Dated: 27th November 2023

Exhibits: DOCUMENT PROVISION ATTACHED

Witness Name: Martina Ferguson

Statement No.: 1

UK COVID-19 INQUIRY

WITNESS STATEMENT

OF MARTINA FERGUSON

I, Martina Ferguson will say as follows:

1. I am one of the group leads of the Northern Ireland Covid Bereaved Families for Justice ('NICBFFJ')

Northern Ireland Covid Bereaved Families for Justice ('NICBFFJ')

2. NICBFFJ is a branch of the UK-Wide CBFFJ Group. It was established with a purpose of co-ordinating activity in Northern Ireland, co-ordinating involvement with the UK-wide inquiry into the handling of the pandemic and leading calls for a separate Northern Ireland (NI) Public Inquiry.

3. NICBFFJ was started in or around December 2021. Prior to that, a number of our members were involved in engaging with state entities and public representatives throughout the pandemic or were involved in other support groups and memorial groups.

4. Those in our group who did engage with state agencies and entities did so in an attempt to highlight issues, safeguarding concerns, care partner (referred to in the UK as essential care giver) failings in care settings, no wellbeing during end of life (EOL) arising due to the pandemic, or to address the detrimental impacts arising from failures to implement effective policies, including those intended to benefit the most vulnerable. The aims were to gain access to residents and patients, improve the quality of care for those young and older adults and those with a disability living in nursing and residential care, and to engage with those in authority on government policies and operational decisions and guidance that was not working at both ground and operational levels. By way of example, I have been an instrumental member of the NICBFFJ group and have engaged since the very start of the pandemic (March 2020) with senior officials from the Department of Health (DOH) and its Arm's Length Bodies (ALBs) in NI: the Public Health Agency (PHA), the Regulation and Quality Improvement Agency (RQIA), the Patient and Client Council (PCC), senior management representatives from various Health and Social Care Trusts who are responsible for providing services at various health facilities (hospitals, care homes), the Commission for Older People (COPNI), the Northern Ireland Human Rights Commissioner's office and the former UK Prime Minister Boris Johnston.

5. In addition to this, I was heavily involved in the activities of the Relatives Dementia Care Support Group. This support group was set up in 2015 and had engaged with members of the NI Legislative Assembly over the years due to families having issues such as poor staffing levels and standards of care in [I&S] Care Homes. I, along with members of the bereaved families group also engaged with key decision makers including the Minister of Health since March 2020 on issues relating to the protection of vulnerable residents in care.

6. The NICBFFJ group was formed as both a support group and an action group, seeking to challenge decision makers in an attempt to highlight issues and safeguarding concerns and address the detrimental impact that visiting restrictions were having upon patients and residents in hospitals and care homes and of course, on their families. Draconian visiting restrictions in care was not protecting the vulnerable and this was also discussed when our campaign leads met with all five of the Northern Ireland Political Leaders during the summer of 2022.

7. NICBFFJ aims to:

(a) Apply pressure to ensure that there is accountability and transparency on the UK and NI Government's past actions, including their response to the Coronavirus Pandemic, and their ongoing approach.
(b) Provide a collective voice for bereaved families and a supportive space for them to connect.
(c) Ensure families are well-informed on their rights and options for seeking accountability in relation to their loved ones' deaths.
(d) Make sure that families who have been bereaved by Covid 19 are involved in the commissioning of Covid-19 memorials, and that the National Covid Memorial Wall is made permanent.

8. NICBFFJ represent, and are made up of, members who have lost loved ones, both young and old, to Covid-19, in a variety of circumstances including care homes, hospitals and in the community. Since its inception NICBFFJ have campaigned, in conjunction with CBFFJ UK for policy reviews and changes to prevent avoidable mistakes from being repeated.

9. NICBFFJ continues to empower members to hold the Government and public bodies to account to ensure that the circumstances leading to the deaths of their loved ones are avoided in the future. NICBFFJ's membership reflects a broad demographic of Northern Irish families who are united by the aim to learn lessons and save lives when we face future epidemics, pandemics and healthcare emergencies.

10. Our group supports a full judge led public inquiry into the handling of the pandemic by the UK government, the Northern Ireland Executive and public authorities, including decision making and funding at all levels during the pandemic, locally, regionally and nationally that took place.

11. Our members, collectively and some individually, also have in-depth knowledge and experience of how the NI health and social care systems operated in practice, including knowledge obtained from prior to the pandemic. As a result of that knowledge, we have significant concerns relating to the effectiveness of the healthcare system in Northern Ireland to the Covid-19 pandemic. Without wanting to rehearse material matters which have gone before in Modules 1, 2 & 2C, the starting position is unimpeachable, namely that the 2017 Cygnus Report foresaw the inability of the social care system to cope with patients (via a process of reverse triage) were moved from hospitals into social care facilities. The 2016 Exercise Cygnus was not given its due regard and priority.

