IN THE UK COVID-19 PUBLIC INQUIRY

On behalf of NI Covid-19 Bereaved Families for Justice

MODULE 3 OPENING SUBMISSIONS

Introduction

1. NICBFFJ has campaigned to ensure that the voices of the bereaved are heard and considered by this Inquiry. Whilst this is important in every module in which NICBFFJ is a core participant, it has particular importance in this module which considers the impact of Covid on healthcare systems across these islands. In the midst of the volume and breadth of the evidence which the Inquiry is to consider in M3, including statements from politicians, civil servants, healthcare workers, interest groups, experts and NGOs, the reality of the experience of patients and their families, who were entirely reliant on this system in their hour of greatest need, risks becoming lost. The statements before the Inquiry from NICBFFJ demonstrate in a very human and painful way, not only that the healthcare response was inadequate and under resourced, but that in many cases it caused deaths through healthcare acquired infections or caused significant additional distress through fundamental failures in care and communication.

2. We emphasise from the outset that we fully adopt the opening submissions of CBFFJ UK, with whom we continue to work closely. The Inquiry will have noted the striking similarity across the independent accounts provided by NICBFFJ witnesses and those provided on behalf of CBFFJ UK, CBFFJC, SCB as well as from other relevant interest groups. We would urge the Inquiry to ensure that all those accounts are given centrality in the consideration of the issues in Module 3. It is important that any high-level assurances of effective policies or best practice are assessed against the realities of the experiences of those who were at the mercy of our healthcare systems during the pandemic.

3. NICBFFJ has provided evidence of systemic failings in the healthcare response, as experienced by members themselves, and this submission will address important aspects of these accounts below. We will also seek to identify key issues arising from the material provided to the Inquiry which assist in putting those accounts, and the concerns they raise, in context. This may assist in identifying key factors which contributed to the failings identified. Before addressing these however, we feel it essential to reiterate our concern at the level of scrutiny which is to be afforded to NI healthcare in this Module.

Limits of the Inquiry for NI

4. The limited extent to which the Inquiry will hear evidence from and directly related to NI, and therefore limitations on the Inquiry's ability to make meaningful recommendations in relation to healthcare in NI, has been and remains a matter of concern for NICBFFJ. Healthcare is a devolved issue and, as has been repeatedly stressed by and on behalf of NICBFFJ (with support from professional witnesses, including from the DoHNI), the NI healthcare system is in a particularly dire state, even when compared to the failing healthcare systems of England and the other DAs. NICBFFJ consider it not only essential that NI should not be a mere afterthought when it comes to identifying what went wrong, but that, in order to make recommendations for the future, this Inquiry must have a full understanding of how and why, across each of the Health and Social Care Trusts, healthcare in NI performed so poorly during the pandemic. That is a complex task. As is apparent from the statements received from Dr McDonnell and Dr Hagan on behalf of the two NI 'spotlight' hospitals, each Trust faced acute challenges, the responses to which, it appears, did not always align. It will be important for the Inquiry to scrutinise this evidence when it is heard.

5. There were important features of the healthcare system in NI which distinguished its response from its neighbours. Notably NI has a joined up health and social care system, which, on one view, should have left it better placed for joined up decision-making. The Department of Health corporate statement suggests that "*integration provides the opportunity for comprehensive assessment of both health and social care needs and allows the Department to plan services based on Programmes of Care. A single budget has also promoted the coherent development of objectives within a unified strategic planning process, which spans acute and community based care."* When assessing the NI healthcare response, and looking ahead to consideration of the care sector in Module 6, NICBFFJ, the overwhelming experience of NICBFFJ members is that any theoretical advantage in having an integrated system of health and social care is belied by the reality of their experience and the experiences of their loved ones during the pandemic.

