BEFORE BARONESS HEATHER HALLETT

IN THE MATTER OF: THE PUBLIC INQUIRY TO EXAMINE THE COVID-19 PANDEMIC IN THE UK

OPENING STATEMENT

ON BEHALF OF THE COVID-19 BEREAVED FAMILIES FOR JUSTICE CYMRU

MODULE 3

INTRODUCTION

1. CBFJ Cymru is a group of Welsh bereaved families who came together to campaign for truth, justice, and accountability for all those bereaved by Covid-19 in Wales, following the devastating loss of their loved ones in the most traumatic of circumstances.
2. It is of fundamental importance that the voices of the bereaved continue to be heard in this Inquiry. It was painfully evident in previous modules that those in power are far removed from reality of the lives of the people they purport to serve. The Inquiry concluded in Module 1 in respect of Wales that *"For an administration that prided itself on its efficiency of movement because of its relative lack of scale, and which had described itself as operating, effectively, "under one roof", the reality did not match the rhetoric. The system was labyrinthine.....An opportunity to create a coherent and, therefore, dynamic system in Wales had been hampered by undue complexity."*
3. Decisions made and the impact of the pandemic on healthcare systems, must be understood through the lived experiences of the bereaved. It was the bereaved who saw first-hand the failures and deficiencies in the preparation for and response to the pandemic. It was the bereaved who witnessed day after day the individual and systematic failures in response and the catastrophic failure to adequately protect their loved ones as Covid-19 rapidly spread through hospitals and care homes in the context of inadequate infection control.
4. Powerful testimony has been received from the bereaved to date and CBFJ Cymru is encouraged that will continue in Module 3. This opening statement highlights some of the experiences and concerns of the Welsh bereaved to frame the central questions on healthcare that this Inquiry must address in this Module.
5. CBFJ Cymru has previously highlighted that the evidence has revealed a passive, slow and disjointed response to the Covid-19 pandemic by the Welsh Government. In Wales, Sir Frank Atherton had warned the First Minister by 24 January 2020 that "*there was a significant risk the virus would arrive in Wales*" (INQ000371209, p.23). The UK Government and Devolved Administrations should have been electrified into action from the end of January / start of February 2020 onwards.

6. The result of the failures by the Welsh Government to respond to the nature and extent of the risk posed by Covid-19 led to devastating consequences. The response to the pandemic should have been driven towards the protection of life and the prevention of death. The Welsh Government was, and remains, under a positive obligation under the Human Rights Act 1998 to safeguard the lives of the Welsh people from the imminent risk of death. This obligation was not displaced by the global crisis and scale of the death toll. Robust healthcare should have been at the heart of a clear and cogent system to prevent infection and death; hospital should have been the safest place for individuals to turn to during this time. Instead, the experiences of CBFJ Cymru members were of mass chaos, with individuals left questioning who they could trust to look after those whose lives were at risk.

7. The Inquiry will hear in this Module of poor preparedness and systems, that the Welsh Government was slow to respond to known science in particular on asymptomatic and airborne transmission, that implementation of available IPC on the ground in Wales was chaotic and dissemination of guidance was without leadership. There were major gaps in protection and safety in hospital leading to mass outbreaks on wards without the possibility of segregation or testing, so that nosocomial infection rates soared in Wales. A key focus was on the lack of appropriate PPE, a failure to recognise symptoms of Covid-19, delayed testing and frequent movement of cohorts of patients around hospitals. Access to GPs was limited. Dignity of patients in death was ignored and bereavement support was absent. Mindful of the absence of a Welsh specific inquiry into pandemic responses, the Inquiry is urged to take particular note of the experiences on the ground in Wales, and the impact of specific characteristics of demography and governance.

THE VOICES OF BEREAVED FAMILIES IN WALES

8. On behalf of CBFJ Cymru in this module the Inquiry will hear and consider evidence from Anna-Louise Marsh-Rees, Sam Smith-Higgins and Paul Jones. Anna-Louise Marsh Rees, a co-leader of CBFJ Cymru, will speak to the concerns identified by over 350 bereaved individuals in the group, as well as her own experience of losing her father to hospital acquired Covid-19. Sam Smith-Higgins, a co-leader of CBFJ Cymru, will give evidence of the loss of her father to Covid-19 following his cancer diagnosis and subsequent admission to hospital and also the experiences of her mother, who had two strokes during the pandemic. The story is one of conflicting information, sub-standard care, and repeated re-traumatisation. Paul Jones, a Response Sergeant with South Wales Police, will speak about his family's experiences which led to the tragic loss of his daughter Lauren, who was only 25 years old when she died in December 2020 of Covid-19. Lauren had been admitted to hospital only a few days before her death after a period of feeling unwell and coughing. During her time in hospital, Lauren deteriorated unexpectedly and required ventilation. Her family were told that she required transfer to London for Extracorporeal Membrane Oxygenation treatment but were subsequently informed that she was not a candidate for transfer. Later that day, Paul and his wife had to make the difficult decision to switch Lauren's ventilator off. His experience

with the healthcare system in Wales was one of confusion and poor communication; it was "*truly disastrous*".

