Witness Name: Anna-Louise Marsh-Rees

Statement No.: 1

Exhibits: 0

Dated: 19 September 2023

UK COVID-19 INQUIRY

WITNESS STATEMENT OF ANNA-LOUISE MARSH-REES

I, Anna-Louise Marsh-Rees, co-leader of Covid-19 Bereaved Families for Justice Cymru ("CBFJ Cymru") make this statement on behalf of CBFJ Cymru. This statement is in response to the Covid-19 Public Inquiry's request for evidence, dated 16 August 2023, concerning the impact of Covid-19 on those CBFJ Cymru represent. The request sets out four questions which I have taken in turn below.

Question 1: Who the Covid-19 Bereaved Families for Justice Cymru represent and how and why the group was established.

- CBFJ Cymru is a group which represents the full spectrum of families in Wales who are bereaved by Covid-19. Our group comprises of over 350 individuals, led by Anna-Louise Marsh-Rees, Sam Smith-Higgins, and Liz Grant.
- 2. Our group originated as an autonomous group out of the Covid-19 Bereaved Families for Justice ("CBFJ") group. The group was set up by Welsh members of CBFJ on the 15 July 2021. We are a Welsh focused group dedicated solely to campaigning for and giving a voice to those bereaved by Covid-19 in Wales. The group is committed to ensuring that there is proper scrutiny of all governmental decision-making relevant to Wales, including those decisions made in Westminster and by the devolved administration in Wales.
- Our group's purpose is to emphasise and protect the interests of the Welsh bereaved by
 ensuring that Welsh decision-making on fundamental devolved matters (most notably health,
 social care and education) is robustly scrutinised.
- 4. Our group is acutely aware of the importance of full and proper scrutiny of decision-making in Wales in respect of Covid-19. Our group is therefore determined to ensure that the UK Inquiry carries out proper scrutiny of decision-making which impacted on Wales during the

relevant period. The group has campaigned tirelessly, and continues to do so, for justice for families in Wales who are experiencing bereavement due to the Covid-19 pandemic.

Question 2: How Bereavement During Covid-19 Affected Those Within Your Group.

- 5. During the pandemic myself and members within CBFJ Cymru encountered countless and wide-ranging issues which made the process of losing a loved one an extremely painful one. Bereavement from Covid-19 posed a unique and unprecedented grieving process. Due to restrictions in place at the time, those bereaved by Covid-19 were unable to meet with friends and family to seek comfort, love and support; all of which are essential during the grieving process. The restrictions placed on the number of attendees at funeral services took away the opportunity for consolation and prevented a dignified and compassionate send off for our loved ones.
- 6. CBFJ Cymru is particularly concerned with the total absence of bereavement support offered by the Welsh Government, both practically and psychologically, following the death of our loved ones; there is a general consensus amongst members of the group that the bereaved were simply forgotten about. Members of CBFJ Cymru feel that they were emotionally isolated and left entirely on their own to process the death of their loved one. CBFJ Cymru are not aware of any Welsh Health Board that had implemented bereavement support processes before or during the first 18 months of pandemic, despite the National Bereavement Framework for Wales being in place since 2019.
- 7. Losing a loved one during the Covid-19 pandemic had a profound impact on our ability to grieve. I have set out below a list of the issues that demonstrate how bereavement during the Covid-19 pandemic affected those within CBFJ Cymru:
 - a. We have numerous members within the group who have no idea what happened during the final days, or hours, of their loved one's lives. Poor communication between health care services and families, coupled with the restrictions to visit their loved one in person, meant that many individuals do not know precisely how or when their loved one died. Many members recall receiving inconsistent and contradictory updates from the hospital.
 - b. There were contradictory rules and restrictions in place regarding hospital visits during the Covid-19 pandemic. Some 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 one from the outside of a hospital window or via a video call. Heartbreakingly, some members were not able to

say goodbye to their loved one at all. One member was not offered a video call whilst her father was dying, and it was not possible for her to say goodbye to him through the hospital window because he was on the 5th floor. She explained that all she could do was say goodbye to her father via a text message and hope that it would be read out to him.