12. Prior to setting out the evidence derived from my own experience and examples from the families that I represent, I believe it is very important that the Inquiry pause here to note representations made by the Northern Ireland Health Minister Robin Swann on Tuesday 24th March 2020 per Hansard from the Executive Committee Business he said:

"Members will be aware from my previous statements to the Assembly that my department, including the health and social care system, has been planning extensively over the years for an event such as the outbreak of a pandemic. This is to ensure that we are well prepared to respond in a way that offers substantial protection to the public, as has always been the case. My priority as Minister of Health is to ensure that all effective measures continue to be put in place in Northern Ireland, but I stress that, for the social distancing measures that were announced yesterday to work, everyone in Northern Ireland needs to understand clearly that the vast majority of commercial premises must close. Only those providing essential goods and services can stay open. All others must close, and close now. Let me be crystal clear about what that means. As the Prime Minister said yesterday, this is not merely guidance or advice. It is an instruction. If it is not heeded, we will not hesitate to enforce it with penalties that will include an unlimited fine. It is as stark as that."

Evidence will show whether materially this statement in respect of preparedness was misleading. Unquestionably, the cost was the loss of our loved ones.

13. The 2016 Exercise Cygnus and the 2017 Cygnus Report were fated to be Cassandra for what was to come. The NICBFFJ invest their hope and faith in this process that the same metaphor will not be continued, and the psychological and emotional suffering we have endured as a result of this pandemic will be believed and acted upon. On that note, I turn to my own personal experiences and that of a number of the individual members of our group to add a lived in texture to the issues we seek are raised and considered. It is important when reading these concerns, that one bears in mind, that the issues raised are not in their abstract, but related directly to trauma and distress experienced by real individuals which we, as a group have identified as common causes amongst us.

My own personal experiences in relation to the response of the healthcare systems in Northern Ireland to the Covid-19 pandemic

14. My mother was Ursula Derry, born on Personal Data and died on 4th January 2021 in Irrelevant & Sensitive Hospital, a hospital under the remit of the I&S I&S. Prior to her death in hospital, she was a resident in Irrelevant & Sensitive I&S (which was a I&S nursing home) as she lived with Alzheimer's and vascular dementia and had nursing needs.
15. Prior to the Covid-19 pandemic I would have visited my mother at the Care Home several times a day and every night (except when on holiday). During these visits I put my mother into bed most nights or assisted nursing and care staff. Prior to the introduction of the hoist, I changed my mother into night-time attire, washed and dried my mother at bedtime (face, hands and teeth), changed my mother's wet and soiled pad, disposed of wet/soiled pads and applied a dry pad, laundered her clothes (some stayed in the Care Home and some were brought home by myself and family to launder), closed her window, adjusted her heating, ensured my mother's bedside lamp was switched on (as she was frightened of the darkness), said prayers together, laughed together, sang together, chatted about family, reminisced about old times and looked through old photos and videos, and left my mother's clothing attire out for staff the following morning. Every night upon leaving the care home I would have advised the nurse on duty and/or the staff that I was leaving and that my mother was comfortable in bed. I would have asked the staff to check my mother was positioned in the bed correctly for health and safety reasons and for the staff to check the operation of the alarm bell mat which lay on the floor on top of my mother's crash mat. I was always present during the bedtime routine (with the occasional exception). The benefits of this to my mother was accepted by the care home manager in her email to me of 26 July 2018.

16. An email dated 26 July 2018 from the Home Manager (I&S) to me confirms that I was involved with my mother's personal care and recognised the benefits to my mother regarding my presence. The Care Home Manager stated: "I have stressed to staff that it is very important that your mummy has visual of you so that she does not become anxious. Please carry on with what you have been doing". My mother was much more settled and happier when I was with her.

17. My mother had two hospital admissions during the Covid-19 pandemic which lasted a period of approximately 2 weeks in July 2020. She was first admitted on Sunday 5th July 2020, the reason for admission was a seizure, this was also the principal diagnosis upon discharge on Wednesday 8th July 2020. I had asked Doctor I&S in Irrelevant & Sensitive I&S to keep my mother in for an additional 24-hour period under observation as I felt she was not well enough to return to the Nursing Home. Despite my concerns, I&S discharged my mother as she felt my mother was medically fit for discharge. My mother was subsequently re-admitted to Hospital within 24 hours on Thursday 9th July 2020, the reason for admission was a seizure, and the principal diagnosis upon discharge on Wednesday 22nd July 2020 was Pneumonia (CAP) & PO Thrush.

18. Upon both arrival and admission to and from the hospital on both occasions my mother did not look or seem well, she experienced some mild tremoring following admission. My mother was not familiar with the hospital staff and some staff were not familiarised with the needs of dementia patients. I had an arrangement with I&S to visit my mother during feeding times, I attended the hospital for 4-6 hours daily as my mother would take longer to drink and feed because her oral intake was low. I advised the Nurse on 7 July 2020 that I believed IV fluids were required as I felt my mother was not getting enough fluids. After spending 1-2 days with my mother to help with feeding and hydration she began to look well and alert. She was pleasant, happy and comfortable that I was by her side, and we shared lots of laughs.

