about the way that their loved one behaves in stressful situations. So actually visiting wasn't just something that would provide reassurance for the family member and the individual, but it was absolutely vital if the care was to be successful*" **[21/76/25].** Proper consultation with family members was also, in her experience, vital to ensuring that informed consent was obtained for treatment of patients with learning

disabilities (and the same would be true of others with cognitive impairments or a need for support to understand medical advice and give consent), but this was often not achieved during the pandemic: **[21/20/101]**.

34. The witness statement of Clare Cole (INQ000421875), a carer for her father who had Parkinson's disease, provides a stark example of how a person's care can suffer, and their condition deteriorate, if they are denied access to their carers. Her father was admitted after a bad fall and, for the first 12 days of his admission, she or her brother were with him from 11am-8pm daily, keeping him company and doing exercises with him, assisting with meals, medication and personal care. During this period he was *"completely lucid"* and chatting about a range of topics, reading and listening to the radio, with every hope of a recovery and return home. When he was moved to a Covid ward and prevented from seeing anyone, so that his contact with Clare was limited to a daily phone call, his condition deteriorated dramatically. When Clare was eventually permitted to see him, she was *"shocked by the state I found him in: dehydrated, unresponsive, and a terrible colour"*, unable to swallow, speak and "*completely deconditioned*". He died shortly after.

(ii) Failure to recognise the essential role of family carers or strike the right balance

35. There was little recognition of the important difference between social 'visitors' and family carers. The latter always ought to have been treated as indispensable members of the patient's care team. While 'visitors' can, as Dr Shin, Professor Gould and Dr Warne observed at §8.18 of their report (INQ000474282), provide "*important psychosocial benefits at a stressful time*", the role of family carers is more crucial than this. The CPs support the language used by the Pregnancy Groups in the context of maternity visiting, which is equally applicable here: family carers are "*Not visitors but partners in care*" **[40/162/25]**.

36. In Julia Jones's oral evidence she set out the "*need to look at the difference between visiting and caring. … one would of course want to reduce footfall in health and social care institutions. And people themselves would wish this to be the case, people don't want to go bringing infection into hospitals or indeed acquiring infections in hospitals. But if you know that the outcome for the person who you care about, who you support, is going to be dire without you, that's where there needs to be flexibility -- well, yes, flexibility and conversations. Infection prevention and control needed to be much more*

complex and nuanced and appropriate for individual need" **[21/6/13 – 21/7/1].** As was recognised in the closing submissions of the Covid-19 Bereaved Families for Justice UK, Ms Jones's evidence highlighted "*the need to imbue protective measures with compassion and common sense*"" **[40/60/8-16]**. Caroline Abrahams of Age UK expressed a hope that *"new laws and regulations will come into place to make it clear that if somebody with dementia is in hospital or is in a care home that their family carers, under certain conditions, should always have the right to be with them. That would have made an enormous difference to the well-being, and the survival I think, of some older people*" **[21/56/2-21].**

37. Many witnesses agreed that family carers should have been allowed to support patients in healthcare settings at all times. Others agreed that exceptions should have been allowed earlier for certain groups.

    a. The Chief Nursing Officers of all four nations all agreed.
        i. Professor Jean White (CNO Wales) explained that, in Wales, there were five iterations of visiting guidance; the early versions were made without consulting people like disabled groups but later they listened to issues raised by (e.g.) people with dementia **[6/130-131]**. She said she was not sure they got the balance right **[6/132/2-3]**. She said "*I think we should have been much more careful around giving support, so if somebody's got dementia, it's a very difficult situation and having someone they have some recognition of, so there's lots of folk that I think we should have made more exceptions of earlier on*" **[6/136/16-21]**.
        ii. Dame Ruth May (CNO England) agreed that it would have been dreadful for people who needed extra support (e.g. people with Down's Syndrome) not to have visitors **[6/78/6-12]**. She agreed that, in a future pandemic, it would be important for guidance to make clear that people who relied on family carers were allowed to be with them **[6/90/1-13]**.
        iii. Charlotte McArdle (CNO NI) said that, from a healthcare perspective: *"long-term separation from loved ones, particularly those who would have been regular supportive visitors prior to the pandemic"* was an issue, and *"a more nuanced approach was appropriate*" (INQ000474226 at para 265).

    iv. Fiona McQueen (CNO Scotland) focussed on the exclusion of visitors in the maternity setting and identified that permitting visitors for new mothers *"would have been beneficial"* **[6/212/21 – 6/213/18].**

b. Dr Shin (IPC expert) agreed that carers could be distinguished from visitors and there should have been more acknowledgement in the exceptions to visiting restrictions to allow carers to attend on their loved ones **[8/121/20 - 122/3]**. Dr Shin gave the specific example of dementia patients needing family carers to reduce confusion, disorientation and distress **[8/122/16-23]**. He agreed that in a future pandemic it would be helpful to consider widening guidance to allow family carers to come in for people with dementia (or those with learning disabilities) **[8/123/1-11]**.

c. Stephen Powis agreed it should have been made clearer, earlier, that 'visitors' for patients with dementia and learning disabilities were expressly permitted **[28/114/11-24]**. He said it should have been more explicit in the guidance that, in relation to visiting, it was necessary to look at "*risks and benefits for individual patients, whether a human rights focus or a public sector equality duty focus*" **[29/14/4-9]**. He also described discussion about "*whether carers should be included as members of the healthcare family or as visitors. And our view was that they should be included as, in essence, as part of the healthcare family and not counted as a visitor. We clarified that later. But that was I think part of our learning process in producing guidance in an area that we had not previously had experience*" **[28/114/25 - 28/115/9]**.

d. Matt Hancock suggested guidance for a future pandemic needs to make this clear **[37/54/1-13]**.

