Witness Name: TOM BLACK & MARTINA FERGUSON
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UK COVID-19 INQUIRY

WITNESS STATEMENT OF
TOM BLACK AND MARTINA FERGUSON, ON BEHALF OF NICBFFJ

We, Tom Black and Martina Ferguson, will say as follows: -

1. We are members of NI Covid Bereaved Families for Justice ('NICBFFJ') and make this statement in response to a request from the Inquiry for the purposes of Module 6.

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 coordinating activity in Northern Ireland, in particular coordinating 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, an absence of wellbeing and communication during end-of-life care (EOL), or to address detrimental impacts arising from failures to implement effective policies, including those intended to benefit the most vulnerable. The aims were to ensure visiting rights for residents, patients and their loved ones, to 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, operational decisions and guidance that was not working at both ground and operational levels.

5. 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, a fact that was also discussed when our campaign leads met with all five of the Northern Ireland political leaders during the summer of 2022.

6. 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.

7. 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 in 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.

8. 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.

NICBFFJ and views on Module 6 generally

9. This Inquiry is considering a vast amount of material and information. NICBFFJ is able to assist the Inquiry not because they were involved in compiling high level policies or plans, or the implementation of safeguards, but because, in contrast to many of those in authority, we have first-hand lived experience of the outcome of those high-level plans and policies, generally in distressing and tragic circumstances.

10. The fact that we are a diverse group of individuals adds particular weight to our evidence in circumstances where the issues we raise are common or frequent across many members of our group, as this tends to suggest that only systematic failings could have resulted in these common and tragic experiences.

11. This module is examining the Care Sector, and touches on experiences of a significant number of our members. Statements on behalf of NICBFFJ have previously highlighted what we consider to be thematic issues which have arisen in relation to or across modules, and our members experience of the care sector is no different. These include:
    (i) Inadequate measures to protect those in care homes against Covid 19;
    (ii) Inadequate provision/use of PPE within care settings;
    (iii) Failure to effectively use PPE, testing, or (after vaccines had been developed) vaccination, to lessen restrictions on visiting;
    (iv) Staffing issues – the impact of low staffing levels resulted in detrimental care and/or a failure to effectively protect against Covid 19 infection.
    (v) Dissolution of discipline and the impact of isolation, providing a window of opportunity for malevolent actors;
    (vi) The belief that loved ones did not "catch" Covid 19, but were rather "given it" in hospital or care home settings;
    (vii) The apparent policy of "flooding" care homes with patients from hospitals. *(Reverse Triage)*
    (viii) Failure/delay in diagnosing Covid 19 either by GP or in hospital/care home settings.
    (ix) Insufficient, inadequate or inaccurate communication/updates to family members about the care of their loved ones and their state of health, patronizing or paternalistic communication, and even suppression of facts;

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

(xi) Use/misuse of palliative care in care home settings.

(xii) An institutional pessimism/resignation/fatalism in relation to those in their care on the part of health professionals, leading to decisions not to provide treatment, or alternatively policies or practices of care/treatment rationing;

(xiii) Loved ones dying alone;

(xiv) The denial of funeral rituals;

(xv) The detrimental impacts of isolation, due to families having little or no contact with loved ones while in hospital/care home settings;

(xvi) The inaction/quietude of agencies/statutory bodies to whom families reached out during the course of the pandemic;

(xvii) Political/institutional failures continuing throughout the pandemic (i.e. lack of lessons learned) and being at the heart of failings.

12. In this statement we will outline some of these thematic issues, identifying some examples from our members to demonstrate the concerns. The Inquiry will appreciate that there is some overlap between these issues, and so we do not propose to treat each of them individually. We also emphasise that not all of our members wish their own cases to be specifically raised or their names used, and the particular cases identified are therefore raised only as a sample of NICBFFJ members' experiences.

13. We will then outline the details of the deaths of our own relatives, Kathleen Black and Ursula Derry, and highlight the extent to which a number of the concerns raised were also a feature of their care and their deaths. One reason we are taking this approach is to demonstrate that the concerns raised are not at all isolated, but rather most of our members raise a number of these common concerns which

suggest there were a series of systemic flaws in the care and treatment of their loved ones by the Care Sector during the pandemic.

Inadequate measures to protect care homes against Covid 19

14. One of the most commonly raised concerns is that there were inadequate measures in care homes to protect residents from Covid 19, whether this be related to inadequate provision or use of PPE or testing, or inadequate measures to protect against the spread of Covid-19 once a case or cases were identified in homes.

15. Basil Elliott, the brother of our member Anne Elliott, passed away after contracting Covid in his care home in I&S Anne had been vocal, both to the home and to entities such as the RQIA, in raising concerns that there were inadequate measures to guard against Covid 19 in the home, including flooding of the home with patients from hospital, and the inadequate use of PPE. Basil passed away in December 2020, and Anne believes this was roughly four weeks after a number of staff in the home had gone off sick with Covid 19. She believes this confirms that her concerns at the inadequate use of PPE were realised as, whatever measures were in place, they were clearly inadequate in practice to prevent the spread of Covid among care home staff and patients. Anne believes that this cost her brother his life.

16. Bridget Halligan was the mother of our member Agnes McCusker. Bridget passed away after contracting Covid early in the pandemic in a care home in I&S. Agnes describes attending the home on a number of occasions to bring items or medication for her mother. She would dress in PPE on such visits, in order to protect residents and staff, only to be met by staff members who were not wearing any PPE. She is concerned that this showed a failure to protect residents from Covid transmission despite the extreme measures which had been introduced to

isolate residents within the home. Her concerns were reinforced as she believes that another resident had been sent to hospital then re-admitted to the home shortly before her mother contracted Covid, and that this resident also died from Covid in the days after her mother passed away. Inadequate use of PPE in these circumstances clearly placed other residents in the home in unnecessary risk. After her mother contracted Covid in the home, staff also advised Agnes that they would go in to see her mother without wearing PPE. Agnes again did not understand the reason for this. Although it was early in the pandemic, the risks of transmission and the importance of PPE were known from an early stage, and were known to Agnes.

17. Agnes is also concerned that the lack of proper staffing meant that infection protocols were ineffective in practice. For example, she identifies that only two nurses and two care assistances were on duty in the home on the night her mother passed. Due to visiting restrictions Agnes could not be there, and as a result no-one was with Bridget when she passed, which is something that haunts Agnes. A time of death could not therefore be precisely identified. Bridget would have turned 100 this year. Instead, she passed away on Easter Sunday 2020.

18. Paula Creighton's mother, May Shanks, passed away after contracting Covid in a care home in I&S in November 2020. Paula's concern was that this was many months into the pandemic, and those running and staffing the home should have by then learned how to deal with the virus and how to prevent residents in the home being infected. Instead, Paula was left with the feeling that her mother had been exposed to the virus in the home.

19. A frequently raised concern amongst our members is that there was effectively a culture of denial in homes when there were cases of Covid 19. The failure to acknowledge and address reality in some cases appeared to result in the spread of

Covid within the home, and inevitably a greater number of preventable deaths. This culture of denial is highlighted in the description of Ursula Derry and Kathleen Black's case below.