- c. Important post-death ceremonial traditions and rituals could not be carried out which had a significant impact on the ability to gain closure. Discrepancies also stemmed from contradicting, confusing and ever-changing rules and regulations concerning funeral services. Members recall being able to approach one funeral director who would allow a maximum of 5 attendees at a funeral whereas another funeral director within the same vicinity would be able to offer a service with a maximum of 10 attendees.
- d. Families and friends were not able to get together to mourn and celebrate the life of their loved one; for many, this is a vital part of the grieving process. People were not able to come together to share their grief. One member had to wait 18 months until she was able to meet with her family and friends to celebrate her mother's life.
- e. The Welsh Government's lack of investment in technology and infrastructure in NHS Wales' buildings meant that some hospitals did not have adequate Wi-Fi and technology on the wards. With the restrictions on visiting in place, this made it difficult for members of the group to communicate and to say goodbye to their loved ones at the time of their death. In addition to these challenges, numerous members have explained that healthcare staff did not help patients to charge their mobile phones; neither did they help patients to make or answer phone calls with their families. We have been assured by all the health boards that there were Patient Liaison Officers in place at the time representing the needs of patients in terms of helping them communicate with loved ones via iPads or phones. No member is aware of these officers being present or that their loved one received help to communicate with their family digitally. This has a significant impact on the bereavement process.
- f. Many of our member's loved ones were treated with a lack of dignity, both during treatment and in death. Members of CBFJ Cymru have countless stories of being given the incorrect personal belongings of their deceased loved one from the hospital. Several members received their loved one's personal belongings in a bin bag which was securely tied and were told to wait two weeks before they could open the bag. One member was given another patient's belongings which were soiled and soaked in urine. Some members had to wait months before their loved one's belongings were returned. Other members

noted that their loved one's belongings had gone missing, despite the fact that they were listed on the admission form. Witnessing your loved one being treated in such an undignified way following their death deeply impacts on the anger and frustration felt during the grieving process.

- g. Some members, with no prior warning, traumatically came across photographs of their loved ones posted on Twitter. These photographs were taken during their loved one's time in hospital and were being used within a book which was endorsed by a Welsh health board and the CEO of NHS Wales. Further, one member's loved one was filmed by a news channel whilst he was being treated with CPAP oxygen; this was so traumatic for his family to see on TV with no discussion or prior warning given. These thoughtless and careless acts intensified the bereavement for many.
- h. The lack of empathy and compassion shown towards the deceased and the bereaved was prolonged further by the Welsh Government's failure to sufficiently plan for and invest in adequate infrastructure for excess deaths. Such Welsh Government shortcomings resulted in capacity issues within hospital morgues and led to an inability to initially locate loved one's bodies. At least four of our members were informed by the hospital that they were unable to locate their loved one's body.
- i. There was no practical support on what to do after the death of our loved ones. Some were told to burn their loved one's belongings; others were told to dispose of them in the rubbish or wash them. Bereaved members had to navigate the process of registering their loved one's death with the various restrictions in place. Many members were not informed upon their loved one's death that you were not allowed to embalm, wash and/or dress your loved one after they had died of Covid-19.
- j. A number of member's felt that there was a lack of religious representation in the hospital during the pandemic. Further, we understand that there were inconsistencies within the various religious services being offered. Within some hospitals the services of a Chaplin were offered yet in others, they were not allowed to enter a Covid-19 ward.
- k. Some members struggled to meet the financial burden of funding funeral and other post death arrangements at a time where members might have been out of work or relying on reduced income due to the pandemic and the associated restrictions. Whilst some schemes such as furlough and "Eat Out to Help Out" were introduced to protect employees and

businesses, little to no thought appears to have been given to the impact of the financial burdens on the bereaved.