6. It is also apparent that the NI healthcare system was the poorest placed of the healthcare systems in these islands to cope with the pandemic in early 2020, and was stretched far beyond its limits by the pandemic. The NI CMO acknowledged that the health and social care system in NI "*had been operating at over 100% of its capacity for some time*" by early 2021 (INQ000421784_0052§54). Other unique factors include the small size of the jurisdiction, which may have limited the expertise available for a response. Features of this include the extent to which the CMO was spread too thinly, the lack of a full time CSA, and

the lack of facilities to treat HCID. The statistics included in the DOH statement of Dr Mooney and Ms McWilliams are a vivid visual reinforcement of this point. Waiting lists for appointments and treatments across orthopaedics, cardiology and CAHMS (and doubtless other medical departments) in March 2020 were already interminable with some targets being missed more routinely than they were met. From that desperate starting point, the post-pandemic statistics demonstrate all too clearly that the consequences of the NI response to the Covid pandemic on the NI healthcare system has been little short of disastrous [INQ000474243, cf Table 6, Table 8, Table 12]

7. Against that background, it is a matter of concern that, in a module lasting 10 weeks, aside from two NICBFFJ witnesses, only five professional or political NI witnesses will give oral evidence to in this Module, their combined evidence spanning less than four days in total. The concern is not based on the proportionality of NI evidence alone; it includes the extent to which this permits in-depth scrutiny of the impact of the pandemic on healthcare system in NI. It is also notable that there are important differences in the extent of evidence obtained from NI actors in contrast to the healthcare response from other jurisdictions, most notably Scotland. It is assumed that the fact of the Scottish standalone Inquiry is one reason that such evidence was more readily available, however that in itself serves to demonstrate the limits of a UK-wide module considering what went wrong in the NI healthcare response, and ensuring that such mistakes are not repeated in the future.

Key Concerns with the Healthcare Response

8. Prof Summers and Dr Suntharalingam, in their expert report on intensive care provided to the Inquiry for this Module, observe "*we coped, but only just. We coped, but only at the expense of degrading NHS staffing and capability. We would have failed if the pandemic had doubled for even one more week, or if a higher proportion of the NHS workforce had fallen sick. Through the prism of critical care, it is crucial to understand how very close we came to a catastrophic failure to the healthcare system.*" (INQ000474255_0009)

9. It will be for this module to consider whether that assessment holds true, not only of critical care but of the wider healthcare system. For too many families in the UK, including the NICBFFJ, it was all too apparent that, across all areas, the healthcare system was not coping nor nearly coping. Notwithstanding the work and dedication of many of those working in healthcare throughout the pandemic, in particular the many frontline professionals who personally risked their lives to care for others, the outcome for far too many families was indeed catastrophic.

10. Moreover, the benchmark of success in a healthcare response to a pandemic should never be limited to whether critical care narrowly avoided suffering catastrophic failure through being overwhelmed. It should also be judged against a basic standard that it should "do no harm". For many of those we represent, aspects of the healthcare response did in fact cause harm, whether it be through losing their relatives to avoidable nosocomial infection, or unjustifiable decisions in relation to end-of-life care, or cruel levels of isolation which contributed to mental and physical deterioration of their loved ones causing lasting guilt, or failures in communication which have resulted in continued trauma. In order to understand and address the reasons for some of these consequences, the Inquiry must consider the role of scientific misconceptions which appear to have played a significant role in guiding the healthcare response from the outset.

Errors Underpinning the Healthcare Response

11. Some of the evidence which the Inquiry is to consider suggests that key mistaken beliefs informed and influenced the healthcare response from the outset, despite the fact that appropriate experts at the time knew that these beliefs were flawed. Expert witness Prof Clive Beggs identifies that "*the misconceptions held by the medical community*" on the definition of droplets and aerosols "*had far-reaching impact on the preparedness of the UK and the world*" for the Covid-19 pandemic. He describes how an incorrect 5 microgram threshold applied to the definition of droplets "*became ingrained into the medical literature*", and was adopted by the *medical* community. In contrast, scientists from different fields knew that such a threshold "*was not consistent with the physics of droplets and aerosols*" because they knew that particles which the medical community defined as "droplets" could remain airborne for longer times and across greater distances, depending on the strength of exhalation/talking/singing and even on air currents in a room. He identifies that "*from an aerodynamic standpoint, the 5 microgram droplet threshold stated above is completely nonsensical*." (INQ000474276_0046-0047§§118-119). This lead to two erroneous premises which had significant consequences for IPC Guidance, namely that the vast majority of the viral load from an infected person was contained in "droplets" which were considered to be any particle greater than 5 micrograms, and that these droplets could not travel further that 2 metres (see Beggs, INQ000474276_0105§300). The risk of infection from these mistakenly defined "droplets" (as well as from contact), was then erroneously prioritised. Prof Beggs observes that "*the overwhelming physical science evidence strongly suggests that the inhalation of infectious aerosol particles is likely the dominant route by which SARS-CoV-2 transmission occurs.*" INQ000474276_0009§18