e. Professor Colin McKay said "*I do think that we could have been more flexible in our approach early on*" **[32/28/10-11]**.

f. Amanda Pritchard agreed that family carers should be involved in supporting the professional health teams **[29/57/12-16]**. She recognised the value that family carers provide in planning and supporting the ongoing delivery of healthcare once someone is discharged from a healthcare setting: "*but actually having a good joint understanding of the needs of the person who is being discharged and in this case has been delayed for whatever reason, such that* *when they do get discharged, you know, plans are in place to support them to get the care they need once they're not in an acute environment any more, you know, we know <u>all the evidence says that that involvement of families and carers is crucial</u>*" (emphasis added) **[29/158/6-14]**.

g. Professor Michael McBride (CMO NI) confirmed that there was no pre-pandemic planning for visiting guidance **[10/145/3-10]**. He believed they did not always get the balance right and that it is important not to wait for the next pandemic to start thinking about what the approach should be **[10/146-7]**. He said: "*I'm not certain we always got the balance right around end-of-life decisions around visiting. … we need to perhaps take a more nuanced approach and greater flexibility around particular circumstances, give greater agency to professionals working in those environments. I think blanket approaches more generally are not helpful … we should bear that in mind that not being able to visit someone -- you know, you don't get that time back again*" **[10/146/14 - 10/148/9].**

h. Judith Paget said that visiting needed to be allowed in the context of end of life care, vulnerable adults and for "*people who act as carers for others*" **[31/50/5-15]**. She agreed that, in the maternity context at least, the recognition that partners or close family members were essential partners in care, not just visitors, came too late **[31/168/1-8]**.

i. Robin Swann MLA said he wished they had allowed care partners into care settings and hospitals sooner **[33/77/1 - 33/78/19]**.

j. Vaughan Gething said that "*In hindsight I think that we might have done more to enable visits*" **[35/81/16-19]**.

38. While unpaid family carers were routinely excluded from healthcare settings, they were nevertheless expected to step into the breach and fill the holes in healthcare provision for patients outside hospital. 4-5 million additional people become unpaid or family carers during the pandemic – in effect unacknowledged healthcare providers - when patients were discharged from hospital prematurely, when operations were cancelled, when regular treatments and community support were unavailable. Julia Jones noted in her oral evidence that, "*The CQC in their State of Care report highlighted the strain on the health and well-being of those people, and I really feel that the contribution*

made by those people to the continued functioning of health in our four countries should be recognised, and I don't think it was recognised" [**21/20/19-25**].

39. These things are ongoing issues, and they matter now, not just in the future.

(iii) Inconsistent application of rules

40. Belated modification of blanket exclusion policies, frequent changes in guidance and the psychological effect of initial prohibitions on fearful and overstretched staff meant that carer access was still too often refused even when the guidance improved. As Charlotte McArdle observed, "*Many of the families I represent have reported what they see as inconsistent implementation of the visiting restrictions that were in place in different hospitals at any given time*" **[7/58/18-21].** Those wards and hospitals which successfully welcomed carers showed this was possible and beneficial. As Julia Jones noted in her evidence, "*clearly in a pandemic you can't just go along as normal and nobody would wish you to but you can find positive ways round the regulations, you can find positive and safe ways to balance the risk of not caring for somebody in need and welcoming in a personal supporter … trying to find a way to say yes rather than the default of saying no"* **[21/18/6-14].** While some settings managing to say "yes" to personal supporters, and alternatives such as Simon Ball's successful ICU liaison team (discussed in his evidence at **[28/32/18 – 28/33-17]**), demonstrated that family involvement was still possible, these were rare examples and variability within the system added to distress where access was denied.

41. Martina Ferguson described a "*very mixed picture amongst the group. Some people, you know, got to be with their loved one, some people didn't*" **[39/134/13-15]**. She also described how there was no monitoring of the implementation of the care partner role introduced in care homes in Northern Ireland in September 2020 and extended to hospital settings in February 2022, leading to failures in communication between health or care staff and families that resulted in family carers continuing to be inappropriately excluded (INQ000360941 at para 40). Anna-Louise Marsh-Rees of Covid-19 Bereaved Families for Justice Cymru explained how "*The contradictory rules and restrictions in place regarding hospital visits during the Covid-19 pandemic meant that group members were able to be by their loved one's side when they died whereas other members had to say goodbye to their loved on through a hospital window or via a videocall […], some members were not able to say goodbye to their loved one at all*" (INQ000343992 at para 29).

42. The CNOs acknowledged that there was inconsistent application of guidance. Professor Jean White (CNO Wales) said that visiting guidance was applied inconsistently across boards, hospitals and even wards **[6/133/2-5]**. Charlotte McArdle (CNO NI) said that the impression that the guidance was applied inconsistently was "*confusing and distressing…and indeed frustrating*" **[7/59/8-10].** Professor Gould (IPC expert) agreed that there were variations in how visiting guidelines were implemented and this would need to be considered more in a future pandemic **[8/210/11-21]**.

43. Judith Paget agreed that there should be consistency in what is deemed to be essential visiting **[31/149/14-20]**. Gregor Smith (CMO Scotland) admitted being aware of instances of inconsistent application of visiting rules around end-of-life care **[11/161/8-15]**. He said it is "*absolutely right*" that there should have been a more consistent approach **[11/162/4-10]**. This was difficult to achieve, however, because (as noted, for example, by Jackie O'Sullivan: **[21/80/21]**), terminology such as "*essential*" and "*non-essential*" is open to significant interpretation and was poorly understood and applied.