20. One point which we consider should not be lost is that the consequences of the spread of Covid within homes were not always confined to the homes themselves. Our member Patricia Brooks herself worked in a care home in Belfast during the pandemic. At the start of the pandemic, she was required to shield due to a pre-existing condition. When shielding advice was lifted, she returned to work and to care for residents in the home. She describes not being informed that one of the residents she was caring for had symptoms of Covid until after she herself had tested positive for the virus. Although Patricia herself recovered, by then her mother Anne Brooks tragically became infected, and sadly passed away as a result.

21. Patricia's case is significant given her position as a worker in a care home. Many of our members experience of care homes was grounded in the experiences of their loved ones in the home, and their knowledge of failings comes from their observer status or, for some, is limited to informed suspicion, coupled with experiences which arguably only allow the inference (albeit a strong and informed one) that such failings occurred. As a member of staff in a care home, Patricia's experience confirmed that there was a lack of communication about important information for preventing the spread of the virus. She can identify in reality that, well into the pandemic, there was a lack of communication between managers/senior staff regarding handovers with patients who were displaying symptoms , and describes how staff were expected to care both Covid patients and non-Covid patients on the same shift, without adequate measures to protect against infection. She describes how staff were fit-tested for respirators, but how those respirators were then not provided or used, with the advice to use surgical masks instead. She reports that the hygiene in the care home was poor and there

was little to no ventilation due to the age of the building. She also raised an issue with the use of agency staff as creating greater risks of exposure to the virus.

The belief that loved ones did not "catch" Covid 19, but were rather "given it" in Hospital or Care Home settings.

22. Inextricably linked to the apparently inadequate measures to protect against Covid in care homes is that many of our members describe feelings to the effect that not only were their relatives not protected, they were positively exposed to the virus and "given" Covid as a result of the procedures or actions of those charged with caring for them.

23. Ann Archer had five children and thirty grand-children, and was a happy woman who was loved amongst her local community. She was also the mother of our member Nicola Archer. Ann was placed in a home in Belfast in January 2020 for respite, only because Nicola's father had broken his hip. Nicola describes being informed how another resident had been admitted to the home with Covid in March 2020, but being advised that there were procedures in place to deal with this. Despite this, the home held a party with staff and residents around Easter 2020, and videos of this party were then publicised in the media exhibit TBMF/01/INQ000520345. Nicola received a call not long after this party to advise that her mother had tested positive for Covid. A DNR was placed on her medical records without discussion with the family, and they later received a call to advise she was being put on a syringe driver. Ann passed away on 29th April 2020. Her family were not offered an 'in-person' visit before she passed away, and were denied a wake or normal funeral. They were left with the feeling that Ann had been given Covid in the home and then simply abandoned to her fate on her own.

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

24. The view of the NICBFFJ group members is that there was an apparent presumption of consent to the imposition of DNR notices by medical professionals in circumstances where family members were adamant that their loved one would never have consented to such an imposition, or was not in a position to provide consent at the relevant time, is a concern repeatedly raised by our members and is one which the Inquiry is well aware from previous modules.

25. Ann Archer's case, noted above, identifies that her family was one of the many families who were not consulted about a DNR notice being placed on their loved one.

26. The case of Kathleen Black (addressed below) identifies a different misuse of DNR notice, where it appears to have been used to justify a decision to restrict other treatment and a decision not to bring Kathleen to hospital when her condition deteriorated.

27. Many of those who were bereaved have highlighted the necessity/imperative for legislative reform in this area in order that, at the very least, clarity and provision of information to patients and loved ones prior to the imposition of DNR notices become legal norms.

An institutional pessimism/resignation/fatalism in relation to those in their care on the part of health professionals (nurses, doctors, care staff, ambulance crew).

28. This has been frequently mentioned/detected by a number of family members, who describe the feeling that medical professionals had *"given up"* on their loved ones. The family members in question have expressed shock that such a mindset

was prevalent on the part of those whom they expected to be resolved to preserve life.

29. This is an issue linked to the improper use of DNR, identified above, but the extent to which it extended beyond that issue is highlighted by a number of our members, including the case of Kathleen Black, outlined below.

30. This was also a feature of Agnes McCusker's experience after her mother Bridget contracted Covid in her care home. Agnes describes asking staff in the home what they would do if her mother's condition deteriorated. One of the critical care team advised her that they would not be sending her mum to hospital, as they said that someone who was forty years old would be treated before her.

31. The repeated nature of such concerns on the part of our members supports a conclusion that there was in fact a practice of placing a ceiling on the care of older or more vulnerable individuals after they had contracted Covid, who were treated as less worth saving than those who were younger or perceived as being less vulnerable, whether or not there was an official published policy to this effect.

32. This issue is also linked to the use or misuse of palliative care, which is another issue of concern repeatedly raised by our members.

The detrimental impacts of isolation, due to families having little or no contact with loved ones while in a care home setting.

33. The Inquiry is already familiar with NICBFFJ's concerns that the detrimental impact of isolation was not only limited to mental health, but also physical deterioration, as in many cases it allowed inadequate care in circumstances where there was no-one to speak up for the vulnerable. This is a feature of the cases of

both Kathleen Black and Ursula Derry described below. Ursula Derry's case in particular highlights the apparent lack of consistency or necessity in the draconian length of isolation imposed on many care home residents. That is because Ursula was admitted to hospital for a period in summer 2020, at which point her daughter Martina was able to visit her in person on a daily basis, something that was denied to her in the care home both before and after her hospital admission. This made no rational sense. The scale of deaths in care homes suggests that these draconian visiting restrictions were not only ineffective. Ursula Derry's experience also suggests they lacked real justification.

34. There is also significant evidence that these restrictions caused or contributed to deaths, to the extent that they permitted serious failings to those in care. This was again highlighted in Ursula Derry's case, where neglect was only identified once Ursula was admitted to hospital in summer 2020 and Martina was then able to visit her in person. Martina comments that her mother was "*protected to her death*".

35. The Inquiry will also recall that this was a feature of the case of Marie Reynolds, the aunt of Marion Reynolds who gave evidence on behalf of NICBFFJ in Module 2C. Marie was profoundly deaf, and had suffered with eating disorders throughout her life. Had Marion, or another family member, been permitted to visit, they could have assisted Marie with eating and drinking. Instead, when Marion finally managed to get in to see her aunt after a number of weeks in a care home, she found her dehydrated and emaciated, and believed she was close to death. She also found her wearing someone else's clothes, despite her own clothing having been left for her, and found the TV in her room was not plugged in.

36. The restrictions on visits by loved ones, as well as on professionals, also gave rise to a concern that procedures were not being followed given the lack of outside

visitors. Margaret Whyte was the mother of six children, including our member, Terry Whyte. She had all her faculties but was admitted to a nursing home in Belfast after a stroke. Terry believes his mother deteriorated significantly as a result of the lack of in-person visits. However, he also believes that staff were lax as a result of the lack of family members (or others) not being able to physically visit the home. He describes one occasion when he had visited and could see through his mother's window that the nurse tending to her was not wearing PPE. He describes this nurse then seeing him and leaving, then returning wearing PPE. It gave the impression that protective measures were not being taken seriously, and that there was inadequate oversight as a result of the lack of visits. Margaret passed away in January 2021 after contracting Covid in the home.