12. That a misplaced focus was placed on droplets/contact at the expense of transmission due to aerosolised particles remaining in the air following exhalation is not merely the view of Prof Beggs. It is apparent from a range of documents (including the IPC's Guidance published 27 March 2020 (INQ000251675_008§1)) which continued to focus on droplets notwithstanding that evidence already suggested that the theory underpinning the approach to droplets was based on flawed scientific analysis. Moreover, that focus on droplets continued after evidence that the virus was "airborne", suggesting that the risk of infection stemmed not only from "droplets" but aerosolised particles, was accepted by the UKCMO (INQ000130504_0003§4).

13. The significance and reach of these errors is demonstrated by the fact that, for years, they continued to result in misplaced emphasis on transmission through "droplets" and "contact", and limited mentioning any risk from aerosols to circumstances where aerosol generating procedures where undertaken, rather than from exhalation by infectious individuals. By way of example, the "Infection Prevention and Control Measures for SARS-CoV-2 COVID-19) in Health and Care Settings", which was amended for use in NI in May 2022 (notably only one month before this Inquiry was established), continued to place the greatest emphasis on these risks and stated "*at a minimum, contact and droplet precautions should be applied when caring for patients with known or suspected COVID-19. In specific circumstances airborne precautions should also be applied, for example, when performing AGPs, and in high risk settings or where an unacceptable risk of transmission remains following the application of the hierarchy of controls and dynamic risk assessment, it may be necessary to consider airborne precautions for patient care in specific circumstances.*" ((INQ000408137_0006§2). Notably absent from these minimum requirements is any acknowledgement of the importance of aerosolised particles as the "dominant route" in transmitting the virus, and the need to consider appropriate counter measures in response. The focus on droplet and contact transmission in May 2022 when considering minimum standards suggests a long term failure to acknowledge the significance of airborne transmission. This is no doubt why the expert report of Drs Shin, Gould and Warne provided to the Inquiry to address Infection Prevention and Control emphasised in their recommendations:
"*13.14 Guidelines must be up-to-date and reflect the most recent evidence. At present transmission-based precautions still distinguish between droplet and airborne routes of spread.*" (INQ000474282_137)

14. An obvious problem with flawed guidelines is that where people lack faith in them they risk not being followed. As the IPC expert report notes:

"Guidelines are unlikely to be put in place effectively unless the health professionals who will be obliged to use them know about them and have faith in the information they contain (in WHO parlance, the guideline must provide a 'convincing narrative' to 'meet the hearts and minds of users'). Health professionals must believe in the processes used to generate the evidence. Throughout the pandemic, doctors, nurses and other groups consulted their own professional bodies because they were anxious and confused about the guidance and did not perceive it to be trustworthy. Lack of compliance and improvisation were reported in relation to the use of PPE and RPE. During the pandemic some professional organisations resorted to publishing their own guidance." (INQ000474282_136§13.13)

15. Whilst that note of caution focuses on decision-making by healthcare professionals, the logic underpinning it would also appear to apply to healthcare users and their families who were confused about such guidance or procedures and did not perceive it to be trustworthy. This is an important consideration, particularly where those restrictions lead to the isolation of their loved ones, a feature we will return to below.

16. These IPC errors in the healthcare response are significant for a number of reasons. Firstly, they were recognised as errors by key experts early in the pandemic. This suggests that the healthcare response itself, and those healthcare facilities that the population relied on for care and treatment, were not responding to the virus in the most effective manner to prevent transmission. Put another way, they were not in fact "following the science".