- 1. Many members have had to engage in complex and lengthy complaints procedures following the death of their loved one. The complaints made by members to their relevant Health Board has uncovered inaccuracies and inconsistencies; many members have received contradictory and unsatisfactory replies. The lengthy complaints process has prolonged the bereavement of so many members of our group. It has hindered their ability to receive some sort of closure. Some family members have been given subsequent contradicting information concerning their loved one's cause of death years later and have uncovered distressing information such as DNACPR being put on their loved one without the family's knowledge. The National Nosocomial Covid-19 Programme causes further stress and, sadly, delay is all too prevalent in that programme too. This, coupled with the lack of inquests being conducted into the significant majority of deaths arising from Covid-19 has resulted in the bereaved lacking answers as to how their loved one sadly died.
- m. A number of our members feel that the three Covid-19 memorial woodlands in Wales, commissioned by the Welsh Government, do not adequately bestow the respect that is due to the deceased and Covid-19 bereaved. For example, the woodlands are inaccessible, they become completely waterlogged in the winter and there is no plaque containing the names of those who lost their lives to Covid-19. How can this be used as an accessible place for the bereaved and people of Wales to visit and mourn the thousands of people who died in Wales. These factors have had a serious impact on our bereavement process; many are left feeling that no one cares and a sense that people now want to forget and move on.
- 8. The issues set out above each impede on our ability to receive proper closure and obstructs our ability to grieve properly. Our bereavement was accompanied with the general sense of fear which comes with living amidst a pandemic. For many, their bereavement is continuous as they still fight for answers today.

Question 3: Provide some individual summaries of the experiences from members of your group bereaved by Covid-19, where such are relevant to the scope of Module 2 in particular.

9. CBFJ Cymru continue to feel deeply aggrieved by the UK Government's decision to downgrade Covid-19 from a High Consequence Infectious Disease (HCID) on the 19 March 2020. This decision subsequently prompted the downgrading of respiratory protection across the UK-wide NHS and further augmented the risk posed to our vulnerable and frail loved ones. Many members within CBFJ Cymru feel as if the UK Government downplayed the severity of

- Covid-19 by downgrading Covid-19 from a HCID; it is perplexing that the Welsh Government omitted from challenging the UK Government on such a decision.
- 10. The guidance, particularly that within Wales, was found by our members to be very confusing and unclear; it was everchanging and misaligned with that in England. For example, from the 1 August 2020 those who were extremely clinically vulnerable in England no longer needed to shield from Covid-19, they were advised that shielding had been paused. In Wales, on the 16 July 2020, the Chief Medical Officer advised those who were shielding in the country, due to being extremely clinically vulnerable, no longer needed to do so after 16 August 2020. The communication through the medium of Welsh was also found to be poor.
- 11. During an already highly worrying period, it was difficult for many in Wales to understand what their family members, and loved ones, were allowed, and not allowed to do. This was especially pertinent for CBFJ Cymru members based in England, including myself, who were visiting their loved ones in Wales. The variation in the rules led to confusion and increased anxiety. One member explained that the decisions he and his family made during the relevant period would have differed greatly had the advice, and guidance, they received not been so poor and unclear.
- 12. I and many other members note that the UK Government failed to clearly distinguish between messaging and guidance on topics not affecting all the devolved administrations when providing their televised daily briefings. This made it particularly confusing for the elderly, such as my father, who were known as the 'Silent Generation.' A generation which is characteristically known for being less likely to question guidance and known for being more compliant. The confusing and contradictory advice which blurred the lines between UK Government advice and advice from the devolved administrations put elderly individuals, who are less likely to have the relevant technological skills and equipment to research into matters further, at a disadvantage.
- 13. At the start of the second wave of the pandemic in September 2020 Welsh citizens in local lockdowns were prohibited from leaving their local area, whereas in England citizens maintained the freedom to travel wherever they desired. Many members of CBFJ Cymru, and I, understand that this divergence in guidance between the Welsh and UK Government resulted in numerous outbreaks within Wales caused by cross border travel, subsequently this heightened the risk of our vulnerable loved ones contracting Covid-19.