37. The fact that care homes were permitted to impose such draconian isolation requirements suggests a failure at a high level to appreciate the importance of in person visits for residents of care homes, for both their mental and physical health. That conclusion was sometimes reinforced by decisions of the Department itself. A few days before Christmas 2021, the DOH issued guidance stating that the definition of a "fully vaccinated" NI care home resident was a resident who had 3 doses of vaccine. This different from the definition used by the UK Government, who regarded fully vaccinated as 2 doses of an approved vaccine, or one dose of a Janssen vaccine). This decision meant that residents who had been doubly vaccinated and hoping to spend Christmas with their families, or to take a trip out for coffee, were suddenly unable to do so without experiencing 14 days isolation and undertaking lateral flow tests for 10 days following their return. As a consequence, many Christmas plans were cancelled. We respectfully suggest that this consequence was inevitable, and detrimental insofar as it reinforced isolation of those in such homes, and that this should have factored into the decision.

Communication Failings

38. In light of the isolation imposed on those in care homes, flaws in relation to communication were particularly concerning to many of our members. These include concerns that care homes were not up-front in identifying the Covid was present in a home, or providing accurate information about the condition, care and treatment of loved ones.

39. Linked to inadequate communication is the issue of positively detrimental communication, where care home staff were condescending or even accusatory in their communication with loved ones. By way of example, Paula Creighton raised concerns about the health of her mother, May Shanks, after a window visit where it appeared that her mother was out of breath and delirious. When she raised her concerns with the head nurse in the home it was suggested that the family were at fault, and that her health issues were because her mother was overweight due to snacks and treats they had brought for her to the home. This was profoundly offensive, and also suggested a failure to acknowledge the presence of Covid in the home, which is inconsistent with taking effective steps to prevent transmission in such a vulnerable environment.

40. As noted above, although the breadth and frequency of these issues being raised by NICBFFJ members is significant, there is also significance in the frequency with which such issues are apparent in individual cases.

41. With that in mind we would wish to set out the details of the circumstances surrounding the deaths of our own loved ones.

Kathleen Black

42. I, Tom Black, met Kathleen when I was 17 and Kathleen was 20. We married on 3 July 1971, and had one daughter, Gail.

43. Kathleen tragically died as a result of Covid on 4 June 2020. I believe her case demonstrates a number of significant failings of relevance to this Module, and also reaffirms concerns on the part of NICBFFJ that many failings were systemic in nature.

44. Kathleen had been diagnosed with Alzheimer's in 2011. From July 2012 I gave up my job. I had worked almost all my adult life, firstly for BT for 32 years, then for HMRC. I retired on 31 July 2012 to become Kathleen's full-time carer. I cared for Kathleen in our home as long as I physically could, before she was admitted to I&S care home on 30 November 2015.

45. After Kathleen was admitted t I&S, I spent a lot of time in the care home. I visited Kathleen every day, and during my visits I became very friendly with the other residents and staff members and got to know them all well. Because I was there so much I grew to understand the routines in the home, staff shift patterns, and the different care needs of other residents. I knew the details of the notes that were taken, recording food and drink brought and taken, and medicines recorded on a Kardex. At times I would even have helped to care for the other residents, for example, by helping to feed them. I felt like part of the furniture.

46. I did not have any concerns about the home or the quality of the care provided until Covid hit, save in one respect. From long before Covid arrived, when regular nursing staff were absent and agency staff were required, it was clear that they did

not know the basics when it came to specific care needs of the various residents, and would frequently attempt to give food or medicine the wrong way. By way of one small but significant example was a resident who tended to pour orange juice on their cornflakes if given them together, and so staff in the home knew not to give their cereal and orange juice at the same time – in order to ensure that the resident ate their breakfast. I saw agency staff attempt to give this resident orange juice with cornflakes and would have let them know not to do this. I assume such specifics would have been recorded in patient notes, but if it was either it was not done in a way that agency staff would notice, or else they were failing to have regard to such notes.

47. I believe this was significant despite it appearing to be the down to the granular level of care needs. Such individual details are significant for many residents of care homes, especially those with dementia. Kathleen, for example, had been on what was described as a "stage 3 diet", which meant she required her meals pureed. This also meant that she required her medication in either liquid form or crushed up in her meals. She therefore had to wait to eat breakfast until the medication was brought round. If this was not appreciated, and if she was brought her breakfast first, or if she did not eat her meals, it meant she would not get her medication. That was obviously significant for those caring for her to know and take into account.

48. Sadly, Kathleen could no longer speak. This meant I was frequently required to speak for her. Normal nursing staff would have known not to give Kathleen her food until medication was brought, but I would not have trusted agency staff to be aware of this and to ensure it happened. This created obvious concern when I could not attend the home during Covid, and when normal staff were also off, as I was very concerned that agency staff would not be capable of ensuring that Kathleen's care needs were met.

49. On 14 January 2020 I had signed a DNR form on Kathleen's behalf, and within days it was entered into her records at her GP surgery. I understood then and continue to believe that this DNR form meant that she would not be resuscitated in the event she had a cardiac arrest. To be very clear, it did not mean that if she contracted a life-threatening illness that a ceiling could be placed upon her care, that she should be denied any other medical care or treatment, or that her life was not otherwise worth protecting or saving.

50. In early March 2020, I had taken a holiday with a friend to Florida to play golf. While I was there the news about Covid really took off. I got the last flight out of Orlando on 16th March, which I believe was shortly before the USA closed their borders.

51. At that point there was talk in the media that Covid could be transmitted asymptomatically. Because of this, and because I had been travelling, I had decided not to go to see Kathleen even before a decision was taken to close care homes to visitors. When I arrived back, I contacted the home to tell them that I would not be visiting, but also to ask them not to bring Kathleen into the lounge at that stage due to the risks from Covid.

52. I now understand that a patient was discharged from hospital into Kathleen's care home on the date I had flown home, on 17th March 2020. I was informed that this had occurred by I&S I&S, who told me this on 17th June 2020, shortly after Kathleen had passed away.

53. On 25th April 2020 I was advised that Kathleen had a temperature and would be tested for Covid, and the following day I was informed that the test had been

positive. I understand from Kathleen's medical records that her GP surgery was informed of the positive test the following day. What was also striking about those notes however was that, on the same date, her GP surgery again made a note of the DNR form which I had signed in January, and which the home had already recorded. It is not at all clear to me why this would need recorded again, particularly when this was at the same time that a positive Covid test was recorded. This gives rise to a number of concerns, including:

(i) That the DNR form was being used to guide decisions over care and treatment beyond a decision not to resuscitate after a cardiac arrest;

(ii) The immediate resort to the DNR form gave the impression that Kathleen had already been given up on.

54. The Inquiry will appreciate from the contents of this statement that these are concerns expressed by many other members of NICBFFJ in relation to the treatment of their loved ones.

55. In and around this time, and for around two weeks, the staff who normally would have cared for Kathleen seemed to all be off due to Covid, either with the illness or otherwise required to isolate, and it seemed to be mostly agency staff caring for her instead. Just about the only normal staff member during this time seemed to be the assistant manager. This was very concerning for me, not only because it suggested that the measures the home had in place to prevent or limit the transmission of covid had comprehensively failed, but specifically in relation to Kathleen's case this was concerning given my previous experiences of agency staff identified above.