17. Secondly, they were significant because understanding how the virus was most commonly transmitted was necessary in order to identify the most appropriate way to prevent transmission of the virus. This was significant in both identifying the most appropriate PPE in healthcare settings, as well as for identifying other mechanisms which were significant in lowering risk of transmission in healthcare settings, including, in particular, ventilation and air-filtering. As Dr Jones of CATA notes, adherence to the pandemic flu 2011 strategy, as opposed to the guidance identified for a SARS coronavirus pandemic, "*necessarily resulted in the wrong and inappropriate controls of infection in settings where healthcare was provided.*" (INQ000273913_0025§81). Notably, a Rapid Review conducted by Imperial College Hospital in 2020 (entitled "Triaging of respiratory protective equipment on the assumed risk of SARS-CoV-2 aerosol exposure in patient-facing healthcare workers delivering secondary care: a rapid review") reached similar conclusions:
"*RPE guidance is increasingly stock driven. If RPE must be triaged due to unavailability of stock, FRSM wearing HCWs may be exposed to aerosolised SARS-CoV-2. …*

HMG PPE guidance is based on preparedness for an influenza pandemic. … HMG's PPE guidelines are underpinned by the assumption of droplet transmission of SARS-CoV-2. …"" (INQ000300561_8-9).

18. Effectively, failing to "follow the science" ensured that there was a failure to act effectively to "protect the NHS".

19. The mistake was also significant because it was permitted to continue long after experts in these fields had identified it as erroneous. The evidence demonstrates that it continued to affect the approach to IPC measures even approaching summer 2022 and beyond. This raises a significant issue which the Inquiry must grapple with if it is to ensure that similar mistakes are not repeated in future. While may be understandable that mistakes can be made when first responding to a new virus in a pandemic, when the knowledge and expertise exists to remedy those mistakes, why is it they are permitted to continue to influence the healthcare response for so long? As Dr Jones reasonably queries "*why [were] the constitutional and legal mechanisms designed to ensure that science informs public and employer decision-making … consistently ignored.*" INQ000273913§101

20. It should never be overlooked that individuals were being asked to accept extreme measures based on the assertion that the Government, following their advisers, knew best. Where the IPC measures imposed do not effectively address the risk, at best such measures will necessarily appear irrational, which undermines faith in the state's approach. At worst, it will result in the imposition of punitive measures which cause acute distress in circumstances where they do not provide any or adequate benefit in limiting or preventing risks from transmission. One of the primary concerns of those we represent is that these errors simultaneously resulted in unnecessary levels of infection and death due to nosocomial infection while imposing harsh and punishing isolation on loved ones in their final days and weeks.

21. A tragic example of this in practice is found in the experience of Catherine Todd who, together with her partner, was required to dress in full PPE to hold and say goodbye to her dying newborn Ziggy. She and her partner had tested positive for Covid, and were alone in the room with Ziggy to say goodbye in his final moments (INQ000494257). It is not at all clear why it was considered necessary for them to be dressed in full PPE, particularly as this occurred in summer 2021. Tragically they will forever be reminded of the distress this caused, due to the fact that they were required to remain in such PPE for the only photos they have of themselves with Ziggy.

Hospital Acquired Infection/Nosocomial Infection

22. Long before any updates appeared in Guidance, or before the expert opinion of Prof Beggs or others became known publicly, bereaved families were raising the alarm about the rates of hospital acquired Covid infections.

23. The NI CMO notes "*Analysis of Covid-19 outbreaks … presented to SAGE in January 2021 … reinforced the initial fundamental principles that transmission risks were highest in poorly ventilated and crowded settings, where mixing of people was for extended periods of time and where population turnover was high.*" INQ000421784§69 Whilst the CMO went on to discuss the risks in industries such as food-processing, it is striking that the description of poorly ventilated and crowded settings could also be applied to areas within healthcare facilities, including busy wards or waiting rooms. The Inquiry will wish to consider whether the consequences of design deficiencies, and the significance of environmental health factors in reducing transmission of the virus, was adequately appreciated. Was a failure to appreciate the significance of environmental health factors in reducing transmission of the virus or was there institutional inertia to make necessary adaptions? Certainly, the UK CMO's technical report felt it necessary to make clear that *"the design of buildings and other infrastructure … also impacted trusts' and clinicians' ability to implement IPC guidance and to optimise mitigations..."*(INQ000177534_0365§1)

24. In this regard, the Inquiry may wish to consider whether the functional absence of the NI Chief Environmental Health Officer from his role during this period may have caused detriment to the healthcare response (INQ000421784_0114§177).