19. During my mother's time in hospital in July 2020 I was also able to help her with personal care and hygiene. I washed her face and hands after mealtimes, moisturised her skin fixed her hair and cut her nails. I frequently helped with administering my mother's medication, thickening the liquid medication which needed to be spoon-fed to her. My mother's food and liquid intake was challenging, and I believe the time that I was able to provide as well as the close observation was valuable to her. I asked Nursing Staff for food charts to commence on her subsequent admission, which was the next day on 10 July 2020. I requested an SLT assessment on the 11th July 2020 when I noticed that my mother appeared to be having difficulty swallowing and was coughing. I was concerned that her drinks/fluid level needed to change levels. The SLT Professional visited on 20 July 2020 (due to holiday season and leave) and assessment confirmed the changes required in drinks/fluid levels. It is this kind of 'partnership of care' that I previously provided to my mother in the Care Home, but which was being denied to her.

20. In early July 2020, I initiated a Human Rights based legal challenge as an individual regarding the visiting restrictions when I discovered the poor state of my mother's personal care and hygiene on admission to I&S Hospital from the Care Home. I could clearly see when I was up close and personal with my mother that her basic needs around hygiene in the Care Home were not being met and that adequate care was not being delivered during the first 15 weeks of lockdown and a blanket ban on visiting. Initially in August 2020 Legal Aid was refused, it was then appealed, and we had to wait until October 2020 for a decision that Legal Aid was granted. Pre-action papers were lodged and an application for leave to apply for Judicial Review was made at the High Court in November 2020. My affidavit **(MF/1 – INQ000226346)** explains my mother's period in hospital during July 2020. Neglect was confirmed following an I&S Adult Safeguarding Investigation (ASI) investigation in November 2020 which was related to my mother's personal care and hygiene in I&S which was managed by I&S I requested a copy of the I&S ASI Report which is also attached hereto.

21. If I move forward to another key date 23rd December 2020 (the day after we buried my mother-in-law who had been battling cancer during the pandemic), I received a phone call. The phone call was from one of the nurses in my mother's Care Home who advised me that my mum required hospital admission due to high heart rate and that she was going to phone for an ambulance. No-one from the Care Home told me or our family that my mum was going to hospital with *suspected Covid*. I met my mum at A&E after she was triaged and tested for Covid-19 (testing for Covid-19 was routine at the Hospitals at that time for patients.) later that night in A&E, a doctor approached me to advise my Mum had tested positive for Covid-19 and needed to be transferred to the Covid-19 Ward in I&S The Doctor spoke to me about a DNR which I wasn't happy with and I explained that I would need to speak to my family as I was one of six children. If I recall this was I&S (A&E at I&S on 23rd Dec 2020).

22. My mother was transferred to the COVID Ward on Christmas Eve, 24th December 2020. I thought my Mum was going to recover after receiving some treatment. There were so many areas of my Mum's care that I highlighted and brought to the attention of the nurse-in-charge during her stay/death in hospital between 23rd December 2020 and 4th January 2021. These included:

(a) The wrong levels of food & consistency delivered to my Mum [who had assessed needs and was at risk of choking] by Healthcare professionals;
(b) Soiled clothes not being changed regularly;
(c) Tablets left for my mum at her bedside by Nursing Staff despite my mum being on liquid medication for many years prior to the Pandemic which was in her hospital notes and records and which I had advised the same Hospital prior to COVID;
(d) Staff lacking training and understanding of Dementia patients despite the I&S and other Trust Hospitals across Northern Ireland having implemented prior to COVID the butterfly scheme for dementia patients.
(e) Midazolam and morphine were given to my mum without my consent. I&S on the COVID Ward said my mum was "uncomfortable".

23. My mother spent approximately 2 weeks on the COVID ward. I spent time with her during her stay and challenged the I&S visiting policies at that time. My mum sadly passed away on 4th January 2021. I discovered following my Mum's death (a couple of months later) that my Mum was "*suspected COVID*" when being admitted to I&S Hospital. This was shocking for me to read.

24. I now, as a lead member of the NICFFJ, am one of the many family members who have proactively obtained the relevant records for my late mother only to discover specific references to *"Covid-19 Suspected"* and the symptoms consistent with what the public were informed to be symptoms of Covid-19. From my own personal experience, and the learned experience of our group, I know that there was a distinct lack of information and qualitive communication between the care homes and families and the hospital and families such as those in my circumstances. I requested and obtained my mum's hospital notes and records, and I made a Subject Access Request for the 999-call record through the Northern Ireland Ambulance Service.

25. I now know that my mother's care home had specifically advised the 999-emergency operator that the reason for the admission to the hospital in ambulance was 'PT query covid'. It was also noted in my mother's Hospital A&E admission form that my mother was a suspected Covid-19 patient. Not only was I not informed of this at the time, but it is also frankly shocking that I would never have been informed of this had it not been for my own efforts to reveal the truth.

An overview of the concerns which NIBFFJ has identified about the response of healthcare systems in Northern Ireland to the Covid-19 pandemic during the relevant period contracting Covid 19 in Hospital or Care Home setting

26. Many of our members who lost loved ones were anxious about their loved ones' health before the pandemic struck. A large number of our members strongly believe that their loved ones were allowed to be exposed to the pandemic and the health and social care in Northern Ireland was so devoid of resilience to the pandemic that it was inevitable that their loved ones contracted Covid-19. Put bluntly, they were given Covid-19 because nothing was being done to prevent it. This flies in the face of the Health Minister stating on the 24 March 2020 at the NI Executive Committee Business Meeting "*Members will be aware from my previous statements to the Assembly that my Department, including the health and social care system, has been planning extensively over the years for an event such as an outbreak of a pandemic. This is to ensure that we are well prepared to respond in a way that offers substantial protection to the public, as has always been the case*" In addition to this, I was personally given assurances around safeguarding and protection of older people in care when I met the former health minister in person (outside with other families) on 21 May 2020 (8 weeks into lockdown). I called out risks, shared trauma and raised concerns of what families were expecting on the ground (IPC concerns, inappropriate donning and duffing of PPE, locum staff working across care settings putting the vulnerable at more of a risk than family members) and sadly nothing was done that was effective, despite being 9 months into the pandemic.