Operational Preparedness, Resilience of the Healthcare Sector in Wales

NHS Estate

9. Professor Beggs highlights, inter alia, that UK wide, the *NHS was not adequately prepared for a pandemic of airborne viral disease* and *did not have the necessary ventilation infrastructure in place to adequately mitigate transmission of SARS-CoV-2 on general and acute wards.*
10. In Wales, notwithstanding that the Welsh Government had long been aware of deficiencies in the NHS Wales Estate and the impact these deficiencies had on implementing effective IPC measures, it appears that little to nothing was done to rectify them. It was therefore unsurprising that when the pandemic struck, difficulties surrounding the implementation of IPC procedures came in to sharp focus. It was recognised by Welsh Government that these issues were pronounced in Wales due to factors such as limited individual isolation rooms and ventilation arrangements in older hospitals and geographical spread of facilities in less densely populated areas (INQ000385689).
11. The End of Programme Learning Report of the National Nosocomial Covid-19 Programme published August 2024 concludes that ageing estates across health boards in Wales presented a number of challenges in relation to the Infection Prevention and Control during the Covid-19 pandemic noting: "*Many healthcare settings have limited access to single rooms which means there is less opportunity to isolate patients. As a result, many patients were cohorted to reduce the spread of infection, which often meant patients experienced multiple ward movements. Bed-spacing and ventilation were also a challenge in some areas which limited the ability to manage the risk of infection. There is room for improvement in the design of future healthcare settings – the pandemic and subsequent learning has highlighted the impact modern estate design, such as the availability of single rooms, can have on strengthening IP&C.*"
12. CBFJ Cymru highlight that despite the Welsh Government's awareness of the issue, not enough was done to assess and mitigate the risks associated with its NHS Estate prior to or at the outset of the pandemic or crucially thereafter to tailor IPC Guidance accordingly.

Infection Prevention and Control

CBFJ Cymru's Experience

13. A number of CBFJ Cymru's members witnessed first-hand the results of inadequate attention being paid to IPC measures. Had there been proper IPC measures in place, their loved ones would not have acquired Covid-19 in hospital and would not have gone on to die a painful and lonely death, isolated from their loved ones who were unable to say a proper goodbye. One member was unable to say goodbye to their loved one in hospital, even to wave through a window, as their loved one was on the second floor and the hospital would not facilitate video calls. The isolation of the bereaved from their loved ones is made even more

galling due to the lack of isolation of Covid-19 patients, or people suspected to have Covid-19, from other patients in the hospital.

14. Our members witnessed healthcare workers wearing inadequate PPE, or failing to collect new PPE as they entered a different part of the hospital. Sam Smith-Higgins witnessed agency staff moving between wards wearing inadequate PPE. One member, whose 31-year-old daughter died before her family were allowed to see her, noted that none of the healthcare workers they encountered were wearing masks. Nurses and healthcare assistants walked from ward to ward with their face mask on their chins. They also witnessed Covid-19 patients mixed with patients who did not have Covid-19; a total failure to segregate patients in order to address the significant risk of nosocomial transmission. Members also report their loved ones being placed on a ward where there was no Covid-19, but still contracted Covid-19 in hospital. One member had a loved one with dementia who was moved onto a Covid-19 ward due to an error in a test result. Patients were also moved from ward to ward without proper testing. For example, a member, whose mother died at the age of 74, was informed that her mother was placed on a mixed ward with both suspected Covid-19 patients and other patients on the ward, despite taking immunosuppressant medication to treat her ulcerative colitis. Even with the knowledge that her mother's immune system left her vulnerable to infections of all kinds, staff continued to move her from ward-to-ward multiple times before being provided with a room of her own. This total lack of attention to the need to segregate patients – particularly those at high risk due to suppressed immune systems – and follow IPC protocols, resulted in her mother contracting Covid-19 and dying alone, without her family around her to say goodbye.
15. Another member's husband, who died at 81 years of age, was treated in his own room, meaning that the only people entering his room were healthcare staff. Still, he contracted Covid-19 and died alone with his wife not being allowed to see him. She witnessed healthcare workers leave hospital in their scrubs, where they would walk around Tesco before returning to the hospital. She also witnessed a patient moving freely on and off the ward. Though she raised this with a nurse, the issue was never addressed.
16. One member, whose father died at the age of 85, wore an apron, gloves, a mask and plastic goggles to protect not only herself, but to ensure that she could not spread infection. However, none of the healthcare workers she witnessed wore any PPE. She was only permitted to visit her father for fifteen minutes. The only people she saw wearing full hazmat suits were undertakers who were attending another death in hospital.
17. What is noticeable and significant is that our clients experienced these incidents in hospitals across Wales. These were not isolated incidents but a pattern of poor IPC practices which ultimately put their loved ones at unconscionable risk and led to them contracting Covid-19 in the place where they were supposed to receive medical treatment to keep them alive. They also witnessed these poor practices, not only in the first wave, but in the second and third waves, by which time all healthcare workers and health boards should have known about the need to implement IPC Guidance consistently. The bereaved want to know why no lessons were learned between the first and second wave.