25. It appears to be accepted in some of the statements on the part of the DoH that nosocomial infection was a significant issue and therefore a valid concern. However, at other points, it appears to be suggested that such concerns on the part of members of the public were ill-founded. By way of example, the NI CMO suggested that decisions to delay seeking healthcare for non-covid related reasons may have been due to stay at home messaging: "*As the response to the pandemic became extended beyond the first wave there were growing concerns from health professionals and professional organisations that people were avoiding seeking health care when it was in fact appropriate and necessary to seek health care…It is difficult to ascertain what impact the public messaging to "stay at home" (or similar messaging) may have had on patients who were in need of treatment, but who delayed seeking care.*" INQ000421784_0114§193). Later in the same statement there is a reference to the "*perceived risk of being in hospital.*" (§217)

26. One concern about the phrasing of these passages, which was no doubt inadvertent, is the implication that this risk was simply one that was perceived, rather than one which was entirely valid and supported by evidence. The lived experience of many NICBFFJ members, backed up by statistical evidence, suggests that the risk of being in hospital for non-COVID related reasons during the pandemic was in fact a risk to life, with the factual reality for many being that this resulted in the death of their loved ones.

27. The statement of Fidelma Mallon describing the loss of her beloved husband Mickey to a nosocomial infection (in the same hospital where a close relative had recently passed away as a result of a similar infection), demonstrates this starkly. They were of course not alone. Martina Ferguson's statement identifies a sample of the large number of NICBFFJ members whose families have similar suffered bereavement, and sometimes multiple bereavements, due to hospital acquired nosocomial infection during the pandemic.

28. These accounts are not anecdotal. The SAI report on the nosocomial COVID-19 outbreaks in two hospitals within the Southern Health and Social Care Trust, states: "*it was estimated that 10-20% of patients admitted to the hospital for non-COVID-19 conditions, acquired COVID-19 during their hospital stay*" and that "*up to one in six SARS-CoV-2 infections among hospitalised patients with COVID-19 in England during the first six months of the pandemic could be attributed to nosocomial infection*" (INQ000417468_0033§5). While the report seeks to emphasise that this amounts to less than 1% of the Covid cases during that period, that is not a reassuring statistic – to the contrary it merely serves to demonstrate that there was a greater risk associated with nosocomial infection than from community transmission. As the SAI report observed: "*the impact of nosocomial infections in terms of morbidity and mortality is greater in hospitalised patients due to advanced age, frailty, and presence of co-morbidities.*" (INQ000417468_0034§1)

29. It is also important to note the reliance on statistics from England to inform a report on the Southern HSC. Once again, there was insufficient data to reach informed conclusions about the extent to which this was a feature of NI hospital admissions, notwithstanding the NI PHA's dashboard which included records of nosocomial infections.

30. The Inquiry should consider whether there was a failure to address the real risk of nosocomial infection for those who were required to attend hospital, and whether this should have led to greater efforts to provide treatment at home where possible. Again, this is not a hypothetical concern. A number of NICBFFJ's members continue to believe that

the loss of their loved one was entirely unnecessary, not only because they had protected their relative only to find that they contracted COVID after they were entrusted to the care of the health service, but also because they believe that a hospital admission may not have been necessary, and could have been avoided, particularly had they been aware of the degree of risk. For example, Agnes Hollyoake's mother was admitted to hospital to receive antibiotics in circumstances where her neighbouring Trust would have provided the same treatment in the community. As a result of her hospital admission she contracted Covid and passed away a few days later (INQ000360941_0011§53). In her statement, Fidelma Mallon describes how her family, and particularly her daughter, blame themselves for her husband's death after he contracted Covid following his hospital admission, for failing to insist that he be provided with antibiotics at home. (INQ000494735§§10, 55)