- 14. Many members within CBFJ Cymru believe that the Welsh Government's deviation from the UK Government's facemask policy in 2020 enhanced the vulnerability of our frail loved ones contracting the virus and ultimately led to the deaths of many of our member's loved ones. The wearing of facemasks in indoor public places only became mandatory in Wales in September 2020, whereas mask wearing in indoor public places in England had been made mandatory two months earlier in July 2020.
- 15. Many members of CBFJ Cymru and I are particularly disturbed by the Welsh Government's delayed decision to implement a firebreak lockdown on the 23 October 2020; despite SAGE warning a month earlier that immediate action was required to limit a second wave of Covid-19 and that the burden of a second wave would disproportionately affect the frailest within society. I personally recall my father receiving a letter from Dr Frank Atherton in October 2020 that instructed him to no longer shield, even though evidence suggested that the second wave was peaking. We as a group strongly believe that these shortcomings by the Welsh Government resulted in the deaths of many of our loved ones during the second wave of the pandemic who were identified as frail and most at risk to Covid-19.
- 16. Several members of CBFJ Cymru recall the difficulties and the additional risks that they, or their loved one, had to take as a result of the Welsh Government's failure to follow the UK Government in providing supermarkets with the relevant register to help retailers identify vulnerable people. This caused a subsequent delay in vulnerable people in Wales having the ability to access food delivery slots at the start of the pandemic and led to member's loved ones to risk shopping during peak shopping hours; thus, increasing their risk of contracting Covid-19. Poor digitalisation of services in Wales can be demonstrated further by the fact that in England, anybody registered with a GP can order a prescription online and have it delivered to their home via Lloyds Pharmacy. In contrast, in Wales, you are only able to order prescriptions online, and have them delivered to your house, if you are housebound. A digital delivery of prescriptions, similar to that in England, would have been invaluable in Wales during lockdown; it would have reduced the risk of exposure to Covid-19 and alleviated the anxiety of increased exposure to the disease.
- 17. I personally, as well as many members of CBFJ Cymru, experienced firsthand the systematic failure of inadequate infection control, which is a key devastating factor at the heart of the Covid-19 pandemic. As a result of our firsthand experiences, many members strongly believe that poor infection control within health care settings led to the increase in transmission of the disease which devastatingly led to an excess in deaths. We did everything within our power to

keep our loved ones safe; we followed government guidance stringently. The agonising pain and feeling of betrayal, felt by myself and many of our members when our loved ones contracted Covid-19 within a healthcare setting is unfathomable. The lack of PPE and RPE available; the use of agency staff who were moved around different wards, hospitals and health boards; the movement of patients from ward to ward; the movement of healthcare workers from ward to ward; the lack of testing available all propelled the nosocomial transmission of Covid-19. The poor infection control impacted on the life expectancy and quality of countless lives.

- 18. Despite Covid-19 being airborne, , testing was woefully inadequate. We believe that the testing of asymptomatic healthcare workers, and regular testing of patients, was introduced far too late by the Welsh Government. We maintain that such dilatory decision-making by the Welsh Government undoubtedly exacerbated nosocomial transmission of Covid-19 and led to healthcare workers becoming vectors of the disease to other patients and staff. We are also aware that many NHS Wales workers were living together in houses of multiple occupancy throughout the duration of pandemic, therefore making it impossible for them to isolate.
- 19. Members of CBFJ Cymru have identified systematic issues with the Welsh Government's vaccination programme, particularly in relation to the priority groups. Many of our members recall how non-frontline NHS Wales workers were prioritised for a vaccination over their elderly and vulnerable loved one. This was especially distressing for a member of our group who lost their loved one to Covid-19 only days before they were due their vaccination.
- 20. Furthermore, a number of our members have expressed their concerns, and the subsequent distress caused, in relation to the use of the clinical frailty scale being used by clinical practitioners to 'score' and triage patients based on their age, frailty and illness. Many felt that their loved ones were discriminated against by the use of clinical frailty scoring to prioritise/begin initiating treatment. I understand that clinical frailty scoring is not designed for use in a SARS virus pandemic and does not lend itself as a tool to predict treatment outcomes.
- 21. Many feel that their loved one was neglected in hospital because they were 'old.' Numerous members of CBFJ Cymru went through the trauma of being told that, based on their loved one's clinical frailty score, they were being refused a ventilator. We have also been informed that even the basic administration of anti-virals was being refused based on an individual's clinical frailty score. This led to some members having to plead with healthcare practitioners.