27. Lindsay McWilliams' husband underwent a liver transplant in I&S in August 2021. He was returned to the I&S Hospital I&S I&S) in early September 2021 to recover. While there, he reported that staff were wearing masks around their chins, with one individual putting on the mask after leaving the ward. Patients were walking outside for a smoke with no mask. He and his family continually raised and enquired about this potential exposure to Covid-19 on 29th of October 2021.

28. ***Sharon Nicholl's*** father John Arthur contracted Covid-19 before he passed away on 26th May 2020 in I&S When Ms Nicholl's and her family asked the staff how her father contracted the virus she described a distinct feeling of "*being fobbed off*". She had noted a lack of systems/procedures and protocols in place in the hospital at the time and when she challenged this she was told by one doctor "*we are all still learning about it and that anybody could catch it*".
Deborah Braiden's father Arthur was admitted to hospital with a cardiac event. He apparently contracted Covid-19 within the clinical setting and died on 29th March 2021. Despite his underlying health condition, his family have been left with the heavy feeling that he would have been fine had he not been admitted to hospital.

29. ***Tracy Deehan's*** father Ronald McArthurs died in I&S after contracting Covid-19 on the cancer ward. Another patient admitted to the ward had tested positive 2 days after admission. The family feels it is likely that an unvaccinated nurse, who also then tested positive, caught Covid-19 from the other patient and passed it to her father. Further, as part of a Serious Adverse Incident investigation, it was further discovered that the ventilation system in the ward was faulty and inadequate prior to, and during, the outbreak **(MF/2-INQ000226347).**

30. I'm aware there was a further Serious Adverse Incident investigation announced by the Health Minister Robin Swann at the Craigavon Area Hospital (SHSCT) on 07 September 2020 following a number of patients who were being treated in the Haematology ward (non-covid patients), who contracted Covid-19 on the ward and died.

    Helen Coyle's father George McGrattan, was admitted into I&S Hospital I&S in relation to a non-Covid illness. He was not tested on his release, resulting in him returning home ill. Mr Mc Grattan was subsequently re-admitted into I&S Hospital one week later. He tested positive for Covid-19 upon being re-admitted to hospital. He died on 10th May 2020. Helen's mother, Mary Pamela McGrattan tested positive a few days with her father's re-admission. She sadly died four days after her husband.

31. ***Jacqueline Heron's*** mother Margret was admitted to the I&S Hospital I&S where she was tested for Covid-19 the following day with a negative result. She was given a bed on a ward 2 days later. Another patient was then admitted to the ward who subsequently tested positive for Covid-19. Margret died a few weeks later.

32. Anne McIvor was the mother of ***Marie McArdle, Rodney McIvor and Tom McIvor,*** all members of our group. She was admitted to I&S Hospital I&S with swelling on her leg in April 2020, but contracted Covid-19 after another patient on the ward tested positive. She passed away on 20th May 2020.

33. ***Caitriona Daly*** describes how her father, Peter Joseph Clarke, was admitted to a Covid-19 ward in I&S Hospital I&S although he had not tested positive for Covid-19. Her subsequently contracted Covid-19 and died on 23rd December 2021.

34. ***Julie Murray*** describes how her husband had been admitted into hospital for a routine operation in December 2020. The operation was a success but he was moved 5 times within the hospital within the period of a month. Julie pleaded with the hospital (there was increasing risk due to the number of people he was exposed to) to stop moving him but staff kept saying they were moving him to protect him from Covid, whereas the reality was that moving him around the hospital was increasing the risk due to the number of people her husband was being exposed to which made him more susceptible to contracting Covid-19. He died alone in January 2021.

35. ***Claire Smith*** recounts how an untested person was permitted onto her mother's hospital ward where her mother was being treated for heart issues. Her mother contracted Covid-19 and was moved to a Covid-19 ward at the I&S Hospital I&S where she died 2 days later.

36. ***Jane Cosgrove's*** husband Samuel died at 69 years of age from Covid-19 in I&S Hospital I&S having been admitted to hospital with broken ribs. He should have been protected in hospital but instead was evidently infected in a clinical setting.

37. ***Jennifer Currie's*** mother, June McGrath, was admitted to I&S Hospital I&S on 23rd November 2020 with a severe leg infection. During a hospital visit, her sister was promptly informed that visiting hours were to be abruptly ended as one of the patients (who was situated furthest from Mrs McGrath) had tested positive for Covid-19.