IPC Guidance

18. The original version of the IPC Guidance issued in January, was agreed by all four nations and adopted by Wales, as were the subsequent amendments to the Guidance (unlike for non-pharmaceutical interventions). At that stage, Covid-19 was classified as an airborne HCID, requiring patients to be treated in specialist HCID units, of which Wales had none.
19. However, the Guidance suffers from the same inadequacies that Welsh Government policy exhibited, which was a lack of appreciation of the potential for asymptomatic, pre-symptomatic or pauci-symptomatic transmission, and the potential at that early stage for transmission to be by all routes, including by aerosol transmission.
20. In the Guidance dated 19 February 2020 (INQ000348304), there is only one reference to the risk of asymptomatic transmission in the context of visitors. As a result of this omission, this Guidance only provides for healthcare workers to wear FFP3 respirators when caring for patients with *suspected* Covid-19. Further, there was undoubted, over-reliance on the description of Covid-19 as being transmissible by droplets only despite early knowledge of aerosol transmission. Given what was known and taking a precautionary approach, more care could and should have been taken to emphasise the risk of aerosol transmission.
21. The 6 March 2020 Guidance removes the need for healthcare workers treating suspected patients to wear FFP3 masks and introduces for the first time the requirement for healthcare workers to wear FFP3 masks only when AGPs were taking place. This was based on shaky science which did not properly identify the risk of aerosol transmission from non-AGP procedures such as coughing, sneezing, breathing, and talking. CBFJ Cymru take a firm view that the Guidance is not a true reflection of the scientific picture. Instead, the Guidance was being led by, inter alia, the availability of FFP3 respirators, due to the decline in the national stockpile and lack of pandemic preparedness.
22. The consequences of this were fatal. Nosocomial transmission of Covid-19 was widespread in hospitals across Wales (INQ000227307), meaning that people who were not infected by Covid-19 went into hospital looking for treatment to make them better, and in the cases of our clients' loved ones, never left hospital to rejoin their loved ones. It is the firm view of CBFJ Cymru that many of these deaths could have been prevented by the Welsh Government.

Implementation of IPC Guidance

23. The disclosure received in this module demonstrates systemic and widespread failures to properly implement the four nations IPC Guidance. By July 2020, the Senedd identified that there was poor PPE provision for healthcare workers in the first wave (INQ000349686) but these lessons were not learned in time for the second wave. Even after the initial acute period of needing to distribute high volumes of PPE in a short timescale had passed, frontline staff continued to worry about the ongoing supply. It was known by Welsh Ministers that properly used PPE limits transmission between staff and patients but that

transmission was still occurring between patients and staff (INQ000396261). Transmission between staff was also observed due to a lack of social distancing in non-clinical areas.

24. Further, the evidence from spotlight hospitals confirms that IPC Guidance was not being followed to the letter. National guidance was followed but at hospital level interpreted more purposively than literally. The planning and implementation of patient streaming, isolation and screening needed to be adapted to the design and nature of the hospital building (INQ000475209). In other words, the IPC Guidance was theoretical only, and merely because that guidance existed, it cannot be taken for granted that IPC measures were being implemented on the ground. In fact, on the basis of what our clients witnessed when they visited loved ones in hospital, it appears that failures of implementation or adherence to the Guidance were widespread.
25. A further difficulty is that for reasons which are not clear, Public Health Wales ("PHW") would announce any changes to the IPC Guidance on a Friday as opposed to a Thursday, which was when Public Health England made their announcement. Staff would become aware of the new guidance through the media before hearing about the changes from PHW. This unexplained divergence from England resulted in unnecessary anxiety for staff and also presented operational difficulties in implementing the Guidance over the weekend. The decision to announce the changes a day later than England also built in further delay to the production of posters, signage, and other communication tools used to disseminate the information to staff.