- 22. Many members believe that elderly people were put at a disadvantage following Public Health England and Public Health Wales's refusal to change the symptoms of Covid-19 to align with those supplied by WHO. We understand that PHE and PHW insisted on retaining the 'top three' symptoms of Covid-19, these being: a cough, high temperature and loss of taste/smell. CBFJ Cymru understand that most older people experienced differing symptoms, such as: extreme fatigue, headaches, diarrhoea. The fact that these symptoms were not recognised placed older people at risk of being ignored and misdiagnosed.
- 23. A large proportion of our member's loved ones were part of the older generation which had no or limited access/understanding on how to use digital devices and access telehealth during the pandemic. There was a lack of acknowledgement that older people might need help accessing and using digital technology. One of our member's loved one, whilst in hospital suffering with serious health issues himself prior to catching nosocomial Covid-19, used his own personal iPad, and IT knowledge, to facilitate video calls between patients on his ward and their loved ones. This act of extreme compassion gave many families the invaluable opportunity to say some sort of goodbye to their loved one. Additionally, many parts of Wales are very rural with poor internet connection and poor mobile phone signal. Structures could have been incorporated within social distancing and lockdown measures to ensure that digital exclusion was avoided or kept to the very minimum at the least.
- 24. Throughout the pandemic, our members lost their loved ones. As can be seen from the above, and the many examples the Inquiry will hear, the same mistakes continued to be made. Mistakes which were avoidable. Had the Welsh Government learned from its mistakes, and acted on any learning, some mistakes would not have been made and lives might not have been lost.

Question 4: Provide a summary of any representations your group made during the pandemic to core political and administrative decision-makers to influence decision-making.

- 25. Since its inception, CBFJ Cymru has lobbied for changes to the response to Covid-19 in Wales. CBFJ has worked with the following core political and administrative decision-makers, organisations and individuals to bring about essential and overdue changes to the system:
 - a. The Welsh Government we have met with the First Minister of Wales, Mark
 Drakeford, on the following dates: 7 October 2021, 2 December 2021, 26 January
 2022, 24 February 2022 and the 30 August 2022, to lobby the Welsh Government

into implementing bereavement support within health care settings. We made representations to the Welsh Government to investigate care home deaths and lobbied the Government to look at why patients during the first wave, with hospital acquired Covid-19, were discharged without testing. We also raised issues such as: the lack of staff testing (even those who were symptomatic) due to a shortage in tests; the lack of sufficient levels of PPE and oxygen; and the fact that there was no requirement for the vaccination of healthcare workers. CBFJ Cymru have met with the First Minister's team on the following dates: 16 December 2021, 12 January 2022, 7 February 2022, 17 Mar 2022, 29 June 2022 and the 18 April 2023.

- b. CBFJ Cymru met with the Welsh Health Minister and her team, Eluned Morgan and Dr Chris Jones (DCMO), on the 3 February 2022 and the 4 May 2022, and separately with Dr Chris Jones on the 9 January 2023, 16 March 2023, to play a key role in influencing the Welsh Government to invest £4.5million into the Wales National Nosocomial Covid-19 Programme, a programme investigating nosocomial deaths in Wales. However, we have concerns that this is not working as it should:
- c. In addition to lobbying the Welsh Government, CBFJ Cymru have also liaised and worked with the opposition parties within the Senedd. They have lobbied these parties to raise questions on their behalf, within the Senedd, concerning bereavement support, older people's rights, care home and hospital acquired Covid-19. Below is a breakdown of the individuals from the opposition parties, and dates, with whom CBFJ Cymru have liaised with:
 - CBFJ Cymru have visited the Senedd on the following dates: 3 November 2021, 1 March 2022 and the 21 March 23.