31. It is also important to note that statistics are limited in the extent that they can provide a true picture of what the consequences for real people were of such failings. Martina Ferguson's statement highlights the case of NICBFFJ member Helen Coyle, whose father George Grattan was admitted to hospital for non-Covid reasons. After his discharge he was not tested for Covid, resulting in his returning home ill. He was re-admitted to hospital a week later, this time as a result of the Covid which it seems he had acquired in hospital during his initial treatment. Helen's mother, Mary Pamela Grattan, then herself tested positive shortly following his re-admission, apparently having been infected by her husband following his initial discharge. The couple tragically passed away within days of each other. (INQ000360941_0007§30) Mary's death, and possibly even George's death, may not have featured in statistics on nosocomial COVID-19 infection/mortality, but they were most certainly victims of a failure in the healthcare response.

Lack of PPE

32. A further concern about the flawed focus on droplets/contact/fomites is the link with deficiencies in the provision of PPE. There is evidence before this Inquiry that the lack of available or adequate PPE to combat the risk of build-up of exhaled infectious aerosols influenced or perhaps even underpinned the guidance which continued to recommend levels of PPE more appropriate to address the risks from droplet/fomite transmission. That evidence calls for careful public consideration.

33. Moreover, in addition to concerns that the IPC guidance continued to recommend PPE after it was known to be inadequate, a repeated concern of NICBFFJ members relates to inadequate provision of PPE, or inadequate use of the PPE that was provided. Martina Ferguson highlights the account of Hazel Gray, who describes paramedics staffing the

ambulance which collected her father wearing only "ordinary" masks rather than adequate PPE. She was informed by them that if they all wore the PPE they would have nobody to do anything. (INQ000360941§58) Lindsey McWilliams described how her husband underwent a liver transplant in September 2021, and while recovering in a Belfast hospital described staff wearing masks around their chins, or putting them on after leaving the ward. He contract Covid and passed away in October 2021 (INQ000360941§27)

34. Issues in relation to PPE are of course being raised before the Inquiry by those concerned about the health and lives of healthcare workers, however it is also self-evidently an issue for all in the healthcare system. Any increase in infection among HCWs increased the risk to their patients, and undermined healthcare capacity.

Failures of Communication

35. The experience of NICBFFJ members is that there were significant, systemic failures in communicating with loved ones of those who were in hospital. These failures in communication spanned a variety of issues but inevitably caused significant distress. At the forefront is the widespread poor communication about decisions in relation to end of life care including the use, or misuse, of DNACPR notices.

36. NICBFFJ member Rhonda Tait has never been provided with a satisfactory answer to her queries about why a DNR notice had been placed on her mother's medical notes once she was in an ambulance. Jacqueline Harron recounts a disturbing conversation with a doctor who insisted on imposing a DNR despite Jacqueline making clear her objections, stating that she would not like to "*smash her sternum.*" (INQ000360941_0010§53). These and other distressing accounts from NICBFFJ members are strengthened by other sources, including the joint statement issued by the Commissioner for Older People, together with similar entities from England Scotland and Wales, criticising the pressuring of older people into decisions about end of life care, as well as apparent blanket decisions having been made about care and treatment options for older and vulnerable people (INQ000417337_0008-0009).

37. It is notable that such concerns were investigated by the regulator for health and social care in England, the CQC, who produced an interim report in 2020 and a subsequent final report reviewing the use of DNACPR decisions during the Covid-19 pandemic (INQ000235491; INQ000235492). That interim report described accounts of apparently blanket DNACPR decisions, "*where DNACPR orders were placed on numerous people routinely.*" (INQ000235491_0007) There were additional issues of communication and

consent, including examples of patients or their families not finding out until they were quite unwell that a DNACPR order had been placed on them, or cases where medical staff asserted that consent had been provided in circumstances which suggested that this was not or could not have been informed consent (INQ000235491_0007§1-3). These accounts resonate strongly with the experience of many NICBFFJ members.