Dissemination of Updated Guidance to Healthcare Workers

26. In Wales, despite SAGE having identified nosocomial transmission as an issue as early as March 2020, the Nosocomial Transmission Group ("NTG") was not set up until May 2020 in order to understand the evidence regarding nosocomial transmission. However, what is not clear, is how the NTG's findings and understandings were cascaded to the Health Boards and ultimately healthcare workers who needed to understand the risk posed not only to themselves, but to the patients in their care. While CBFJ Cymru have identified the list of guidance materials issued by the NTG, as well as the Four Nations IPC Guidance, it remains unclear whether there was also an ability to disseminate broad, headline findings on the science in bullet point form to the relevant Health Boards and healthcare workers. There is some evidence that this was the responsibility of health board leadership, but the precise format and detail is not clear (INQ000485721). Rather than simply relying on healthcare workers to follow guidance handed down from above, more was needed to inform and educate healthcare workers as to the reason why the measures were necessary to secure compliance.

PPE/RPE

27. The Module 1 Report refers to Exercise Shipshape, which took place in 2003 and tested the healthcare response to a SARS outbreak in Wales and South West England. Recommendations were made, but never

properly implemented in Wales, including the need for appropriate grade PPE, and a PPE stockpile. Recommendations from subsequent exercises were also not implemented. CBFJ Cymru strongly feel that had these recommendations been followed in Wales, the healthcare system would have been better placed for a pandemic.

28. Furthermore, the key principles underlying PPE were undoubtedly understood by employers who were well versed in implementing statutory regulations on personal equipment safety; yet when the pandemic struck, the health and social care sectors failed to apply those well-established principles and scrambled to justify the measures taken, or perhaps more accurately, sought to justify the lack of measures taken.
29. Employers, including health boards and hospital trusts, are under a duty to ensure that suitable personal equipment is provided to workers who **may** be exposed to a risk to their health or safety while at work, except where and to the extent that such risk has been adequately controlled by other effective means. Moreover, regulations make it explicitly clear that PPE ***shall not be suitable unless*** it is appropriate to the risks involved and is capable of fitting the wearer correctly.
30. It was or should therefore have been known at the time that the airborne risk presented by Covid-19 meant that FFP3 masks were the most suitable PPE and that the efficacy of such masks would be compromised unless the wearer had undergone the appropriate fit test.
31. Instead, once again we submit that the guidelines produced and their implementation on the ground in Wales appears to have been adapted to fit with the lack of availability of appropriate PPE as opposed to the protection against the actual risks that were presented. This was a commonly held view of those working in Wales, as illustrated by the Chartered Society of Physiotherapy Health & Safety Rep at Hafan Y Coed Hospital, who reported as much on 28 April 2020 (INQ000339547).
32. Even following the Senedd's report of July 2020, there was a lack of analysis as to the type of PPE that was required, instead deferring to the UK-wide Covid-19 PPE hub (INQ000349686).
33. There are numerous accounts in Wales that healthcare workers were required to share PPE with colleagues, re-use PPE beyond their life-span and/or ration PPE to occasions when the wearer "would really need it", even though it was abundantly clear from an early stage that transmissibility was high in all healthcare settings. There was evidently a failure in providing appropriate RPE (namely FFP3 masks) and the consequence was to increase the nosocomial infection rate and the number of avoidable deaths.

Testing of Healthcare Workers

34. Many of CBFJ Cymru's members experienced issues with the testing of healthcare staff, for example, one states "*My father caught Covid while in hospital. The nursing staff were quite open about the circumstances – the nurses had gone to work thinking they had a cold, when really they had Covid...*".
35. The evidence in Module 2B revealed that the testing was an area where the Welsh Government were consistently behind UK Government, particularly in respect of testing healthcare workers. The Welsh Government's initial position on testing of healthcare workers was confined to testing those who were

symptomatic to allow them to return to work sooner than the 7 / 14-day self-isolation periods (Module 2B INQ00080850).