Welsh Liberal Democrats

o Jane Dodds MS on the 21 September 2021

Plaid Cymru

- Adam Price MS on the 13 July 2022, 19 September 2022 & 16 November 2022;
- o Rhun ap Iorweth MS on numerous occasions;
- Peredur Owen Griffiths MS, Luke Fletcher MS, Delyth Jewell
 MS

Welsh Conservatives

- o Andrew RT Davies MS during August 2021
- o Russell George MS
- o Janet Finch-Saunders MS
- Mark Isherwood MS

Welsh Labour

- o John Griffiths MS
- Dawn Bowden MS
- o Jack Sargeant MS
- o Joyce Watson MS
- o Huw Irranca-Davies MS
- o Mike Hedges MS
- o Mick Antoniw MS
- o Lynne Neagle MS
- Hefin David MS
- o Buffy Williams MS
- o Jo Stevens MP on the 16 January 22
- Chris Evans MP who offered very vocal support for a Wales
 Inquiry and also appeared as a guest speaker in our Group
 session.
- d. National Bereavement Steering group CBFJ Cymru have worked with National Bereavement as well as John Moss, Bereavement lead in the Welsh Government, to implement bereavement support in hospitals and to provide an approach for mandatory online bereavement training in NHS which is currently under review. CBFJ Cymru met with the National Bereavement Steering Group on the 10 June 2022 and with John Moss on the 27 October 2022 and 6 January 2023.
- e. Welsh Health Boards CBFJ Cymru have liaised with and lobbied various Welsh health boards throughout Wales to influence change and reform to their 'Putting Things Right' complaint process. They have also raised issues concerning the process for access to mortuaries after the group was made aware that a photographer had gained access to a hospital mortuary. The group has also liaised with the Care After Death team within each Health Board to ensure that after death care is a dignified process for both the deceased and families/loved ones. Below

are some examples of the numbers meetings we have had with the Welsh Health Baords:

Swansea Bay University Health Board – 8 September 2022

Cardiff and Vale University Health Board - 3 November 2022 and 10 January 2023

Cwm Taf Morgannwg University Health Board – 18 November 2022

Betsi Cadwaladr University Health Board – 18 January 2023, 26 January 2023 and 16 February 2023

Velindre University NHS Trust - 24 November 2022

Aneurin Bevan University Health Board – we met with the CEO on the 5 April 2023 and 19 May 2023

- f. In conjunction with the above, CBFJ Cymru campaigned for patient privacy and the right not to be photographed for books and PR purposes when dying/dead in NHS Wales hospitals. From 5 January 2022 we have lobbied for patient privacy including changes to the process for accessing hospital mortuaries via Human Tissues Authority. CBFJ Cymru ensured that images were removed from websites, social media, galleries and newspaper articles.
- g. CBFJ Cymru have liaised with MS Mark Isherwood, Chair of the Cross Party Group on Hospices and Palliative Care in the Welsh Parliament, on the 18 April 2023 and met with the Cross Party Group on the 27 April 2023, to discuss issues relating to palliative care and hospices and to lobby for change;
- h. The group is due to meet with AFCP (Advance & Future Care Planning Strategy Group) on the 29 November. They have been liaising with Professor Mark Taubert, chair of AFCP and the national strategic lead for Advance & Future Care Planning on the 1 September 2023, to lobby for change in the DNACPR decision making process in Wales. CBFJ Cymru intend to discuss with the group matters such as improving DNACPR and TEP consultation process and digitise form and process;
- Community Health Councils (now known as Llais/Citizen's Voice) CBFJ Cymru have lobbied for a change in the complaints processes and Welsh Government Listening Project. CBFJ Cymru have met with the Community Health Councils on numerous occasions, for example, 10 August 2022, 31 August 2022 and the 18 October 2022.

- j. Older People's Commissioner for Wales CBFJ Cymru have met with Helena Herklots to lobby for change concerning DNACPRs, care homes and complaint procedures on the 6 October 2021, 16 December 2021, 4 April 2022, 26 April 2022, 11 August 2022, 16 September 2022, 21 November 2022;
- k. Wales Evidence Centre on the 28 September 2022;
- Since its inception, CBFJ Cymru have had a consistent presence in the media and used this as a tool to drive change: including BBC Question Time, BBC Wales Politics Live, S4C- Y Byd ar Bedwar.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Personal Data

 $_{\text{Dated:}} 19/09/23$