38. The CQC's Final Report stated "*we did not find there had been a national blanket approach to DNACPR, there was undoubtedly confusion at the outset of the pandemic and a sense that some providers felt under pressure to ensure DNACPR decisions were in place.*" (INQ000235492_0041§2) This would appear to be consistent with the views of COPNI on these issues: "*so far as I am aware, these policies did not originate from one particular organisation but rather were the result of clinical decision-making or local behaviour and actions at the relevant time.*" (INQ000472298_0048§145) However the COPNI's view was not based on any comprehensive investigation of the use of DNACPRs in NI, as there does not appear to have been any equivalent to the CQC report. It is notable that the effective equivalent to the CQC in NI, RQIA, was effectively stood down for a period early in the pandemic. NICBFFJ strongly encourages the Inquiry to establish the extent to which there were widespread decisions to routinely impose DNACPR orders on individuals. They also encourage consideration of the extent to which the failure to engage patients and where possible or necessary, their families, over such decisions, was so systemic that it forces the inevitable conclusion that this was deliberate.

39. Similar systemic concerns have been raised about other decisions on end of life care, including concerns at apparent following of the discredited Liverpool Pathway, as well as the use of the "syringe driver" or particular drugs to effectively hasten death. Again, concerns relate to both communication about such issues as well as the practices adopted. It was only after Christine Tumlinson's father passed away that she discovered he had been administered midazolam. She believes that this hastened his death and that there was no good reason to administer this drug. NICBFFJ strongly encourages the Inquiry to consider whether there were blanket decisions, or a widespread practice, of the inappropriate use of this and similar drugs for vulnerable and older people who were hospitalised having contracting COVID.

40. Many of the accounts which describe failures in healthcare communication reveal a shocking lack of compassion. The Inquiry has received Fidelma Mallon's statement, in which she describes receiving a call from the hospital on 24 February 2021 to inform her that a syringe driver had been inserted for her husband Michael two hours previously, and

that he would shortly be dead (INQ000494735_0011§47). In response to a complaint in relation to this (among a variety of other significant concerns about Michael's treatment and ultimate death) her family were advised that Michael had consented to this the previous evening. This was stated without acknowledging that Michael had at that stage become confused, or explaining how this could be properly regarded as appropriately obtained informed consent in the circumstances (INQ000494735_0011§48).

41. What is striking about these and similar accounts from many more from NICBFFJ members, as well as the bereaved from England, Scotland and Wales, is that the concerns focus not just on the DNR decisions themselves or the decisions about the administration of certain drugs but they include clear and systemic failings in communication to family members about these life-shortening decisions.

42. We would urge the Inquiry to consider these failures in communication as no less significant than the substantive decisions themselves given the lasting damage that they have caused. There do not appear to be any policies in place which suggest that such decisions should be concealed from family members. Rather there is repeated emphasis on engaging with patients and their families, particularly where patients themselves lack capacity, whether permanently or temporarily. The Inquiry should consider whether culture or staffing pressures, or both, were factors in such apparently systemic behaviour.

43. Moreover, in considering issues in relation to end of life care, it is notable that there is some evidence that steps were taken in NI to at least prepare for scenarios whereby individuals would be denied treatment which they would normally have benefitted from had it not been for the pandemic. By way of example, a Military Assessment Team was commissioned to advise the NI Department of Health on planning for a Regional Surge. Their assessment included a number of recommendations, including:
"Recommendation 13: "*To engage with Regional Ethical Committee regarding the following issues.*
-What do we do at the point when we have reached surge capacity …
What authority would be given to negatively triage (actively looking to disengage in critical care interventions in patients making poor or no progress and expected to consume resources despite predictable poor outcome)?
Should critical care teams spread themselves further and further at the risk of falling all their patients or should they draw a line in the sand in their capacity.
Is there any point at which we prioritise certain clinical diagnoses (not specifically Covid) for ICU in the expectation of achieving better outcomes for more people?

-Whose responsibility is it when we ultimately cannot provide correct skill sets, correct treatment regimes, adequate setting (e.g. HDU on wards) and timely patient transfers? There is a need to protect individual from carrying this burden.