36. Nosocomial infection was discussed at SAGE on 31 March 2020. TAC was asked for advice (INQ000228309). Dr Chris Williams of Public Health Wales advocated routine testing of healthcare workers, recognising that weekly testing would help encourage healthcare workers to accept testing and promote self-consideration of symptoms. When he gave evidence to the Inquiry, Dr Williams confirmed that symptom-based screening alone was insufficient to reduce the risk.
37. On 28 April 2020, an expansion of Rapid Antigen Testing programme which was at that stage only testing critical NHS staff was announced in England and applied also in Scotland and Northern Ireland. The programme was expanded to include asymptomatic healthcare workers and NHS patients (INQ000162249). However, it was not until 16 May 2020 that the testing regime was expanded in Wales to match that in the rest of the UK.
38. In Module 2B the Inquiry heard that Mr Gething and Mr Drakeford were asked to account for this delay in Wales. It was of great concern to CBFJ Cymru to hear that Mr Gething, on 30 April 2020, in front of the Health, Social Care and Sport Committee, was stating that there was no evidential basis for asymptomatic testing and that he didn't understand the "rationale" behind the UK Government's approach. This wholescale misunderstanding of the ample evidence available at the time was then repeated in a press release on 2 May 2020: "*At present, the evidence does not support blanket testing – it points to testing people who have symptoms and isolating them until the test results come back.*"
39. When lateral flow tests became available in Autumn 2020, it became possible for more routine screening of healthcare workers to take place. Routine testing of healthcare workers in hospitals was only announced by the Welsh Government on 4 December 2020, 6 weeks after its introduction by the UK Government on 16 November 2020. (INQ000227387). Even then it was widely reported by the BBC (INQ000420994 and INQ000420993) that routine testing of healthcare workers without symptoms was not properly rolled out in practice until mid-March in some Welsh hospitals. When asked, Mr Gething was unable to give a reason as to why Wales was so much later than the UK Government in announcing testing (Transcript 11 March 2024, pp.204-205). Professor Kloer states that although the announcement was made for twice-weekly testing of all healthcare workers in December 2020, there were no secure supply lines, or reporting system, in place for the delivery and processing of LFDs. As a result, Hywel Dda University Health Board's Executive Team decided not to introduce general staff screening, but waited to roll out testing until the reporting system was digitalised. The roll out did not commence until 1 February 2021 and did not complete until the end of July 2021.
40. It is crucial for the Inquiry to scrutinise the reasons, and seek accountability for the considerable delays in testing of healthcare workers in Wales.

Testing and Segregation of Patients

41. It is vital the Inquiry questions the application of routine testing and segregation of hospital patients, including those known to be at high risk (and probably advised to shield in the community), together with other IPC measures designed to mitigate the risk of nosocomial infection. CBFJ Cymru's members experienced instances of patients not being tested for Covid-19 on admission to hospital or when being moved between wards / other hospitals and positive cases not being appropriately segregated. One member of CBFJ Cymru has stated "*Since my mother's passing (the Health Board) have informed me, via a Freedom of Information request, that 25 untested patients were transferred from regional acute hospitals to (her) ward between 1 March 2020 and 1 May 2020*". In Wales, it is understood that Outbreak Surveillance reporting was not introduced until November 2020 (INQ000227385, p.2) and a patient testing framework had still not been developed as late as February 2021 (INQ000227307).

Impact of bed capacity on nosocomial infection

42. Upon scrutiny of the evidence it is clear that bed capacity in Wales, including critical care bed capacity, was either inadequate or under-utilised impacting on the health services' ability to treat in-patients safely and effectively. CBFJ Cymru would highlight the lack of use of field hospitals to meet increased demand, despite there being 10 accessible field hospitals in Wales which would, under exceptional circumstances, provide physical access to over 2500 beds (INQ000337304, page 7; INQ000185355, p.2). One of the reasons given throughout previous modules of this Inquiry for the need to discharge patients from hospital into care homes without a negative test is that there was a need to free up beds for the influx of Covid-19 patients. However, as noted, the evidence disclosed suggests that this was wholly misleading. Lack of capacity also led to a failure to implement IPC measures, with bed shortages leading to an inability to achieve adequate isolation for patients with confirmed or suspected Covid-19 and to a failure to space the beds at the required 3.6m between beds (INQ000396261, p.8).
43. The resulting pressure on Health Boards from inadequate critical care capacity during the pandemic is clear from evidence obtained from the Welsh Health Boards (INQ000480136). Research disclosed to the Inquiry suggests that over half of healthcare professionals surveyed reported that some patients could not be escalated to the next level of care due to lack of resources (INQ000499523). This is significant evidence suggestive of a causal link between lack of critical care capacity and a failure to escalate patients to critical care beds in order to receive appropriate care. CBFJ Cymru members provide evidence of patients in Wales whose treatment was not appropriately escalated, and they did not receive the critical care they so desperately needed. The Welsh Government must be asked to account for this.
44. There is a clear line of enquiry that the failure to properly prepare for a pandemic by increasing both critical care capacity and surge capacity in Wales exposed patients in hospital to an unjustifiable risk of catching Covid-19 thereby contributing to the rates of nosocomial infection.