56. On 4th May I was advised by assistant manager I&S that a fellow resident of the care home named Gordan passed away in hospital as a result of Covid. I had been fond of Gordan. He had been in his 60's, and had a bit of

devilment but in a manner that meant you couldn't not like him. I remember him clearly turning to look at me with a playful grin immediately before pulling down Christmas decorations from the mantlepiece in the home. I was also aware of some of his care needs due to the amount of time I had spent visiting the home. For example, I had noticed one morning that agency staff had been trying to give him tablets, which was not how he took his medication, and had advised them of his needs. I was sad to hear he had passed away. I also note that he had been admitted to hospital, and will return to this below.

57. On 7th May I was advised that Kathleen had oral thrush, and that mouth wipes and paracetamol suppositories had been prescribed. I later found out that a nurse had telephoned I&S an out of hours GP services to speak to a GP as Kathleen could not swallow, and a doctor prescribed the mouthwash for oral thrush over the phone. One concern of mine was that Kathleen did not have oral thrush but was in fact unable to swallow was due to a side effect of Covid, however as a doctor did not examine her, I cannot say if this concern is correct.

58. The following morning, around 8.40am on 8th May 2020, Kathleen's medical records show that the assistant manager from the care home had again telephoned I&S out of hours requesting paracetamol suppositories but was told they had been prescribed the day before. One thing that causes me real concern is that this was in relation to pain relief medication, and the nurse was apparently so concerned that Kathleen should benefit from this that she called out of hours rather than waiting the 20 minutes before Kathleen's GP surgery opened. I am also concerned because Kathleen would have been given co-codamol as pain relief if she was agitated. It is not clear why paracetamol was needed if she was in fact being administered co-codamol. I am concerned that this suggests that Kathleen was not getting her co-codamol, which suggests she was either not eating her food or was not given it with her food.

59. On 9th May 2020, myself and my daughter were advised that I&S out of hours had prescribed an antibiotic for viral pneumonia. We were not told that Kathleen had been seen by a doctor in person at this stage. Kathleen's medical notes state that her oxygen reading was 92% and that she had difficulty swallowing and chestiness. The doctor warned that if her condition worsened to contact the GP or send to hospital. One concern I have is that she was never brought to hospital, and that although this advice appeared in the doctor's note, it did not appear elsewhere in Kathleen's medical records, suggesting no note had been made to this effect. Without such a note I would not have had confidence that this would have been remembered and acted upon, particularly where the normal nursing staff were absent.

60. On 12th May I was advised by a nurse from the home that Kathleen's antibiotics were finished, and she needed another course, even though she was supposed to have been prescribed a 5-day course. The following day I rang the home to ask if the next course of antibiotics had been requested from the surgery, but they had not been ordered. The nurse I spoke to agreed to ring and request another course. I understand, again from medical records, that a different doctor from Kathleen's GP surgery prescribed another 5-day course of antibiotics, one tablet twice a day. Instead, the medical records suggest that Kathleen was brought capsules, which she was unable to swallow. As noted above, she required medicine in liquid form or tablets ground and mixed with her food. This cannot be achieved with capsules.

61. Records suggest that this second supposed five-day course of antibiotics was recorded as finished on 15 May, after only 3 days. As I identify below, I cannot be sure that the antibiotic prescribed on 13 May was finished on 15 May as these records from the care home which would show this have never been provided to me. However, I do know that the antibiotic which was prescribed on 9 May (a

liquid antibiotic for the treatment of pneumonia) was again prescribed on 16 May. The antibiotic capsules which had been prescribed had been a general antibiotic.

62. On 16th May 2020 Kathleen's notes shows that her oxygen levels dropped overnight to 88%, and that she was given oxygen. I received a phone call from a nurse in the home to advise that I had a choice of sending Kathleen to hospital or for her to remain in the care home. I was told that if she was admitted to hospital at that stage that she would only receive end of life care. Myself and my daughter together decided that Kathleen should remain in the care home. We believed that if she would receive only end of life care in either place then she would be better in a place she was used to rather than a strange hospital.

63. I was therefore asked to collect a prescription from I&S Hospital. After I had done this a nurse in the care home identified that it should have included the liquid antibiotic. That nurse rang I&S surgery about this, and they apologized for missing it from the prescription, and provided another prescription for this.

64. Kathleen had not really eaten since around 12th May, and as a result she lost a lot of weight. Given how long she survived after contracting Covid, I believe it was really the lack of food and drink which lead to her death, combined with pneumonia, rather than Covid itself.

65. On 22 May, my daughter Gail had called the surgery to plead for subcutaneous fluids for Kathleen, and the doctor at that stage prescribed a two-day course. However, after that they declined to prescribe another such course, suggesting that this was prolonging the inevitable.

66. I am not medically qualified, but by this stage I assume that Kathleen was suffering from complications which had been caused by Covid, and not from the virus itself, as she had tested positive around a month previously.

67. As her condition deteriorated, and because of the length of time since her positive test, in her last days the nursing home permitted me in to visit her in person. By way of example, on 2nd June I was allowed to stay with Kathleen in the home until tea time. Prior to this, since I had been away in the US in March at the time Covid started to really hit, and I had only seen her in person for 10 or 15 minutes since my return. This was very difficult for me as I was used to seeing her every day. I was therefore very grateful to have been able to visit her in person.

68. When I went in to see her, I was offered a plastic apron and a mask, however, instead a friend had some full body protective suits which he lent me. These were size XXXL, and while this was big on me, my daughter also wore one when she was permitted a visit. Helping to put this suit on my daughter, who is a size 10, was an experience.

69. On 3 June I was again permitted to visit Kathleen in person, however when I was leaving on that occasion, I was told by a nurse caring for Kathleen that another nurse in a different unit had complained that I had been "*visiting too much*" and it was suggested that I may not be allowed back. I found this very upsetting and queried this with the manager, who confirmed that I had permission to continue visiting Kathleen.

70. I was again allowed in on 4 June, which was the day Kathleen passed away. I was with her when she passed. I am very grateful I was permitted this opportunity, and realise that many others did not, including many members of NICBFFJ.

71. A nurse on the same day had suggested that Kathleen had needed intravenous antibiotics which could only be administered in hospital. I had also been advised that there were only three other residents in the home with Katherine on that day, including one resident who had been in hospital with Covid, but had since returned to the home. There had previously been fourteen residents, and I was later informed that ten had died of Covid in the short period from 17 March.

72. On 3 June I had been asked whether I wanted Kathleen to be buried in her nightdress or something else. The following day I brought one of her dresses from home, and she was dressed in that to be buried. Kathleen had been a size 12 or 14, but the dress, which usually fitted her, absolutely drowned her due to the weight she had lost. This reinforced my belief that it was not really Covid which killed her, but its consequences, including the fact that she was not eating or drinking as she was unable to swallow. That conclusion was supported by the fact that two nurses from the care home had contacted Kathleen's surgery due to her difficulty swallowing.