44. Policies which offered local discretion, but which were unsupported by a clear understanding at the local level of patient needs and rights, proved damagingly inadequate. Dr Shin (IPC expert) accepted that it is harder to strike a reasonable balance with visiting restrictions in a national pandemic if there isn't clear national guidance **[8/201/24 - 8/202/3]**. As Julia Jones observed:

> "*As the pandemic continued there were [] fluctuations and changes to guidance which unfortunately got people quite confused, and so I think there was a lack of psychological insight, in that when you sent out such a very negative message to start with, and where people are very frightened and where you're looking at death statistics every night, so many people took no notice of all the nuances and the iterations of guidance, particularly, particularly when it became locally -- you could make your own minds up locally which should have been a good idea but actually wasn't. … we became very aware of … some hospitals would listen and take the guidance and have an overall flexible attitude, that if the patient needed somebody and it was essential to their health then the essential person would be welcomed, whereas other hospitals would say no. And it could go down to a really micro level …one of the hospitals who had really taken on the idea of patient-centred visiting, but there was a gentleman, and he was non-English speaking, elderly and he'd had a bad [fall] – [he'd been]*

> *living with dementia, being cared for by his son and daughter-in-law, was taken into a hospital with no provision made for the fact that he didn't speak English, and he got to the end-of-life state and they were now no -- no contact, no support at all. He was moved then into a different ward in the same hospital for his end-of-life care, and the nurse said: but we're a John's Campaign hospital, he has dementia, you could have been coming in all through this time. Think how those people felt. And of course in that case he did revive, he did start to eat, which he hadn't been able to eat before, but sadly it was too late and they kept him better for a week or so and then he died*" **[21/8/1 – 21/9/20]**.

45. Eluned Morgan's statement (INQ00047425 at para 256) described: "*An inevitable consequence of allowing healthcare providers to implement their own rules on visiting restrictions as they see fit is that it can create inconsistencies in approach across Wales*" and Humza Yousaf observed, similarly, that "*ultimately the emphasis should be on a person-centred compassionate approach and therefore there may well be slight variation even between hospital sites or even within a hospital because the situation required it*" **[34/140/7-15]**. However, if there had been clear national guidance to direct local decisions and provide them with a clear and comprehensible basis (accessible to patients and their family carers and loved ones, too) for the individual decisions that were being made, that would have removed many of the issues and much of the distress that arose from the inconsistent way in which the existing guidance was applied and the stress arising for those who were tasked with applying it.

(iv) End of life care

46. It was not until late in 2020 that visiting guidance in care homes and hospitals in England was adapted to ensure in-person visits for people at the end of life, leaving thousands of people dying without the support of their loved ones (see witness statement of Caroline Abrahams, INQ000319639, at para 48). This was an indignity that can never be recompensed and one of the most harrowing aspects of the pandemic. Witnesses from all spheres of the healthcare system and those who represent patients spoke with one voice about the harrowing impact of patients dying alone.

47. Jeane Freeman OBE recognised that "*some of the operational delivery of those [visiting] restrictions they may have been too restrictive. And in particular where families were able to be with a loved one who was dying…I think as we understood*

the virus better and moved through the pandemic, some of the practice of restrictions was too restrictive" **[34/76/12-21]**.

48. Based on her experience on the frontline, Dame Ruth May (CNO England) said that not having visitors was "*awful*" for patients, particularly with end-of-life care **[6/77/18-24]**. Professor Jean White (CNO Wales) said that "*The last thing I ever wanted was somebody to pass away without their loved ones having contact, and that was even from the get go, when we'd locked everything down, I always said that that was something you should enable*" **[6/132/17-21]**.

49. Margaret Waterton powerfully described what it meant to be with her loved ones as they died. She said, "*And I have been described as lucky because I was with both my mum -- I was able to be with both my mum and my husband when they died. I don't consider myself lucky, I consider that that was my right to be with my mum and my husband when they were dying, to offer them as much comfort and love and reassurance as I could in their final moments, and it was equally their right to have me there*" **[39/44/4-13]**. Anna-Louise Marsh Rees described how "*The fact that so many members were kept in the dark whilst their loved one died in hospital impedes on their ability to receive proper closure; thus, hindering their ability to grieve properly*" (INQ000343992 at para 54).

50. Professor Colin McKay said that the risks of Covid transmission had to be "*balanced against harm to the dying person occasioned by absence of family, harm to family who are unable to be present (both immediate and longer term in bereavement), and harm caused to care staff who substitute themselves for absent family and undertake difficult telephone communication ... every participant in the visiting end-of-life scenario is at risk of harm*" **[32/26/10-23]**.

51. Professor Michael McBride (CMO NI) said he does not believe the right balance was struck around end of life decisions and visiting and that it would be better to take a "*more nuanced approach and greater flexibility around particular circumstances*" **[10/147/16-25]**. He agreed that the impact on staff, too, was significant: "*whether you were working in intensive care or working in a ward or working in a care home, these were harrowing experiences that people were experiencing. You know, I mean, we were asking nursing staff to facilitate individuals saying goodbye to family using iPads. They had been present in the most intimate of conversations. So I think that had a very significant impact*" **[10/157/7-14]**.

52. Aidan Dawson agreed that many patients and staff found using or facilitating virtual communications traumatising, particularly around the end of life and admitted that "*I don't think a lot was done*" to address this **[26/95/20-26/96/8]**. He agreed this needs to be reflected on and that it hasn't been reflected on yet **[26/96/13-17]**.

53. The suffering and distress separation from their loved ones must have caused to dying people is unimaginable. Well-meaning but harrowing attempts to facilitate virtual farewells were no substitute. It caused long-term harm to the bereaved and must never be permitted to happen again. As Julia Jones observed in her evidence: "*the legacy of grief, guilt, anger, and mistrust that's left behind it is massive and so if one could do just one single thing, it would be to say, if you are dying you have the right to have somebody with you and we will facilitate that and that is our legal duty*" **[21/42/17-22].**

(iv) *Impact on family members and healthcare staff*

54. The Inquiry has heard it was not just patients who suffered as a result of the overly restrictive visiting practices. Exclusion from healthcare settings as their loved ones suffered was traumatising for family members and close friends. As above, many healthcare staff also experienced moral injury and distress as they held iPads to dying patients, or felt their ability to provide quality healthcare undermined by the absence of a patient's loved ones or family carers.