Shielding

45. The Welsh Government was aware of gaps in the protection of those at (high) risk from infection with Covid-19, exacerbated by the four nations shielding programme that it signed up to, and confusion between those 'at risk' or at 'high risk'. It was also aware of the additional distress due to fears about access to treatment and care, isolation during shielding and abuse (INQ000353436, p.2). The Shielding Patients List ("SPL"|) for those deemed to be 'at high risk' gave rise to immediate concerns among the public as to who should be shielding or why they had not received letters (INQ000486014, p.142). For example, the "at risk" group initially included those over 70 who have asthma or a diagnosis of MS. This group was identified as needing to take extra care, but not to be clinically extremely vulnerable (CEV) so as to be on the SPL. The Welsh Government were also aware that any medically based definition would likely exclude those with critical areas of social need from essential services, and this would include older people (INQ000177836 and INQ000400652).
46. Anna-Louise Marsh-Rees will give evidence of a letter from the CMO(W) in October 2020 prior to a short "firebreak" received by her father, who was on the SPL due to being immunosuppressed. Winter was approaching and cases were rising rapidly leading to raised anxiety especially for those who were vulnerable. The CMO(W) wrote in blanket terms to those who were CEV and previously shielding. He stated that shielding was not restarting. To suddenly be told that you no longer need to shield when you are immunosuppressed or otherwise at risk, can leave you feeling isolated and anxious, including that you are not a priority for treatment, or other support (INQ000400652). The Welsh Government report above notes that many are still unable to access local communities, friends and families, experiencing acute isolation, loneliness, anxiety and depression.

Escalation and Ceilings of Care and DNACPR

47. The treatment of and attitudes towards disabled people and older population have rightly come under scrutiny within this Inquiry to date. In this module, CBFJ Cymru is anxious to understand the extent to which the older population, along with others, in Wales, were overlooked or seen as dispensable by healthcare professionals and the impact this had on their access life-saving treatment.
48. CBFJ Cymru has significant concerns regarding the use of the Clinical Frailty Score and "Do Not Attempt Cardiopulmonary Resuscitation Notices" ("DNACPR"). A number of CBFJ Cymru's loved ones were placed on DNACPRs without due process.
49. Unacceptable practices surrounding DNACPR were widely reported from the outset of the pandemic. One example includes a letter sent on 27 March 2020 by a General Practitioner Surgery in Maesteg to those with life threatening illnesses placing pressure upon them to sign a DNACPR so that inter alia "*scarce ambulance resources can be targeted to the young and fit who have a greater chance*" (INQ000400633), which contributed to the elderly in particular *"feeling that -- that sense of, yeah, just not being valued."* (Older

People's Commissioner's Evidence in Module 2B, Transcript 28 February 2024 Pages 127-128). Such practices are clearly utterly morally reprehensible.

50. Notwithstanding extensive guidance on proper procedures and the need for individualised decision-making, unacceptable practices surrounding DNACPR continued throughout the pandemic including medical professionals making decisions at speed without adequate discussion with patients and families (INQ000339027); individuals feeling pressured to agree to DNACPR notes; relatives being sent letters to sign on a relative's behalf without an assessment of that individual's capacity; care home managers being under pressure by healthcare professionals to sign wholescale DNACPR instructions on behalf of all residents (INQ000319639, p.20).

51. On the Clinical Frailty Score, the National Institute for Health and Care Excellence issued Rapid Guidelines on Covid-19 Critical Care in Adults dated 20 March 2020 (INQ000475240) which recommended the use of the Clinical Frailty Score ("CFS") to inform decisions in respect of DNACPR and to triage and allocate resources including setting ceilings of treatment. The recommendation led to widespread concern, principally because the CFS represented a crude and depersonalised matrix devoid of individual clinical judgment, secondly because it had not been designed or validated for the subsequently excluded groups and finally because the CFS was not designed to predict outcomes or the ability to benefit from critical care during a SARS pandemic. The Guidelines were revised on 25 March 2020 (INQ0002283378) but concerns in respect of its use continued.