73. Kathleen had passed away at around 6.30 pm on 4 June 2020. At that stage I had to ring the undertaker to advise them to come and pick her up. I had to google to identify an undertaker who would do this where Covid was identified as a cause of death. I was also told I could not leave the home until someone had certified Kathleen had passed away.

74. My daughter Gail had travelled to the home on 4 June, but had waited for me in the car park as she didn't want her last memory of her mother to be from that day. Although Kathleen had passed away at 6.30pm I had been asked to wait in the home until death was confirmed. I had not wanted to call my daughter to tell her that her mother had passed away, but wanted to tell her in person. I could see her in the car park but had not been able to leave until death was confirmed. At around

8pm a nurse from I&S arrived to certify death. Gail was still sitting in the car park, and seeing this person arriving and getting suited up she knew her mother was dead, and that the person was there to confirm this.

75. Kathleen was then put in a black body bag and not taken out of that. I was told this by the nurse. The body bag was placed in a coffin and the coffin then sealed. We were not permitted to have a church service with her funeral. We were told by the undertaker that we could have a service with 12 people in nursing home or at the graveside. I was also told that I could not publish details of the funeral in the paper, and was only permitted to announce the death.

76. I would have liked a church service for Kathleen. She came from a big family, had two sisters and three brothers, and they had their own family and, ideally, they all would have been there. Instead, we were limited to 12 people and the minister at the graveside. I do not believe this was a proper burial for Kathleen, she deserved more.

77. Shortly after the funeral I met with the management of the care home on 17 June, to seek information and raise concerns about Katherin's care.

78. One matter I raised was the fact that the first doctor to see her had advised that she be brought to a doctor or the hospital if her condition deteriorated, but this had not occurred. I asked why she had not been brought to hospital at all, not even when her condition worsened. As if by way of an answer, the care home manager left the room, returned a few moments later and placed a copy of the DNR I had signed in January on the table. She also insisted I take a photocopy of this DNR with me at the end of the meeting. The clear implication was that, after I had signed this DNR form, it had been interpreted as meaning that Kathleen should not be brought to hospital. If that is what happened, and I have no reason to doubt what

was being suggested, then it was plainly wrong. The DNR I signed was not intended to suggest that she should not be brought to hospital or benefit from treatment which would help her condition.

79. I was so concerned about this that I contacted Katheleen's GP surgery two days later, to confirm that there was no note that Kathleen was never to be brought to hospital again. A doctor confirmed this, though when asked why Kathleen wasn't brought to hospital after contracting Covid, she advised that Kathleen received the care that she would have received in hospital as she received antibiotics and oxygen. As will be apparent from the above, it is not in fact clear to me that Kathleen did receive the antibiotics prescribed for her, whereas if they had been delivered by drip it would have been clear that they had been administered. Kathleen had also only received oxygen once end of life care was implemented, that is, 16 May 2020. The doctor's assurances therefore did not allay my concerns.

80. Thereafter I sought to make some complaints and seek answers about Kathleen's treatment. On 30 July I made a formal complaint to the care home. On 28 August I received a response stating that it was up to the medical professionals to send Kathleen to hospital and that there was some hesitancy sending residents from care homes.

81. On 8 September my solicitor wrote to the care home asking them to confirm that:
    (a) The DNR did not influence their decision not to request hospitalisation for Kathleen;
    (b) There was no other instruction from me (or anyone) that Kathleen was never to go to hospital again; and that
    (c) I was not consulted about hospitalisation prior to 16 May 2020 (at which point it was too late to make any difference).

82. On 16 September a solicitor for the care home requested more time to consult medical records before providing a response. On 30 October a reminder was sent to the care home solicitor. A response to my queries was not then received and in fact has never been provided.

83. On 3 December 2020 I made an official complaint to the Northern Health and Social Care Trust by email. There was no response or acknowledgement to this. Ironically the next day, the Minister for Health Robin Swann made an announcement on BBC news that no elderly person would be denied access to hospital.

84. At the end of December 2020, I had also sent some FOI requests to the Department of Health seeking details of the number of care home residents who had died as a result of Covid. I sought this information as I was concerned that Kathleen had just been abandoned to the virus, that it seemed that many others in her home had also died as a result, and it appeared very likely to me that this as not an isolated occurrence but had occurred in many other such homes. I received in April which quoted section 41 of the FOI act, suggesting the information was confidential and not in the public interest. I would suggest that this information very much is in the public interest.

85. After I resubmitted my complaint, the Northern Trust eventually responded on 16 February 2021. In that response, they stated that Kathleen had received treatment in the home as she had received antibiotics and oxygen. As noted above, this answer was not sufficient to allay my concerns.

86. In January 2021, I requested a copy of Kathleen's medical records from her GP surgery, and I collected these in February 2021.

87. Following this I engaged in a complaint process with NHSCT, including attending a zoom call with them after I found their responses unsatisfactory. I contacted the PCC who assisted me with this zoom call, including by attending with me. The call took place in mid-April. An official from the Trust advised that at the time of Kathleens death it was thought that elderly residents would be better cared for in familiar settings, and suggested this was why she was not admitted to hospital. I did not and do not accept this response given that two residents from the same suite as Kathleen were sent to hospital. After I followed up this meeting by requesting minutes, I was eventually told (2 November 2022) that none had been retained.

88. I sought Kathleen's GP records from I&S and obtained these in November 2021. These showed that the DNR had been recorded in January 2020, and then re-entered on 27/03/2024, that is, the date the surgery had been informed that Kathleen tested positive for Covid.

89. In November 2021 I wrote to I&S surgery to ask why Dr I&S had not had Kathleen admitted to hospital. On 14th December Dr I&S from I&S Surgery responded advising that Kathleen was not sent to hospital as he was told by a nurse in the care home that Kathleen had improved and that he had no guidance on who he could send to hospital. I was then offered a meeting in the surgery with Dr I&S That meeting took place in January 2022, with Dr I&S and I&S It was during this meeting that Dr I&S queried why the antibiotics only lasted 3 days and 2 days when the course was for 5 days. It was also made clear that it was not apparent who had diagnosed Kathleen with oral thrush (as opposed to her difficulties swallowing resulting from Covid).

90. The PCC also assisted me by seeking Kathleen's medical records from the care home. As a result of gaps in these records the PCC followed these up by requesting further information from the care home in April 2022. A meeting was subsequently

arranged with care home management in September 2022. At that stage I was informed that important medical and dietary records had not been found and may have been misfiled.

91. I have also made a complaint to the ombudsman in relation to Kathleen's care and treatment, and am waiting for their response. I understand they have sought an opinion from a medical expert to inform that response.

92. I have a number of concerns about all of the above, which overlap with many of the concerns NICBFFJ have repeatedly identified.

Inappropriate use of DNRs

93. One of my greatest concerns relates to the apparently inappropriate use of DNR. In Kathleen's case it was effectively suggested that my signing the DNR implied an acceptance that she should not be sent to hospital, or that it was used to justify such a decision. That was plainly wrong. This reinforces the feeling that Kathleen was simply given up on and abandoned to her fate.

94. This has left me with a lasting guilt I have had to live with, the fact that I signed the DNR and the possibility that it contributed to her death, along with my own questioning as to whether, if she had been admitted to hospital around 9 May or shortly after, would she have survived.