    The family questioned why the whole ward was not being tested and were informed that "*following public health guidelines and the patients would not be tested unless they were showing symptoms.*" Following this Mrs McGrath telephoned her daughters and spoke about the coming and goings during this time when the ward was meant to be in isolation. The hospital continued to discharge people and bring in new patients into the ward. A man with mental health problems was admitted to the bed next to her. He wouldn't stay in bed, he was urinating on the floor and she work up one morning with him right up in her face. One of the nurses also told them that he was caught drinking out of Mrs McGrath's cup. The family complained several times regarding this man as Mrs McGrath was scared. Shortly after this he tested positive for Covid-19. Days later Mrs McGrath also tested positive and died on 17th December 2020.

38. The number of examples that could be given under this rubric are all too numerous. They span the entirety of the relevant period, from the very early stages to years beyond. Collectively they reinforce the concern that these were systemic issues, and involved a failing to properly protect the most vulnerable in care and hospital settings.

Mental Health

39. In addition to failures in protecting lives, there are systemic issues which have significant importance for the relationships and mental health of out members. It is not clear whether these systemic issues were permitted to occur because they were symptoms of failures of implementation, draconian measures around enforced separation and isolation in the health and social care systems. Either way, the recurrence of these issues is relevant as it serves to demonstrate failure in the matters which this module is regarding impact now investigating. Many of these matters relating to impact were highlighted to the Health Minister in 2020-2022 and senior officials across the Health Trusts, I&S and I&S to name a few.

Failures in communicating with family members on the part of health or care staff

40. One of the key concerns for the NICBFFJ is the lack of information sharing between the hospital staff, patients, and their families. Many of our group members feel that there was insufficient communication and updates to family members in relation to the state of their loved ones' health whilst cared for in hospital. This has caused those who have lost loved ones to be significantly distressed in relation to matters which could have been easily resolved through simple discussion and access through the care partner role (known as the essential caregiver in UK) which was introduced for care homes September 2020 for residents and their families and extended to hospital settings in February 2022 for patients and their families. Sadly, there was no implementation or monitoring of this by Public Authorities for thousands of families across NI despite families raising the issues.

    We should make it clear that the lack of information was not borne out of apathy on the part of our group. Endless phone calls being made, but responses given were lacking specifically to the questions posed to the extent that the family members felt as though they were being "fobbed off" in terms of responses.

41. ***Michael James Mallon*** was a farmer all of his life. He had 4 children and very big personality. He was well known and respected in his local community. He was a huge supporter of Tyrone GAA and enjoyed singing Irish songs in local bars. He was tee-total and did not drink alcohol. He contracted Covid-19 whilst in I&S in February 2021. His family had to question and probe why they were not allowed to visit their father when other patients in his room were receiving weekly visitors. The staff at the hospital were generally unhelpful and indeed one has been described as "*obstructive.*" The family were informed that staff "*were far too busy to update the family.*" The Trust subsequently apologised for this attitude. Family members also report that it was extremely hurtful to have been told by hospital staff on several occasions; *"your father must have been fond of the drink"*, notwithstanding the fact that Michael was a lifelong pioneer. On 17th February 2021, during the course of a phone call to Michael, the nurse responsible for Michael's care is heard to say; "*I'm sick of your family calling the hospital and annoying me and the nurses/sisters with asking questions about you.*" Moreover, the family appreciate the unequivocal apology provided by the Trust letter dated 24th February 2022, this behaviour was all too common place within the Trust.

42. Another example is given by ***Annetta Milliken*** about her father, an otherwise healthy man who was admitted to hospital with Covid-19. Without consultation a DNR decision was made. The family were not made aware of this and this decision only came to light because the family requested a copy of their father's medical notes and records after his death. It is tragic that this example is not an unusual lived experience for our family members. The family's recollection was that the doctors had told them "*they would give up on him.*" What was further shocking for the family to learn was that their father had also been placed into a medically induced coma. Again, this is an example of material information regarding the patient's wellbeing of which the family was never informed. Of some poignancy is that this gentleman's wife Isobel was admitted into the same hospital also suffering from Covid-19, but the two were kept separate and were not allowed to see one another.

43. Sadly, this lack of information sharing is also the experience for ***Catherine Todd,*** the mother of the youngest deceased within our group. This child lived only a matter of hours. His mother was not told that he was receiving palliative care and she had always thought he was getting better, not that he was going to die. The child did not have Covid-19, according to his death certificate the cause of death was pulmonary haemorrhage, however, I&S listed 'maternal Covid' next to this. A PCR confirmed that the child did not have Covid-19 the family were asked to consent to this PCR. One can only imagine how traumatising the revelation of this information has been for his mother. It is axiomatic that the mother of a newborn baby should have been consulted regarding key medical interventions and is an issue that is indiscriminately repeated time and again by our members.

44. ***Irene Barclay*** describes distressingly little communication from the hospital after her father David Charles Vaughan acquired Covid-19 in hospital. The family never received an explanation of how this could have occurred, and received very little information about their father after he was admitted. He died in the I&S hospital I&S on 19th December 2020.

45. ***Geraldine Anderson*** described receiving little to no communication about the condition of her husband Seamus Martin Anderson, who dies in an ICU in I&S on 3rd July 2021.