52. Some of CBFJ Cymru's loved ones were coldly deprived of potentially life-saving treatment by clinicians. One member stated: "*Following my mother's passing, I received copies of her medical notes from the community hospital. I discovered that an incomplete Do Not Attempt Cardiopulmonary Resuscitation order ("DNACPR") had been placed on my mother. Having discussed this with her previously, I know this is not what my mother would have wanted or agreed to. Additionally, it was noted that she was not to be transferred to an acute hospital. The hospital used her clinical frailty score, at this stage a 7, as justification for these decisions. These decisions were made without any deterioration of her health and without any prior discussion with her LPA's or her family in general. The notes also highlighted several indicators of dehydration, but no fluids were given to counteract this. We were not aware of these issues until receiving my mother's medical notes (...) As a relative with an LPA, it was incredibly distressing to learn that a DNACPR order and an order preventing transfer to an acute hospital for treatment, had been placed on my mother on the basis of her frailty score. This decision was made without our input and was against the wishes of my mother and our family. There was no consultation at all, despite our family keeping close communication with the community hospital and making it clear that we had power of attorney.*"

53. Another member stated: "*On the first day he was admitted with Covid, the doctor had agreed (and my father had insisted) that he be considered for ITU, as my father told them he wanted to be given every chance to lift* [sic]. *The doctor on duty at that time agreed, given he was otherwise healthy. That doctor went off shift, and when another doctor took over, he refused my father to be taken to ITU and told us that if CPAP doesn't*

work, he would be taken to end of life care. He forced a DNAR on my father, which caused him significant distress. The last thing my father said to us on the telephone is that he was being left to die, and the doctors are refusing to save him."

54. Evidence (INQ000499523) obtained by the Inquiry suggests that a significant proportion of healthcare professionals surveyed had experience of being unable to escalate patients due to lack of resources, receiving instructions from their employer on which groups should not be escalated to the next level of care, and having to act contrary to their values. These statistics, together with the visceral lived experiences of the bereaved show the frightening reality of the position on the ground without gloss.

Looking to the Future

55. Professor Lockey of the Resuscitation Council UK (INQ000343994) states that DNACPR is intended to guide clinicians in event of cardiac arrest and it should not have impact on escalation of treatment but it is often misunderstood by clinicians. In England, the RESPECT process has been introduced to mitigate these concerns and to represent a comprehensive summary of personalised recommendations for a person's clinical care. Worryingly, there is no such plan to roll out RESPECT in Wales which instead has a "variety of forms". Professor Lockey suggests that the absence of a nationally standardised process creates patient risk and recommends that the RESPECT process be adopted in all four nations. Similarly, the Older Person's Commissioner for Wales has called for a review as to how the DNACPR decision process works in Wales and what improvements can be made (INQ000276281, p.55). CBFJ Cymru agrees.

Treatment of the Deceased and the Bereaved

Dignity In Death

56. The Inquiry heard in Module 1 that Wales was not prepared for the numbers of excess deaths during the pandemic so that there were inadequate measures in place by way of for example, body bags and mortuary capacity, all of which impinged on the ability to maintain the dignity of those who died. There was no evidence of a plan for excess deaths and the consequences with regard to post death procedures to protect dignity.
57. There is evidence that many individuals in Wales were denied a compassionate death. Our clients experienced their loved ones being treated without humanity. One member's mother, was on life support in hospital as a result of Covid-19. Despite giving permission for a clinical trial to take place, our member was informed that there was not enough blood and so patients names had been "shoved into a hat" and her mother was one of the unlucky ones that wasn't picked. She was also told that at one stage her mother had been taken off life support and left alone in her room, where she choked on her own vomit. Others experienced their loved ones being left without their basic needs being met. Another member's mother was denied ventilation, and instead simply provided a diagram "demonstrating how to breathe properly".
58. The opportunity for loved ones to say goodbye varied considerably across Wales. Many members loved ones were left to die alone. For one member, whilst her daughter was being resuscitated, her family were

told they were unable to visit her. By the time the hospital agreed to allow the visit, it was too late. After death, family members were unable to dress, wash and embalm their loved ones before burials, bodies were lost within the hospital morgues, and belongings of the deceased, if not already lost, were presented back to family members in plastic bags, often covered in urine or blood, without warning. CBFJ Cymru member Sam Smith-Higgins learnt after her father's death in a Welsh hospital that two employees had been given permission by the Health Board to move around and take photographs of patients, both living and dead. These images were published in books, on social media and sold in exhibitions. Not only did these events result in re-traumatisation for family members, they demonstrated a lack of respect for the individuals that had tragically lost their lives. CBFJ Cymru want answers as to why the Welsh healthcare system allowed this to happen.