95. I know that at least two people were admitted to hospital from the home with Covid, but do not know whether there were DNRs in place for those residents. I did ask whether any residents with DNRs were admitted to hospital with Covid but was told by care home staff that such information was confidential. I am not sure why it would be confidential, as I do not need the names of the individuals,

just an understanding of whether this was in fact the policy and whether it was followed in all cases.

96. It also appears to me that the failure to have Kathleen admitted to hospital, or to otherwise ensure she was treated by a doctor, went against the guidance in place at that time. Before meeting with the care home, after Kathleen's death, I downloaded the guidance for Nursing homes which had been issued on 26 April 2020. That was the day I got the call to say Kathleen was Covid positive. The guidance itself said the home should have escalated to the GP surgery within 7 days and should have talked to me and daughter about Kathleen's care. The fact of the DNR should also have been discussed.

97. When I raised this with the care home, they replied by suggesting I probably did not have the right guidance. When I insisted, they told me that guidance was only guidance, which I do not think is an acceptable explanation, and which is another repeated concern in the part of NICBFFJ as identified elsewhere in this statement. When I went to the meeting with Dr I&S and the surgery, they did not seem to know the guidance even existed, raising separate and additional concerns.

98. These responses are consistent with concerns raised by many members of NICBFFJ about responses to concerns of the bereaved being inadequate condescending or inappropriately dismissive.

Inadequate Measures to Protect Care Home residents from Covid

99. I am concerned that the measures which were in place to protect residents of care homes were either ineffective or not followed in practice within care homes. As I identified above, I was very happy with the home until Covid hit, and that

suggests to me that the guidance issued was issued too late or was not adequate or both.

100. I had some concerns about the measures in place, and whether they were sufficient or being adhered to. I was concerned about staff moving between wards, or being required to wear PPE in the home but then being permitted to mingle in close proximity with each other without PPE, for example, in an outside smoking hut. I was also concerned, for obvious reasons, that a resident who had tested positive for Covid was returned to the care home shortly before Kathleen contracted the virus, although I am not sure whether this individual was in the same unit as Kathleen. I also heard from one member of staff that another member of staff had tested positive but was asymptomatic, and was therefore continuing to work as they needed the money.

101. However these concerns are in some respects merely illustrative. The greatest concern for me is that, overall, the scale of Covid infections in the home must mean that measures were inadequate to protect staff and residents. As I noted above, 10 of the 14 residents in Kathleen's unit in the home died from Covid, and one other was admitted to hospital as a result of Covid but survived. For the first fortnight after Kathleen contracted Covid, almost all the staff who would usually care for her seemed to be off sick with Covid or otherwise isolating. I do not believe that this could be consistent with following timely and effective guidance, which is adequate to protect the lives of care home staff and residents. In fact these numbers suggest these residents were abandoned to their fate.

102. Despite these numbers, in the weeks after Kathleen's death I telephoned officials from the RQIA, among others. They advised that they had inspected Kathleen's home and found nothing wrong. It is difficult for me to see how so many people in the same unit could have contracted and died from Covid, yet there was nothing wrong with what the home was doing. Instead I believe this

suggests that either the guidance provided to the home was inadequate, or it was not implemented properly. The RQIA's response also suggests that oversight was inadequate or meaningless.

Inadequate communication

103. The lack of regular staff as opposed to agency staff also meant I found updates by phone less reliable. I frequently sought updates by phone on Kathleen's condition, but was not given much information, simply generic statements like, "she's ok" or "she has no temperature", or "she has a wee bit of a cough". I was not alerted in the first three weeks after her positive test to how serious her condition was. On 16 May I had finally been told the seriousness of her condition, and at that stage elected that she should not go to hospital as she would be going there to die. However, I believe strongly that when her condition deteriorated between 9 and 16 May she should have been sent to hospital where she could have been administered antibiotics intravenously, where she would have had access to oxygen. By the time I was given the choice on 16 May it was too late. It was only after Kathleen was on end-of-life care that she was given oxygen. It is not at all clear to me why this was not provided sooner.

Impact of Isolation

104. The failure to ensure that Kathleen benefitted from the treatment she needed has been very difficult for me to deal with. Given Kathleen's inability to speak I saw it as my role to speak for her, but I was unable to given the restrictions in place. If I had been able to visit her and see her condition in person, I believe I would have realized the seriousness of her illness much sooner and could have fought to have her sent to hospital. In hospital she could have received her medications through a drip and would have had access to oxygen. Instead, I could

not see her and it seems the result was that she did not benefit from the care she needed and deserved.

Agency Staff and Inadequate record Keeping

105. Linked to concerns about inadequate communications are concerns at inadequate record-keeping.

106. I was aware of what information was recorded by the home before the pandemic. They would note what food and drink were provided to Kathleen, would note what she ate and drank, and would note what medicines had been administered. A record of her food and drink was essential for knowing the medicines administered as she had her medicines mixed with her food. However, for what seems to me the most significant period of her illness, for a two-week period in mid-May, the dietary and Kardex records have never been provided to me, and I am advised by the home that they were believed to have been misfiled and are missing. That means the home have not been able to provide me with the records of food and drink that Kathleen had during this period. This also means that it is not possible to know whether she received any medication during this critical period, as she took her medication mixed in with her food. If she was not eating, she would not have taken her medication. These records are particularly important as other medical records show during this period that she was having difficulty swallowing and, among other things, a paracetamol suppository was requested. That suggests that she was not receiving her co-codamol, and also that other methods of administering the antibiotics which had been prescribed may have been required, such as a drip, however there is no suggestion these were even considered.

107. This again demonstrates how detrimental it was for Kathleen that I was unable to visit her and care for her in person during this period. If I had been able to attend the home, and speak for her, I would have ensured she received her medication. My inability to do this was compounded by the fact that during this period the usual care home staff were off and Kathleen was in the care of agency staff who were effectively strangers to her needs. Kathleen would have been reliant on handover notes being clear and comprehensive and acted upon, however my experience of seeing agency staff before the pandemic suggested that these notes were either not adequate or not properly considered or not followed. That reinforces my concerns that those staff may not have appreciated that if she was not eating, she was not getting her medication.

108. It also appeared that there were attempts to justify or explain away these issues. For example, in a meeting with the home, when I raised the fact that she had been prescribed antibiotics in capsules on 13 May, they suggested that the capsules had been broken open and mixed in her food, and so suggested the medicine had been administered. My understanding is that capsule medication cannot be administered in this way, which is why Kathleen was prescribed liquids or tablets and not capsules. Her usual nurses would have identified that capsules were inappropriate medication for Kathleen. I have significant doubts over whether agency staff would have spotted this. I believe the suggestion that capsules could have been broken into her food had a touch of a "cover-up" about it.

109. I also note that there were only eight oxygen readings for Kathleen throughout the three weeks from she contracted Covid until 16 May. That does not seem adequate at all for monitoring a vulnerable patient with Covid. Oxygen readings increased after oxygen was administered, but at this stage Kathleen was in end-of-life care.

110. These concerns were compounded as it was also clear to me from the medical records which I did receive that some notes had been cut and pasted from other patients. For example, at one point there is a note that Kathleen was watching TV in her room. This was not possible as there was no TV in her room.