46. ***Heather McIlwaine*** recounts a similar situation before the death of her husband Alan Cecil McIlwaine, who died in I&S on 30th January 2021, having been admitted there on the 19th January Heather describes having to call the hospital repeatedly to obtain updates on her husband's condition.

47. It is not only the failure to provide information that has been identified, but also the provision of incorrect or conflicting information which has been identified as a recurring issue. By way of example, ***Lauren Mallon*** and ***Paulette McAleese Mallon's*** relative Raymond Emmanuel McAleese died on 26th September 2021 in I&S Hospital I&S after the family has received information from nurses and doctors which conflicted starkly. The family were contacted and informed that he was much better, but five minutes later they received a call to advise them to get to the hospital urgently. They arrived at 06:31, to be informed that Raymond had died at 06:29. They say "*the provision of information was poor.*"

48. ***Sarah Todd's*** mother June Farr died on 20th August 2021 in I&S Hospital. Sarah described receiving very little communication, compounded by receiving mixed messages about her mother's death.

49. We consider that these failures in communication appear systemic. Evidently there was continued reluctance by healthcare staff and failure of hospitals and care settings to follow DOH guidance (weeks, months and years into the pandemic) to ensure that the importance of the guidance and these issues were employed. These are not insignificant issues and have caused lasting distress and trauma to those bereaved who experienced these issues.

The use/misuse of DNR notices and the absence of familial consultation in relation to such notices

50. Linked to the concern about the absence of information sharing, our members have frequently raised concerns about apparent institutional pessimism / resignation / fatalism on the part of the health care professionals. Families were all too often wholly unaware that DNACPRs decision had been made, who had made them or why they had been made. This information often came to light, *after* the death and *only when* the families managed to obtain copies of the medical notes and records of the deceased. One example of this is recounted by ***Rhons Tait*** who discovered that a DNR had ben placed on her mother whilst she was in the ambulance. She pursued questioning of how this could have been the case and contacted local MLAs and the Stormont Executive directly but did not receive a reply. Again, this example is not an isolated one and is a recurring theme all too familiar with the members of our group.

51. From a different perspective on the same issue, ***Jacqueline Heron*** recounts a harrowing experience about when DNR was discussed with her by a doctor. She handmade it clear to the doctor that there was "*no way*" she was prepared to give her consent. The female doctor said that she would not like to have to "*smash her sternum.*" The doctor said that Ms Heron's mother had COPD and she "*had the power to do this without family consent.*"

52. Unquestionably systemic issue were significant during the pandemic. Opposite to the systemic issues, many of our members feel that there was a lack of joined up thinking in terms of the five Northern Ireland Health & Social Care Trusts who were responsible for the administration of health and hospital and social care settings where many of our families' loved ones died. It was the reality of our members that a number of people who potentially already suffered from Covid-19 were in hospital receiving treatment before being sent to care homes which were absent of isolation procedures or measures for the care of vulnerable persons. Procedures were seemingly not put in place to protect the most vulnerable in society, and if anything, they were not placed front and centre in terms of exposure before the general population.

53. ***Agnes Hollyoak*** describes how her mother was admitted into the hospital for the purpose of receiving antibiotic medication. Whilst in hospital she moved from isolation into a mixed was where she contracted the virus and passed away a few days later. The family asked whether their mother could receive the antibiotic at home. They were told that she could not because she was outside the remit of the **I&S** and came under the **I&S** **I&S**. A different approach could have happened as they were told by the GP that is she was in the **I&S** this could be administered at home. Given the risks that being in a hospital presented to Ms Hollyoak's mother it seems imperative that joined-up thinking should have been employed to keep as many people out of hospital, particularly the elderly and vulnerable.

54. Regional Trust forums and groups had been setup prior to the pandemic for sharing information, actioning activities and sharing learning (ex. Trust Regional Carers Strategy Group forum reputation from across HSCTs). The ECHO network was also set up prior to the pandemic and continued during the pandemic for health care professionals. A report was published in March 2022 **(MF/3-INQ000226348)** and healthcare professionals that participated stated that ECHO "was a brilliant experience to be able to feel supported" and that it was "a good way to keep up with other services and trusts". Reflecting on my own lived experience and that of our group I wonder did these groups ever give the impression of action rather than implementation and has this been a good use of public money over the years.

    - many feel these are "tick box" exercises for HSCTs **(MF/4-INQ000226349)**

The use/misuse of palliative care in the hospital/care home setting/possible use of discredited Liverpool Care Pathway

The inaction of agencies/statutory bodies to whom families endeavoured to reach out during the pandemic

55. ***Michael O'Neill's*** mother Esther had just been given her all-clear following her cancer treatment at the end of July 2020. Other than her cancer diagnosis she had lived a fit and healthy life. In January 2021 she contracted Covid-19 and deteriorated rapidly such that the family thought the treating doctor must have had her confused with someone else, given the difference in her presentation to the family on the phone against what was being reported ny the hospital. A doctor came in shortly before Mrs O'Neill passed away and stated that Mrs O'Neill was distressed and that the device that was assisting her to breathe would be removed. Michael objected pointing out she did not appear to be distressed. The doctor relented and the device was replaced. After this, Michael's mother appeared to drift in and out of consciousness. At one stage she asked for a drink. A nurse then brought in a tray that contained a sort of lollipop on a sponge. Later a nurse told Michael not to give his mum water. She said it was not good for her. She died shortly thereafter.