55. Professor Kloer said "*It is obvious to state the introduction of restricted visiting impacted negatively not only on patients but family members, loved ones and healthcare staff. Family visiting is well recognised as an invaluable resource in many direct (hands on) and indirect (morale boosting) ways*" (witness statement INQ000472509 at para 157). He said "*A key issue that emerged during the pandemic… was the distress and upset that ICU staff experienced as a result of being unable to communicate with, and comfort, relatives face to face particularly when those relatives were excluded from a patient's bedside*" (witness statement INQ000472509 at para 201).

56. The important need for communication with family members was heightened by their exclusion but was all too often entirely non-existent. Anna-Louise Marsh-Rees said "*communication is absolutely vital. Clear, honest communication. And I think there were a number of examples when there wasn't any communication from the hospitals,*

calls went unanswered, and loved ones and families were not being given updates either about the progress of their family member, or indeed what kind of treatment they were receiving" **[39/15/22 - 39/16/6]**. Paul Jones described how "*My wife and I were not allowed to see or speak to our own daughter at this stage, which, amplified with our feeling of hopelessness with the hospital, made the experience extremely difficult for us*" (INQ000486000 at paras 18-25). Robin Swann MLA admitted that there were "*weaknesses where the communication systems that we hoped and envisaged to being in place across different hospitals, different trusts, let patients down, let families down at specific points*" **[33/79/7-11]**. All too often, there were failures to make reasonable adjustments to facilitate proper communication and channels of communication were inadequate to ensure patients and/or their loved ones could raise concerns about healthcare provision.

57. Dr Warne (IPC expert) said that updating relatives who were not able to visit patients was "*one of the most difficult aspects for doctors working in that environment during the pandemic...Doing it by telephone was an incredibly impersonal experience for many people and, I think, quite distressing for junior doctors and other healthcare workers*" **[8/125/7-19]**. Sir Stephen Powis said "*for many staff the strain and the trauma of having to look after patients without the benefit of having close family and relatives to aid in that was really challenging*" **[29/13/8-11]**.

58. Dr Saleyha Ahsan, who was able to be present to care for her father in hospital said "*And sometimes the piping from the CPAP would get dislodged and, you know, again, that was his source of oxygen. But if I hadn't been in the room, I don't know how the overworked nurses in that space would have been able to keep an eye on every single side room ... So I just kept thinking, "Thank God I'm here, what about the others?" And I hope that by being there it took some of the pressure off the nurses*" **[39/87/21 - 39/89/13]**.

C. IMPACT ON ACCESS TO HEALTHCARE

59. A profound and continuing consequence of the pandemic has been its impact on access to healthcare for non-Covid conditions. Patients' needs were less well met, there was reduced involvement in decisions about care and a loss of quality control. Delays to treatment have had a devastating impact on patients, both in terms of their mental wellbeing as they await diagnosis, having important operations cancelled and treatment postponed, and in terms of their physical health as undiagnosed or untreated

conditions worsen and, in some cases, became untreatable. The examples in this section demonstrate a failure to take a patient-centred approach to care which seriously harmed patients' experience of healthcare during the pandemic.

60. Jeanne Freeman OBE said, "*one of the unintended consequences of the early messaging, which was Stay at Home, Protect the NHS, was that people took that to be don't ask the NHS for anything unless you've got Covid*" **[34/67/14-17]**. The impact was particularly acute on people in the most vulnerable situations. Dr Finnis described how, in November 2022 and November 2023, 90% of clinically vulnerable people surveyed delayed or cancelled appointments or operations **[18/99/8-16]**.

61. Mr Hancock was aware that "*we had people who were at risk of dying not coming forward*" **[36/51/7-8]**. He was aware that some people were "*actively not contacting NHS 111 and/or not going on to seek help from elsewhere*" **[36/96/2-5]**. However, his only proposed solution to this was making sure this is a "*clear part of communications*," which he insisted was done **[36/96/2 - 36/97/6]**. If it was, however, it was not done successfully: there have been many accounts of patients self-denying treatment to avoid placing pressure on the NHS and, despite Mr Hancock's protestations that "*the NHS was always available to all according to need*", as the Chair rightly pointed out "*it wasn't always available to those who needed cancer screening or who needed a major elective surgery like a hip operation*" **[36/27/16-21]**.

62. Elective procedures are not 'optional' procedures and delaying them can and did cause serious harm. Professor Metcalfe highlighted that "*it's easy to have this belief in a health service that hip replacements aren't important and that elective orthopaedic care isn't important, and actually patients are suffering terribly, they are just suffering terribly quietly at home where you don't see them*" **[24/65/18-22]**. Indeed, the Patient Association's report "Patient experience before the omicron wave" contains an account of a patient who had been on the waiting list for an "elective" cataract operation for 12 months, during which time she had become "*now almost blind in one eye and failing in the other*" (INQ000273426, p.19). Mr Hancock accepted that "*the decision to pause elective care had a significant impact on the waiting times for either diagnosis or for treatment,*" **[36/71/4-7]** and the practical and personal impact on patients of those lengthy increased waiting times cannot be overstated. When questioned about why these services were so slow to resume (including for example a 46% drop in hip replacements compared to only 14% elsewhere in Europe), Mr Hancock said it was the responsibility of NHS England **[36/75-76]**. His view is that, in a future pandemic,

there need to be contingency plans at ministerial or departmental level to ensure the swift resumption of elective care **[36/77/15-21]**. He also thought that insufficient use was made of elective hubs and that there needed to be more of them **[36/78/8-18]**. Similarly, in Scotland, Jeanne Freeman said that future pandemic contingency planning should rely on specialist elective centres **[34/71/23 - 34/72/6]**. The CPs are concerned that insufficient consideration was given to finding safe alternatives or giving patients meaningful choices in recognition of their needs and the potentially serious impact on quality of health and life that the delays had.