Lack of Access to GP

111. I am also concerned at the lack of access or communication with Kathleen's usual GP during Covid. For example, my daughter Gail contacted Kathleen's GP around a month after she took ill, in the week after her end-of-life diagnosis. Her GP had mistakenly believed that Kathleen had only been ill for 2 weeks at this stage. Before the pandemic a doctor from this surgery had attended the home every few weeks to check on the residents, but this stopped after lockdown. I am advised that one doctor (not Kathleen's normal GP) attended the care home to check residents during the lockdown period on a voluntary basis, and this was the only time Kathleen saw a doctor from her positive test until she passed away.

Lack of Mechanisms to Assist

112. As the above account will show, I also believe that there was a lack of safeguards or of mechanisms to assist when care went wrong. The isolation caused by lockdown meant that those usually caring for Kathleen were not seeing her, including myself and my daughter, her usual nurses and her GP. However it seemed there was no one to turn to for help or advice during this time.

113. I have also felt that the home and the Trust have not been as forthcoming as they should and did not adequately assist with my search for answers about Kathleen's treatment, aside from some helpful individuals who effectively stuck their necks out to tell me the truth. I am thinking in particular of the individual

who identified to me that Kathleen was not brought to hospital effectively due to the DNR.

114. I would like to say that the PCC have since been very helpful in attempting to ensure I get the answers I am seeking, and have assisted me by arranging and attending meetings with me for this purpose.

Conclusion of Kathleen Black's case

115. I realise that Kathleen caught covid relatively early on in the pandemic. I expect that it will be said that those caring for her, and possibly those in authority, did not know better at this point because they were still learning about the virus. However what is striking about my account is the extent to which it includes many of the complaints identified by many other members of NICBFFJ who lost loved ones in care homes to Covid throughout the pandemic. It is also striking that such complaints continued long after these early months. That also suggests that they were not considered to be failings at the time, that the issues were systemic, that lessons were not learned from these early days, and that effective steps were not taken to address these failings throughout the care sector.

116. NICBFFJ believe the case of Ursula Derry, among others, demonstrates that these remained issues into 2021.

Case of Ursula Derry

117. I, Martina Ferguson, am one of the group leads of the Northern Ireland Covid Bereaved Families for Justice ('NICBFFJ'), and this is the second statement I have provided to the Inquiry, as I provided a Rule 9 response for NICBFFJ for the purposes of Module 3.

118. My mother was Ursula Derry, born on 2 October 1933. Prior to her death on 4 January 2021, she was a resident in I&S care home, I&S I&S as she suffered from Alzheimer's and vascular dementia and had nursing needs. She sadly contracted Covid in the care home, and subsequently died in I&S Hospital.

119. Prior to the Covid 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. Before she had to use a 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 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 for my mother (with the occasional exception).

120. 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 of 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.

121. I had also been required to act as my mummy's voice, to raise concerns about aspects of her treatment in the home. Shortly before lockdown, on 15 March 2020, I had visited the care home and had raised a number of issues about my mummy's care and treatment with the care home manager, including in relation to feeding, toileting, hygiene, infection control and wheelchair basics. This demonstrated the importance of me acting as my mummy's voice at a point in time just before lockdown. This was another reason that I found the start of lockdown extremely distressing, as I was aware how much my mother relied on me, both to assist her with her needs, and to raise issues on her behalf with the care home.

Lockdown

122. Lockdown was consequently extremely difficult for me, and when it was introduced and I was suddenly prevented from visiting my mother. I was extremely concerned for her as a result. I believed that the care home had introduced a blanket ban on visiting which was not consistent with government guidance at the time. I believed it was not justified, and would be detrimental to the health and lives of the care home residents and their families generally and my mum in particular. I felt it was extremely important that I raised my concerns to ensure that those in authority or with responsibility for speaking up on human rights issues understood the importance of visiting for the mental and physical health of the most vulnerable, including my mummy.

123. In the first few days after lockdown, I therefore contacted a range of individuals and entities in order to raise awareness and to establish what mechanisms were

available to assist those in my mummy's position. By way of example, on 23 March, I contacted the care home manager by phone, and emailed the Regional Manager of the I&S who were responsible for my mummy's care home. I emailed the Southern Health & Social Care Trust, including Senior Management, to enquire about the visiting restrictions, and telephoned the RQIA to establish what action if any they intended to take. I even telephoned the office of the Minister for Health, and called the NI Human Rights Commission, such was the level of my concern.

124. On 26 March 2020 I received a call back from the then NI Human Rights Commissioner, Les Allamby, and he provided a brief explanation of the human rights engaged by the visiting restrictions. He explained, in summary, that we were in a health emergency, measures were being taken to reduce transmission, and that some rights were not absolute and would give way in these circumstances. I understood then that we had to accept these measures, but also understood that these would be imposed only for a temporary period, a matter of weeks.

125. In light of my conversation with Chief Commissioner Les Allamby I prepared for what I believed would be a few weeks of lockdown, until those in authority had worked out how to deal with Covid. However, that did not mean I believed it was right for the care home to deny all access to my mother, or that I should not raise concerns about implementation of the visiting restrictions, or other care concerns about my mother. I was extremely concerned that her health would suffer due to the blanket ban on visiting. I therefore continued to raise concerns with those in authority.

126. Throughout March and April 2020 I contacted, among others, a number of elected representatives, including a local councilor and a number of MLAs, a some of whom were Ministers. Not all responded, though some did by email,

some by phone, and one engaged in correspondence with me and raised my concerns in the Assembly Chamber in the presence of the Minister for Health. Some of these responses lead to further exchanges in my efforts to obtain information about the restrictions and my efforts to be permitted to visit my mother in her care home. I emailed the SHSCT (Carers Co-Ordinator), as I was a member of the Carers Reference Forum as a Dementia Rep. I also engaged in further email exchanges with my mummy's care home, the I&S Group Regional Manager, the Southern Health and Social Care Trust, the Commissioner for Older People, the RQIA, the PHA, the office of the Minister for Health, the House of Commons and even the Prime Minister.

127. I raised concerns not only about the blanket ban on visiting (which had been imposed despite the Prime Minister's statement that it was permissible to leave the house to care for someone vulnerable), but also issues in the care home in relation to covid, including concerns about PPE, as well as concerns at the use of agency staff and the number of new admissions to care homes, both of which appeared to me to undermine the draconian visiting restrictions imposed on residents and their families.

128. Despite my hope that the visiting restrictions would be short, the ban on visiting continued through May, June and July. In May there was an outbreak of covid in my mummy's home, which caused me significant concern, and was a particularly difficult period.

129. Throughout these months I maintained contact or exchanges with many of the individuals and entities already identified above.

130. By way of example, on 21 May 2020 I and a number of other families had met (outdoors) with the Minister for Health together with Doug Beattie MLA, to raise our concerns.

131. I also engaged in email correspondence and even a conference call with SHSCT management. Issues raised and discussed included PPE (supply and usage by staff), contact tracing, deployment of SHSCT staff, staffing levels, IPC measures not being followed, agency staff not knowing the complex needs of residents, no strategic plans re. staffing or utilising family members who are willing should majority of staff in Sandringham fall ill and have to isolate, service in terms of delivery of care unacceptable, staff working with both covid and non-covid residents.