Bereavement Support

59. Careful consideration ought to be given to the impact of the pandemic on the experiences of the individuals, who have been – and continue to be – affected by bereavement. Notwithstanding the sheer number of lives lost during the pandemic and the heart break this has caused, the need for a considered and compassionate response was deepened by the prevalence of complex grief and the disruptions of grieving rituals and support networks. Despite this, communication between hospitals and loved ones and bereavement support in hospitals in Wales was woefully inadequate: "*Our members tell us they were not informed of deterioration, they were unaware that their loved ones were dying, requests for updates were ignored, phone calls to the wards were unanswered and staff were abrupt and made family members feel they were bothering the hospital staff*" (INQ000343992). There was no bereavement support prior to or during the first 18 months of the pandemic, despite a National Bereavement Framework for Wales being recommended in 2019 (INQ000343992, p.8). Under questioning from the CTI and the Chair in Module 2B, Eluned Morgan (Module 2B Transcript 12 March 2024, pp. 32-33) accepted that whilst there was a Mental Health Helpline, there was no specific bereavement support. The National Nosocomial Covid-19 End of Programme Learning Report has identified that Welsh measures came too late for some families, and that their bereavement process was adversely impacted. The Welsh bereaved want to know why this support was not in place.

Primary Care

60. Evidence shows that individuals in Wales faced significant difficulties in accessing primary care during the pandemic. CBFJ Cymru members report that some Welsh GP surgeries were entirely closed to in person visits, despite being required to offer face-to-face consultations when necessitated by clinical need. This is despite guidance issued by the Welsh Chair from the BMA in March 2020 (INQ000472302). Some surgeries closed entirely for periods due to Covid-19 outbreaks amongst practice staff (INQ000492257). Complaints submitted to the Public Services Ombudsman for Wales highlight a lack of face-to-face appointments; insufficient consideration being given to the vulnerability of patients; failures to consider exemptions from mask wearing; and failures to consider patients' disabilities under the Equality Act 2010, leading to

inequalities in the delivery of services. Certain Welsh GP surgeries also failed to offer telephone or video appointments. This rigid approach to appointments resulted in primary care services being unavailable to many.

61. CBFJ Cymru are especially concerned with the impact this rigid approach had on older people, who were particularly impacted by the difficulties in accessing primary care. There was a lack of understanding as to the digital literacy of the Welsh population and its impact on accessing GP appointments; the Welsh Government's National Survey showed that a third of the population of Wales over the age of 75 either did not have access to the internet at home or did not use it (INQ000217415). Others did not feel confident in using online services. Home visits were often not available and individuals – who were rightly concerned about the risks of leaving their home and taking public transport – were required to attend GP surgeries for appointments miles away from home: *"I'm disgusted by their attitude. My mother is torn between a fear of going out and a fear of what might happen if she doesn't have her bloods"* (INQ000282359). Evidence from the Older People's Commissioner for Wales supports these concerns (INQ000282359).
62. Further concerns relate to the information and advice provided to those individuals that were able to access GP appointments. Members were given unclear and misleading advice when presenting with symptoms of Covid-19. Anna-Louise Marsh-Rees will give evidence about four out-of-hours GP appointments her father had following his discharge from hospital; despite her father presenting with symptoms such as severe fatigue and diarrhoea, because they did not fall within the "initial three" category of symptoms – being fever or chills, a cough, and shortness of breath or difficulty breathing – the suggestion that he could be suffering from Covid-19 was never made. The issue was compounded by the GP failing to read her father's medical records, which recorded that he had been exposed to Covid-19 during his stay in hospital (INQ000343992).
63. The Welsh experience of primary care during the pandemic was woefully inadequate and CBFJ Cymru want this to be acknowledged and for lessons to be learned for any future pandemic.

CONCLUSION

64. The issues highlighted in this submission are but a handful of the individual experiences of the CBFJ Cymru group and their concerns. They are intended to throw into relief some of the deep confusion and chaos experienced and raise serious questions over why the Welsh Government was apparently paralysed from responding meaningfully to problems raised in its own reports and by its own people even as it endeavoured to embrace a four nations solution.
65. CBFJ Cymru are naturally anxious to achieve accountability on the part of the Welsh Government and other agencies, and sustainable changes for the future, fully informed by the experiences of the people of Wales.
66. We conclude with the voice of one of the many in Wales who tragically lost loved ones, whose questions about what happened and why must be answered in this Inquiry:

My dad couldn't have lived a fuller life, which makes it all the more shocking that in his final year, he couldn't have been treated any less like a person by his local health board. Some of the actions by the health board will forever remain unforgivable and even to this day, I await a response for what steps will be taken so that nobody will have to suffer as my father did.

CRAIG COURT
HARDING EVANS SOLICITORS

23 AUGUST 2024

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