63. The decision to pause screening programmes also, inevitably, had huge and serious consequences. Professor Bhangu's view is that it was wrong to pause screening programmes and that they should continue in a future pandemic **[24/5/4-11]**. He explains the fall in cancer diagnoses as being due to: (1) the "*perception from patients was that either the GPs were closed or patients shouldn't go to their GPs to overwhelm the system. So some of these patients with symptoms stayed at home and they didn't call anyone, they didn't try to call anyone, they didn't try to contact anyone*"; and (2) "*where people did manage to get through the system our capacity for endoscopy, which are the camera tests, fell dramatically, so it fell to about 5% of what we'd normally be doing. And so our capacity to provide diagnosis during that period also fell*" **[24/9/3-21]**.

64. A particular concern was the basic failure to ensure access to mental health services during the pandemic. The Pandemic Patient Experience Report by the Patients Association (INQ000273424) recorded the views that: (i) "*For many weeks we have had a 'COVID-19 Care Service' and Emergency Care Service; we haven't had a National Health Service because it was basically stopped*" (p. 28); and (ii) "*People have told us that services for mental ill health have become even more difficult to access under lockdown, and that they do not feel mental wellbeing has been a priority for government services. Many have been cut off from friends and family members, and some are extremely isolated as a result of the pandemic, without anyone checking in on their health and wellbeing*" (p. 49).

65. As Mind observed in its closing submissions, "*the guidance about the pandemic's unique challenges to inpatient mental health services came either late or was absent. This had palpable effects on individual lives*" **[40/198/17-21]**. This seems to have been another example of failure to consult or include appropriate stakeholders who would have known what was needed: "if *the mental health sector had been in the room during*

planning and when guidance was being issued, then these perils could and should have been taken into account. Instead, we have this from the witness statement of Lade Smith, President of the Royal College of Psychiatrists: [As read] "It is unclear whether mental health settings were simply forgotten, considered less of a priority, or considered not to need any guidance compared with other settings. All of these scenarios are entirely unsatisfactory and undermine the principle of parity of esteem between mental and physical health" **[40/199/4-17]**.

66. In many cases, despite an awareness of these serious concerns, no one appeared to take responsibility for ensuring these problems were addressed. Professor Khaw (Public Health Wales) admitted that he did not do anything specific to address the problem of people with chronic health conditions not accessing healthcare or attending key appointments **[26/42/1-7]**. The reason for not doing so, he said, was because of the need to work in collaboration with NHS Wales, and other health boards etc **[26/42/8-17]**. These concerns and failings demonstrate a failure to focus on the individual and personal needs of patients, which had significant detrimental consequences.

67. Reduced access to healthcare had a significant knock-on effect on private individuals stepping up to fill the gaps, to try to compensate for failures in the public healthcare system. Nearly 5 million people became additional unpaid family carers during the pandemic: they were, in effect, unacknowledged healthcare support. Carers UK estimated in June 2020 that an additional 4.5 million people had become unpaid carers since the pandemic began (bringing the total to 13.6 million) and the CQC's 2020/21 edition of its State of Care report outlined the increased strain on carers (see INQ000398569). 6 out of 10 carers (61%) said their physical health has worsened as a result of caring, while 7 out of 10 (72%) said they have experienced mental ill health. When patients were discharged from hospital prematurely, when operations were cancelled, when regular treatments and community support were unavailable, family members and loved ones stepped up to fill the gap – often to the detriment of their own physical and mental health.

D. VIRTUAL CONSULTATIONS AND RELIANCE ON NHS 111

68. In the context of worsening access to healthcare, the widespread roll-out of virtual consultations facilitated health care access for some, but they did not work for everyone. They do not work for the digitally excluded, for some older and disabled

people, and for people with specific language needs. The evidence before the Inquiry shows that the problems with virtual consultations for certain groups were recognised early on by governments, but insufficient steps were taken to address the issue. This is again illustrative of the widespread failure to take a patient-centred approach to healthcare that accounts for the diversity and variety of people and the uniqueness of their personal and medical needs.

69. Michael Mulholland described the problems with remote consultations as follows: "*my practice has a lot of elderly patients, many with hearing problems, and they found it hard to hear someone on the telephone…it was much harder for them to communicate. And as GPs we normally took a lot of our cues from how a patient looks, what's in front of us. We were having to learn as well*" **[9/137/3 – 9/138/7]**. He considered that remote consultations were not appropriate for: older people with sense impairments; vulnerable patients with safeguarding issues; and those with learning disabilities, "*because of the communication you might lose if you were not seeing them face to face*" **[9/140-141]**. This was identified as an issue in March 2020 but in September 2020 GPs were still saying they needed guidance on it.

70. Professor Adrian Edwards identified patients who might be "*digitally excluded*" as those who: "*might be, typically, older patients, sometimes less educated, sometimes socioeconomically more deprived…sometimes the ethnic minority groups that… we mentioned earlier.*" It also includes patients with disabilities "*such as sensory impairments or learning difficulties*" and "*depending on the nature of the disability, the particular route of access, whether it's telephone or website, may be more difficult or less*" **[9/30/7 – 9/31/8]**. He is "*not aware of specific programmes*" undertaken to reduce digital exclusion but "*there was an awareness of it… and an imperative, to try to assist people so that as we switched very much wholesale to remote access, triage and consulting in those early months of the pandemic, there was a specific attention to people with particular needs. At the practice level I think, ultimately*" **[9/31/18 – 9/32/2]**. However, "*how we operationalised those solutions, I think we probably needed more… I think actually probably more detail about how to support that could've been valuable*" **[9/33/23 - 9/34/11]**.