DOH response:

Agreed, discussions on some of these issues have already taken place and will continue."" (INQ000276389_0011-0012)

44. The outcome of those discussions is not apparent to NICBFFJ from the disclosure we have considered thus far. In fact, it is not clear at this stage what discussions are being referred to in the DOH response. It is however notable that this issue was touched upon in the Covid-19 HSC Clinical Ethics Forum established by the DOH, which published a COVID-19 Ethical Advice and Support Framework in June 2020. This stated:
"*in the context of finite critical care resources, there is a possibility that some patients who would normally benefit from critical care may not be able to avail of it due to unusually high demand therefore agreed principles around decision-making processes, and agreed clinical criteria are needed to ensure a consistent approach.*" ((INQ000381325_0007§1). The advice was revised and updated in September 2020, though this paragraph remained unchanged (INQ000353597_0007§1).

45. The dates of all of these documents are relevant. The DHSC in England had convened a working group to "*consider and develop a clinical care prioritisation model to be used in the event of saturation of NHS resources*" on 21 March 2020, but was informed on 28 March by the DHSC and CMO that this was no longer considered necessary and that no prioritisation guidance would be issued. (INQ000474255_0046§§109-114) This pre-dates the above cited documents by a number of months, suggesting that such work continued to be contemplated by the healthcare authorities in NI long after it had been abandoned in England.

46. Many members of NICBFFJ have made clear that in their own experiences, their relatives were "given up on" and simply abandoned to their fate. In addressing whether this was the case, in their expert report for the Inquiry, Prof Summers and Dr Suntharalingam identify that it is important to consider not only what the general policy is, but also to acknowledge what occurred in practice. In relation to that latter issue the authors state:
"*critical care staff, including senior decision-makers, were working outside their usual patterns while overseeing teams of redeployed non-critical care specialist staff working in entirely new ways in the midst of rapidly changing clinical practice and understanding of the disease and constant fluctuations in equipment, oxygen, medicines, and protective*

equipment availability. … Under these circumstances, variations in decision-making, conscious or subconscious application of clinical thresholds are likely to have occurred through the sheer complexity of circumstances." (INQ0004742655_0051§123)

47. The Inquiry will note that this assumption accords with the experience of many of the bereaved. The report goes on to emphasise the importance of transparency, and therefore communication, in and around such decision-making. This again touches on a repeated theme for NICBFFJ members – the concern is not only the decision, but includes the feeling that they were dismissed, ignored or treated as afterthoughts, with the truth hidden from them rather than openly explained.

Isolation and Visiting

48. Finally, it is necessary to emphasise the continued distress that restrictions on visiting caused to many members of NICBFFJ, who were prevented from having meaningful contact with their loved ones in their final weeks and days beyond, when permitted, an end of life visit. It is important to emphasise that this concern relates not only to the distress caused by the difficulties in communicating with and comforting their loved one at these times, and the confusion this caused to many elderly and vulnerable patients, but in many cases is interlinked with concerns that the lack of visits meant that inadequate care was provided to those who were too vulnerable to speak up for themselves. The concerns raised by Fidelma Mallon at the treatment of her husband demonstrate this all too clearly. Similar concerns were raised by Claire Bloomfield, whose father told her by telephone from hospital that no one had come near him for 11 hours. After his condition had deteriorated, when she fought to have a visit, she was told that such permission would be conditional upon her consent to switch off his life support machine. She agreed, and describes being "haunted" by this decision ever since (INQ000360941§60).

49. Again the concerns surround not only the decisions, but the widespread communication failings in relation to whether such visits were permissible. Significantly the DoH developed care partner guidance in September 2020 which ought to have lessened the isolation of some of the most vulnerable. However the experience of NICBFFJ members was that this was frequently not implemented and too many of those who should have benefitted from such a policy were not even informed of its existence (INQ000360941§40).

Conclusion

50. In NICBFFJ's corporate statement for this Module of the Inquiry, Martina Ferguson identifies that Exercise Cygnus, and the Cygnus Report were fated to be "Cassandra" for

what was to come. The curse of Cassandra was, of course, that she was fated to give accurate prophecies which were not believed. One feature of the evidence which is to be considered by the Inquiry is that, even at this stage, it is apparent that the information on how best to respond to the pandemic was available, but was not acted on. That suggests that the key test for the success of this inquiry will not necessarily be identifying what went wrong, but identifying how this can be prevented from recurring in the future. The nature of the failings identified above suggest that this will require cultural and systemic change.

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