56. In keeping with the systemic issues theme, an all-too-common issue for our members (who were not as informed as some of the other members) concerned the complicated structure of the Northern Ireland Health and Social Care ('HSC') services, which meant that where members of our group wanted information, or to challenge decision making, it was almost impossible for them to identify from whom to seek review and redress of this perilous situation. In effect the system was not readily accessible or publicly available or effective to these members but also to members who were very familiar with the system of people. It lacked clarity in practice over the duties and responsibilities of various bodies. The HSC bodies themselves were appraised of their structures and responsibilities but this did not mean that the public of Northern Ireland are as well versed. The haze under which the bodies work allowed various entities to avoid responsibility to individuals in practice by "*passing the buck*".

Provision/use of PPE within Hospital/Home/GP/Ambulance/Domiciliary settings

57. The personal care, or lack thereof, provided to many of our collective families was one of the most striking matters of concerning for our members. Incidents such as inappropriate donning and duffing of PPE (in some cases mask wearing below and/or chins, gloves not being worn etc.), lack of PPE equipment, lack of familiarity with guidance across HSCTs, lack of availability of healthcare staff, lack of candour, the lack of funding for same, a lack of empathy or good beside manners employed by healthcare providers was often described as '*cruel*'.

58. ***Hazel Gray*** recounts how, when the ambulance crew arrived to help her father, they were wearing ordinary masks, aprons and gloves. They said that they did not have to wear proper PPE clothing. The ambulance staff said that if they wore all the PPE, they would have nobody to do anything. After the ambulance took her father, she contacted the hospital for an update, but 2 hours later he was still in A&E.

59. ***Claire Smith*** recounts how a junior doctor told her mother that she was dying which left her mother distraught. She described how the remark by the junior doctor had haunted her as she tried to comfort and console her mother.

60. On other occasions patients had been in contact and said that no medic had been near them for hours. In the case of ***Claire Bloomfield,*** before her father passed away, he had telephoned her and told her that "*no one had come near him for 11 hours*". Ms Bloomfield contacted the ward and was told by a nurse that the staff did not realise that her father was a patient and they lost her father's test. She describes feeling "*bullied*" by the treating doctor and that his attitude toward her was highhanded and dismissive. After her father's condition deteriorated, she was presented with an ultimatum by the doctor that, if she gave permission to turn off his life support machine, she would be allowed to go and see her father. Ms Bloomfield made the heart wrenching decision to turn off her father's machine and has been haunted with the reasons for this decision ever since.

61. Whilst receiving treatment, certain powerful drugs such as risperidone and midazolam were administered at striking levels and frequencies to patients who were vulnerable, placid and even incapable of any physical exertion. ***Christine Tumlinson*** discovered that her father had been administered midazolam whilst in the I&S Hospital I&S I&S. She does not accept there was any reason for this treatment to have been administered. Again, it was only after her father had passed away and she retrieved his medical notes and records that she discovered he had been administered midazolam.

62. These accounts again support the conclusion that there were systemic failings in protecting the most vulnerable by failing to ensure that adequate steps were taken by those caring for them on the part of the state. It also suggests that there was inadequate preparation for the provision of PPE despite the known risks of an influenza type pandemic. It is not clear to our group whether these failings were resource driven, in that insufficient steps had been taken to secure necessary supplies, whether they were the response of poor preparation for implementing the distribution of such equipment, or whether it was due to inadequate focus on training relevant staff as to the necessity of such equipment and sanitation procedures during a pandemic of this nature. Our group also feel that the lack of patient-led and patient-centred care, that stopping treatment (covid and non-covid treatment) and stopping GPs seeing patients evidence a lack of care and compassion across the health and social care settings. Each of these explanations are relevant to the issues being considered by the Inquiry in this module.

Recommendations for the Future

63. We consider that the following lessons must be learned for future epidemics, pandemics or national healthcare emergencies in Northern Ireland:

a) In undertaking planning for future healthcare emergencies, greater emphasis must be placed on ensuring that the health and lives of the most vulnerable in our society are effectively protected in practice and their associated Carers [paid or unpaid].

b) Steps must be taken as a matter of urgency to ensure that the absence of a Northern Ireland Executive and Northern Ireland Assembly does not result (and will not result in the future) in pandemic or epidemic planning, as a devolved issue, being left in a constitutional or legislative vacuum.

c) Legislation should be introduced to ensure statutory duties for planning and preparation in this jurisdiction are in line with other jurisdictions under the Civil Contingencies Act 2004.

d) The Northern Ireland Health and Social Care systems must receive adequate levels of funding and have appropriate oversight mechanisms in place to confirm that funding is used effectively, to ensure that they are capable of responding effectively to future epidemics, pandemics or healthcare emergencies. This must include effective capability to protect the rights and lives of the most vulnerable in our society during these times. Never again should an impression be left that the most vulnerable in society have been abandoned to their fate during an epidemic or pandemic, or that they are left to suffer as a result of their very reliance on a healthcare system which is supposed to protect them. We have also seen public money thrown away at the pandemic but there was very little compassion for the elderly, children and those denied lifesaving medical treatments.