71. Caroline Abrahams of Age UK spoke of the "*unequal impact that the digitisation of healthcare services had on older people … the older you are the less likely you are to be online so there is quite big gap… the trend is upwards, more older people are going online over time, but there still remain a significant proportion who are not online …*

these statistics overstate the digital competence of the older population, because we know it is not just about whether you are online or not, it is whether you have the skills and the confidence to be able to do quite sophisticated things, as were required during the pandemic. In fact, about half of the over 65 population, we think, either isn't online at all or is not able to go online successfully and safely. … having a smartphone or some way of being able to interact digitally is absolutely key" **[21/32/19 - 21/34/5]**. As a result, the move to virtual consultations had an obvious and significant impact on older people, who "*found that overnight the way of getting hold of your GP, for example, changed from being able to walk to your surgery and have a conversation with someone behind a desk to having to navigate that process online or possibly over the phone, using telephone prompts. And so that was very, very destabilising for some older people … not helped by the fact that most signposting information and advice was available online ... older people being asked to perform tests or checks on themselves during a remote consultation … then being asked to do things like: take a photo of that wound you are worried about on your leg, and upload it to our website or attach it to an email and send it to us. And that requires a degree of sophistication that is likely to be beyond somebody, for example, who only uses the internet to go on Facebook or to play sudoku, which is not unusual amongst older people … throughout their lives they had gone to a GP, sat in front of a nurse and they'd done it for them, so this was something new and different, which they weren't being particularly well supported to do for themselves*" **[21/35/13 – 21/37/3].**

72. Jackie O'Sullivan of Mencap raised a further problem presented by virtual consultations, being that "*not everyone with a learning disability is IT literate, not everyone is able to use that technology. And then there is the issue of diagnostic overshadowing and GPs not being able to pick up on the signals that are coming from patients if they are seeing them in real life*" **[21/87/1]**.

73. Healthcare professionals also expressed concerns about the efficacy of virtual consultations. Dr Tilakkumar was worried about how effective virtual consultations were **[14/124/4-20]**, and Dr Northover (CYPMH expert) described the serious difficulties in providing some therapies remotely **[24/66/9-25]**. His view is that it would be useful to have nuanced guidance that advises on what can be done remotely and what cannot; he said the guidance that was in place "*was very much more a blanket that, you know, if you can work remotely you should be working remotely rather than thinking more closely around what would work remotely and what wouldn't*" **[24/167/4-**

17]. He said "*I think whilst we have got an opportunity we should be exploring the evidence behind it and then being able to put that into national policy*" **[24/167/20-23]**.

74. Julie Pashley described how her daughter, who has serious mental health difficulties, could not engage with remote therapy: "*No, she absolutely hates remote. Again, I think there is -- when you're with somebody face to face you pick up on feelings and other things that makes it easier to understand that person. When it's a 2D image, she just can't -- she cannot engage at all*" **[24/122/1-7]**. Dr Sarah Hughes, CEO of Mind, said that 26% of clinicians from Children and Young People's Mental Health surveyed by Cambridge University reported that remote consultations negatively affected building a rapport with young people (INQ000479887, para 12).

75. There was limited consideration by decision-makers, at the time, of the impact of remote consultations on certain groups. Robin Swann MLA admitted that the Department of Health did not consider the impact of changing the mode of access to primary health care to teleconsultations on groups such as "*older patients, disabled patients particularly those with sensory impairments, patients whose first language was not English, those with literacy issues, patients in areas with poor internet connectivity, patients who were homeless, patients from lower socioeconomic groups*" **[33/104/17 - 33/105/10]**.

76. Andrew Goodall (Welsh Government and NHS Wales) agreed that concerns about the digital exclusion of elderly and/or disabled people should have been at the front and centre of advice to ministers **[31/110/20 - 31/111/9].** There was, however, little guidance given to practitioners about how to identify those for whom virtual consultations were inappropriate, and how in-person appointments or assessments might still be conducted.

77. Mr Hancock said "*there are always going to be some people who need a face to face appointment…the point is that if you have a more efficient system using modern technology you free up space for more of that rather than less. I'm totally against an online only system*" **[36/174/3-11]**. Vaughan Gething said "*The Welsh Government recognised video consultations would not replace all in person contact, not least because there would be specific groups, including but not limited to the elderly, for whom this would not be appropriate*" (INQ000474252, para 243). And yet there was, and remains, insufficient guidance on how decisions about the mode of consultation for different patients should be determined.

78. Alongside widespread adoption of virtual consultations was a greatly increased reliance on the NHS 111 service, as an additional form of "remote" access to healthcare. Witnesses have agreed that the increased reliance on NHS 111 had similar shortcomings to those identified with virtual consultations generally, and again this is an ongoing problem. Mr Hancock said in his evidence that the NHS 111 service was under "*massive pressure*" **[36/28/18]** – but if there is going to be increased reliance on such services, they need to be fit-for-purpose, have appropriate capacity, and be properly accessible. A stark example of the failures of NHS 111 was given by Dr Sarah Powell's account of the service being unable to call her back using the Typetalk telephone system, excluding Deaf people from full engagement with the service and causing her to have to rely on her hearing child as a go-between in an emergency situation **[21/15/7-18, 21/17/4-10, and 21/24/17-23]**. These are all examples of a failure to account for the diversity of patient needs and to provide patient-centred healthcare that is informed by consideration of those individual needs.

E. DNACPR

79. The pandemic shone a light on DNACPR decisions being made on a 'blanket' rather than individualised basis and intensified pre-existing failures to involve patients (particularly disabled patients), their family carers, representatives and loved ones in advance care planning, including DNACPR decisions (see for example INQ000471158 at paragraphs 340-344). It was unanimously agreed in evidence before the Inquiry that DNACPR decisions should never be imposed without individualised assessments. Indeed, that follows from the engagement of Article 8 of the European Convention on Human Rights ("ECHR") as incorporated by the Human Rights Act (as to which see **Tracey v Cambridge University NHS Foundation Trust** [2015] QB 543 #88, #89, #94).

80. Many witnesses agreed that a blanket approach to decisions on patient care, including DNACPRs, is never acceptable (including Dame Ruth May **[6/79/13, 6/81/9-13]**; Professor Jean White **[6/137/21-23]**; Fiona McQueen CBE **[6/193/12-13];** Professor Michael McBride **[10/121/12];** Gregor Smith (CMO Scotland) **[11/146/10-14];** and Jeanne Freeman OBE **[34/66/12-15]**). Mr Hancock described the inappropriate use of DNACPRs as "*appalling and totally unacceptable*" **[36/106/11 - 36/107/2]**. Dr Mulholland explained the importance of individualised decision-making in this context: "*Sometimes an advanced care plan in some of my palliative care patients includes a*

statement where they have decided that should they die they do not want cardiopulmonary resuscitation attempted. And we would put that into a care plan for some of those patients that are often on a palliative care journey because of cancer or some other illness. But these are individual decisions, they were individual before the pandemic, we recommended and said they should be individual decisions during it, and we continue to work on that basis. … it is unacceptable for advance care plans, with or without a DNR form, to be applied to groups of people of any description, because that immediately removes the individual choice, and that was just something we thought was such a clear line, we needed to make it -- reiterate it to all practitioners as fast as we could" **[9/172/1 – 9/173/25]**.

81. Reports of blanket decisions being taken about DNACPRs, and the (mis)understanding that they were indicative of a decision to deny treatment generally (see the evidence of Professor Wyllie, **[20/15/23 - 20/29/6]**), caused real fear among affected groups such as older and disabled people and their families, that their lives were less valued and that they would not be supported if they needed healthcare. For example, Jeanne Freeman OBE agreed that concerns around use of DNACPRs may have led to people avoiding making "*an appointment with their GP for fear of being deprioritised in relation to ICU care*" **[35/67/8-17].** At a time when access to necessary healthcare was already restricted, it is particularly concerning that reports of poor decision-making and poor communication, and the fear that was generated by these failures, may have led people to eschew the healthcare that *was* available.

82. Witnesses agreed that DNACPR decisions should never be imposed without the participation of patients and their families (including Dame Ruth May **[6/79/8-11]**; Professor Jean White **[6/137/16-20]**; Professor Michael McBride **[10/131/7-10]**; and Gregor Smith (CMO Scotland) **[11/162/18-22 & 163/15-19]**). Professor McKay (Glasgow Royal Infirmary) said "*family were often not present and so these conversations would have to take place by telephone, which is not ideal*" **[32/21/11-14]**. Dr Suntharalingam agreed that if families were not present, there was a risk they wouldn't be consulted over important decisions, such as about DNACPR or other treatment **[19/91/9-17]**. In **Tracey** (as above) #50-#53: the engagement of Article 8 ECHR (the right to respect for private and family life) creates a presumption in favour of patient involvement with 'convincing reasons' needed not to consult the patient. As explained by the Court of Appeal (at #54, #59 and #93), that might be where such patient consultation would be "likely to cause her to suffer physical or psychological

harm"; but, even in that situation, that would not preclude a need to consult with family members rather than causing the contemplated harm.

83. The reports of and concerns about the misuse of DNACPRs are illustrative of the wider issues that patients experienced during the pandemic: once their family carers and loved ones were excluded from healthcare settings, there was a knock-on impact on the quality of care they received including, as here, because important conversations about treatment decisions were not taking place properly. This was a concern also raised by the CQC, whose review of 'do not attempt cardiopulmonary resuscitation' decisions during the COVID-19 pandemic also found that visiting restrictions made it difficult to have discussions with family and representatives regarding advance care planning and for them to advocate for the patient, and that increased pressure on staff meant conversations sometimes took place much faster in busier settings, with people feeling rushed into making decisions (INQ000235492 at p.17). All of these concerns demonstrate an overarching diminution in patient-centred care which seriously harmed patients' experience of healthcare during the pandemic.

III. LESSONS TO BE LEARNED

84. All of the evidence set out above establishes some key lessons to be learned. A good healthcare system is person-centred and treats patients and their loved ones as partners in care. It consults patients and their representatives on the decisions that affect them, keeping them at the heart of the service and ensuring that institutions serve people, not vice versa. It does not exclude or separate patients from their family carers and loved ones.

85. There are significant tools available to ensure that our healthcare system reflects these positive attributes, though during the pandemic they were overlooked and ignored. We draw particular attention to existing statutory obligations that should have guided how decisions were made, especially in emergencies, but which fell by the wayside in the pandemic. The most important in this context are:

    a. The duty to promote the involvement of patients in section 13H of the NHS Act.
    b. The NHS's constitutional commitment – underpinned by a statutory obligation of due regard in section 2 of the Health Act 2009 - to put the patient at the heart of everything the NHS does.

c. The Human Rights Act 1998, which requires individualised assessments to ensure protection of individual rights, for example under Article 3's protection of dignity and Article 8's protection of wellbeing, relationships, participation and autonomy.
d. Obligations of non-discrimination and obligations to make reasonable adjustments along with the public sector equality duty in the Equality Act.
e. The duty to consult families to make best interests decisions under the Mental Capacity Act.