e) Related to (d) above, state authorities must be capable of acting quickly on up-to-date guidance regarding the risks posed by any future healthcare emergency and be able to respond in an informed and effective way to prevent those risks.

f) The importance of communication during a pandemic must be considered a priority in the future. This should include not just communication between agencies responding to the pandemic, but also communication with family members and those affected by the healthcare emergency. We must remember that some of the reasons for the Health and Social Care (Reform) Act (Northern Ireland) 2009 was that we would have structures in place that provided effectiveness and efficiency for patients, clients and carers. Our NICBFFJ group feel there has been a total failure around patient-centred and patient-led care.

g) The importance of informed consent for medical interventions, including DNRs, should be protected, by additional legislation.

h) There must be an acknowledgement of the importance of mental health for resilience in

response to an epidemic or pandemic. This should mean emphasis on the importance of being able to maintain social interaction, particularly for those who are vulnerable or otherwise isolated and/or cannot understand why they have suddenly been left isolated. The visiting restrictions were sadly in place for prolonged periods of time during 2020-2022.

Enforced separation must never be allowed again. Legislation must be recommended and introduced by the Inquiry team especially when we have a senior official from the Department of Health advising families like myself who was representing other families bereaved and others that "The Pathway is guidance, not law." [Visiting pathway that was live during September 2021].

Visiting must be enabled as a default position.

I believe visiting guidance across Hospitals and Social Care amounted to abuse (inhuman or degrading treatment or punishment) under Article 3 of the ECHR. The Social Care Institute for Excellence (SCIE) recognises different types of psychological and emotional abuse: "enforced social isolation", "failure to respect privacy","preventing stimulation..." etc. SCIE also state different types of organisational or institutional abuse: "discouraging visits or the involvement of relatives or friends", "lack of respect for dignity and privacy **(MF/5-INQ000226350)**."

i) I understand that breaches of a convention right are avoided in Public Inquiries and breaches of contracts but not always and there have been Inquiries where this has been done. I firmly believe given my own experience during the Covid-19 pandemic before my mother passed and afterwards up to 2022 (as I continued to be involved in a Task & Finish Group with senior officials from the DOH and its ALBs) that the only way forward to ensure real lessons are learned is to legislate to avoid enforced separation (with little or no mental stimulation), and ensure that patients/residents across healthcare systems maintain human contact and interaction with their families and/or close friends. This should also include acknowledgement of the importance of social rituals, such as wakes and funerals, for those who have suffered from such pandemics as a fundamental part of the grieving process. We have heard of so many families who were separated for months and years from each other, visiting was not proportionate (and inconsistent) across health care settings therefore we must have legislation for Care Partners for residents and patients before we face another epidemic, pandemic or healthcare emergency as I fear (like thousands of families across Northern Ireland) we will have a repeat of what happened during the Covid-19 pandemic [patients and residents were protected from their families to their deaths].

j) Consolidating legislation to identify the rights and obligations owed to users of the health and social care systems, and to provide or simplify appropriate mechanisms to effectively protect and allow those users to vindicate those rights in practice.

k) Consistent with (i) above, steps should be taken to ensure that, where Government policy is issued, particularly where this is to protect the rights of health and social care users, it is implemented in practice. There appeared to be a major power imbalance between the Department and the Care Home Providers which needs to be addressed and rectified. DOH guidance (also endorsed by the NI Executive) left the ultimate discretion in relation to visiting policies and the responsibility of resident welfare to individual Care Home managers/providers and Hospitals which resulted in a postcode lottery of access to residents and patients. There were no inspections by RQIA in the Independent Sector for many months and there was no way in which families could reassure themselves of the care provided to residents.

Never again should independent care homes be permitted to effectively ignore guidance published by the Northern Ireland Department of Health.

In my own situation (despite government guidance issued to Northern Ireland Care Home Providers in September 2020, I received an email from my mother's Care Home Manager I&S on 16th November 2020 at 17:40 hours which specified that I&S I&S will continue with our own organisational approach to the Care Partner role." We should remember that I&S is one of the largest providers of social care across the UK including Northern Ireland.

Such an outcome is not consistent with a coherent or user-friendly system and certainly not in the interests of residents and their families.

Again, legislation must be recommended and put in place by the Inquiry team given we already had regional contracts between I&S and providers that stated all guidance must be complied with. No agency in Northern Ireland appeared to have the power to make independent Care Home providers follow DOH guidance despite their contractual obligations with the Health and Social Care Trusts to comply with this. Many public authorities had responsibility for this sector but yet families were failed, patients and residents were failed and very little to no action was taken to protect those most vulnerable.

(a) Where laws are infringed, including fundamental human rights that protect life or prohibit treatment that is inhumane or degrading, there should be mechanisms in place to identify and hold those responsible to account, even in an epidemic, pandemic or healthcare emergency situation. This includes not just the individuals who have infringed these laws, but also those in supervisory roles who have permitted this to occur. This is required to ensure that the law is implemented and effective in practice. This is also required to prevent any appearance that there is tolerance of acts which amount to life-endangering behaviour and/or may have resulted to death.

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.

Signed Personal Data

Dated 28/11/23