86. We learned during the pandemic and from the evidence in this module that at times of fear and overwork, hasty and poorly thought-out decisions were made at all levels, without adequate or any regard to these essential legal requirements. We ask the Inquiry to re-emphasise the centrality of law and its supremacy over guidance. As Rosemary Gallagher said in her evidence, "*IPC guidance does not exist in isolation. So IPC guidance not only has to be implemented in the context of where a healthcare worker is working, but it also has to align and reflect the needs of other legislation or regulations*" **[25/49/19-23]**. We suggest that training for all healthcare workers should include awareness of this, and of how the relevant legal principles should apply in their everyday practice.

87. As Julia Jones said in her oral evidence: "*we have very good laws in this country, such as the Equality Act, such as the Mental Capacity Act and indeed such as the human rights legislation and I think if those pieces of legislation, particularly the Equality Act had been better observed then I think [] guidance would have been drawn up that was in accordance with legislation, and yes, flexibility then does come in, as Ms O'Sullivan was saying yesterday, people with learning disability for instance who should have reasonable adjustments made for them under the Equality Act not just because somebody is feeling kind, but because that is their legal right*" **[21/10/4-16].** Indeed, "*everybody working in health and social care should, as part of their training, have an understanding of the Equality Act and Human Rights Act and the Mental Capacity Act. Those really fundamental building blocks could be in training*" **[21/28/15]**.

88. Alongside the embedding and wider dissemination and understanding of existing statutory obligations, the pandemic underscored the need for a clear and simple duty to permit the presence of a care supporter. Many of the ills suffered by patients in healthcare settings could have been avoided if they had each had this right. Care Rights UK and John's Campaign, alongside campaign group Rights For Residents, are

calling for this new legal right, and have the support of over 90 organisations, including many CPs to this Inquiry. The CPs note that Charlotte McArdle, having attempted a partners in care scheme for Northern Ireland is helping develop a clear inclusive policy for adoption by NHS England. That would be a welcome start but more will be needed. Julia Jones explained: "*the power imbalance between patients and their families and the institutions of health and social care is so great that we now feel that there should be a legal right lying with a patient that if you're a patient or a service user or a resident, and you need this personal support, you should have a legal right to have it*" **[21/13/20-25].** If this right were established (we say it should be enshrined in statute), then future pandemic planning can focus on practical ways to make that happen, even in difficult circumstances. Dr Warne (IPC expert) described visiting as an "*understudied area*" which should be considered further in future pandemics, including by consulting affected groups **[8/206/12-20]**. Consideration must also be given to how best to support the individual needs of people who don't have support from family or friends.

89. It is also essential not to view healthcare in isolation. The important interrelationship between health and social care, and other external support structures identified in these submissions, cannot be overstated. Amanda Pritchard emphasised the importance of this: '*I would say don't forget social care. I know this Inquiry won't, to be clear, but we can only do what we can do in the NHS if we've got an equally, you know, if we've got that strong partnership with social care, so the staffing, the resourcing, all of the questions you've rightly asked me, I would say that would be a crucial underpinning for our resilience in any future pandemic*' **[29/149/16-23]**. Lessons learned in this Module need to be considered in the context of the wider health and social care structures in order to effect real change and make holistic improvements.

90. And throughout all of this – in the planning for a future pandemic, and in the delivery of healthcare today – there must be adequate provision for the patient voice to be heard. As Julia Jones said in her evidence, "*the patient voice should have been there in the drafting of guidance, but I also think if you look within hospital trusts, for instance, they have patient experience departments and I ask myself: were those patient experience departments well used during the pandemic? And I think, as with so many things, the answer will be in some cases yes, but in other cases no* …" **[21/11/12 - 21/12/10]**. In her evidence to the Inquiry Anna-Louise Marsh-Rees said "*one of the biggest things…for a recommendation, is the lack of a patient voice for the patients themselves and the liaison with the families*" **[39/12/1 - 39/13/16]**. Clearer structures

for consultation with patients, for their feedback and for communication with them, would make a significant difference going forwards.

IV. SUGGESTED RECOMMENDATIONS

91. The CPs specifically ask the Inquiry to recommend four things.

92. First, a new legislative right to a care supporter, such as a relative or friend, for all patients who would like this across all health and care settings. That is something specifically supported by over 90 organisations including Mencap, Age UK and Bliss. The implementation of this right across healthcare settings must include consultation with relevant stakeholders (including patients and their representatives) and must make clear the avenues available for enforcement, challenge and redress where the right is not respected.

93. This recommendation is urgent and should be addressed alongside considerations around suitable infection prevention and control measures. It cannot wait until the intended publication date of the Module 3 final report in Spring 2026, and we invite the Chair to make it on an interim basis as soon as possible.

94. Second, the establishment of proper systems of consultation with patients, their family carers representatives and loved ones, including representative patient groups and organisations, when steps are being proposed that will have a direct impact on their well-being. Such input should not be just sought, it should be acted upon. Some call it a duty to listen.

95. Third, the establishment of better complaints and feedback processes for patients and their family carers and loved ones. They need a clear point of contact in every institution, large or small, to help with the enforcement of the existing protective obligations, and identify difficulties.

96. Fourth, that training on existing statutory equality and human rights obligations – including how they should inform everyday practice – is given to all healthcare and adjacent professionals, so that it informs and is entrenched in their approach to patients going forwards.

V. CONCLUSION

97. Overall, if the concerns we describe had been heard and these recommendations had been in place in the pandemic, lives might have been saved and our society would not have been left with the same damaging legacy of grief, guilt, and anger that blights too many lives today.

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20 December 2024

LEIGH DAY