132. As noted above, I had initially understood the lockdown would be imposed for a few weeks, and at this stage it had lasted months. Therefore, a key issue I raised was the lack of a strategic plan for visitors being allowed back in to visit their loved ones and to spend 'special time' with them. That included no apparent plan for the use of testing or other measures to allow in person visits.

133. Other concerns included that there had been an outbreak of covid in my mummy's care home, but she was not tested for covid (and then, when she was tested, her test was apparently lost and she required to be re-tested).

134. I was becoming more and more concerned for my mummy's health and wellbeing during this period. I recall that my mummy had cried with me one night, and she had never really cried with me before.

135. As will be more than apparent from this summary, lockdown was extremely difficult for myself and my mother. As she had dementia, virtual visits were simply not effective to maintain relationships or to ensure she received proper care. My mother heavily relied on tactile and sensory connections: hugs; touch; a kiss. I believe these were of fundamental importance to her mental health, and yet they were denied to her throughout this period.

136. The issue was not only that such visits were difficult, it was also often the case that they were not effectively facilitated by the home. Issues included finding my mum in the dark when we visited, or finding her turned to face away from the window, and having to wait lengthy periods before a member of staff would turn her (on one occasion we waited two hours). There were also frequently issues affecting telephone calls from families to residents in the care home. Throughout this period I had also been in frequent contact with the care home and with I&S in relation to my mummy's care and treatment, and raised these issues (and other concerns in relation to my mother's care).

137. By mid-June 2020 dates had been announced for different aspects of society to reopen, including shops, hotels, restaurants, and commercial flights. I raised this issue specifically with the care home (as well as many other issues), and sought details of any plan for opening up the home to visitors. No plan was provided.

138. Despite my hope that measures would last for a few weeks until a proper response to the pandemic was identified, the lockdown at my mother's care home continued into July 2020 even though restrictions had effectively lifted for the rest of society. It was difficult to see how this made any sense. Staff in the care home were allowed to travel, allowed to go to bars and restaurants, and were then going in to look after my mother. Many staff were also locum or agency staff who were not only circulating in the community, they were also working in other care homes. In contrast, I was extremely conscious of my mum's health and would not have done anything to risk that, and was also working at home with my husband. In these circumstances, I do not see how visits from me would have increased the risk to my mother or other residents.

Hospital Admission

139. I did not get to see my mother again until 5 July 2020, after she was admitted to

hospital. She remained there until 22 July, save for a 24-hour period between 8-9 July during which she was discharged back to her care home and then readmitted.

140. One very obvious outcome from my mother's admission to hospital for this period was that I was able to visit her in person again. I was allowed to, and did, visit the hospital 4-6 hours each day. This contrasted with the continued lock-down at care homes. This demonstrated the lack of rationality in the restrictions imposed by care homes. Very obviously, even if there was thought to be a risk to other residents in the home from family visits, there would be no less a risk arising from my mother's return to the home. It also appears to me that if the hospital was able to accommodate such in-person visits then there was no good reason why care homes could not.

141. A further important factor was that, as a result of being able to visit my mother in person, I discovered the poor state of her personal care and hygiene, resulting from inadequate care in the care home. Upon arrival and admission to hospital my mother did not look or seem well, and she experienced some mild tremoring following admission. Neglect was apparent as a result of being able to see her in person due to issues that could not be identified at a visit through a window. For example, her ear wax had not been cleaned, she was physically dirty, and her scalp was dry despite the fact that she was supposed to have her hair washed with medicated shampoo. It was very clear to me that my mother's basic needs around hygiene were not being met and that adequate care had not been delivered during those first 15 weeks of lockdown, apparently facilitated by the ban on in-person visiting.

142. I subsequently complained about the inadequate care my mother had received, and neglect was confirmed following an SHSCT Adult Safeguarding

Investigation (ASI) investigation in November 2020 which was related to my mother's personal care and hygiene in her care home. I requested a copy of the SHSCT ASI Report which is also attached hereto exhibit TBMF/02/INQ000511399.

143. I also initiated a human rights legal challenge to visiting restrictions as a result of my concerns, but this was significantly delayed. My mother's application for legal aid was refused on the following grounds, "care home policy on visiting follows regional principles for visiting in care settings in Northern Ireland specifically paragraph 5.3 of the guidance which stresses visiting is dependant on the ability to ensure social distancing to ensure safety of residents and visitors. The home have also stated in correspondence care needs are being met." Pre-action papers were ultimately lodged and an application for leave to apply for Judicial Review was made at the High Court in November 2020. My affidavit, which is attached hereto exhibit TBMF/03/INQ000226346, explains my mother's period in hospital during July 2020.

144. The fact that I was able to visit each day in hospital also allowed me to see the contrast between the detriment caused to my mother by her isolation in the home, and the benefits to her health by my being able to visit. During my mother's time in hospital in July 2020 I was able to help with her 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 spend with my mother, as well as the close observation to her needs, was invaluable 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 11 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 from level 2 to 3. The SLT Professional visited on 20 July 2020 (due to holiday season and leave) and assessment confirmed the change from level 2 to 3 drinks/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. 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 during isolation.

145. The extent to which I was able to visit my mother, and assist with her health and care needs, contrasted strongly with the isolation she experienced in the care home before and after her admission to hospital. In total, in contrast to the few weeks which I expected that isolation would last at the start of Covid, I was prevented from seeing my mother in her care home for approximately 9 months, save for the brief windows when she was admitted to hospital. From my work with NICBFFJ, I am aware of some families who were not able to see their loved ones for over a year, and even of one home which maintained a lockdown into 2022. I found this particularly traumatic, as I had seen the very detrimental effect of such isolation on my mother after less than four months, when my mother was admitted to hospital and neglect was apparent to me and subsequently confirmed by the Trust.

146. After my mother returned to the care home from hospital, I was again unable to visit her in person. I found this very distressing and sought to speak to those in authority to challenge this, and also sought to pursue my legal challenge in relation to this.

July-December 2020

147. During July 2020 a group of relatives had contacted the care home requesting

an outdoor meeting with management, which we considered could comply with IPC requirements. The care home refused this request on the basis that such a meeting could not be effective if it was consistent with social distancing requirements. We followed up this request in August and September with suggestions with venues that could allow a meeting with social distancing, but no meeting ever took place. I believe this was unjustifiable from the home, and suggested they felt unable to justify their decision-making or the failures in care which had occurred, otherwise I believe they would have promptly facilitated a meeting.

148. During my mummy's hospital admission, and after her readmission to the home, I continued contacting many of those individuals and entities identified above. These included MLAs, the Minister for Health's office, the SHSCT and the COPNI.

149. Issues raised included the disparity between my ability to visit mummy in the hospital but not in her care home. I raised, among other issues, the rights of care home residents, and the detrimental impact of the restrictions, the fact that other areas of society had been opened up and the lack of a plan for restarting care home visits.

150. I was also concerned in September 2020 after another covid outbreak in my mother's care home, and engaged with the Trust about the concerns I had previously highlighted at the lack of adherence to IPC requirements, including requirements for PPE, in the home.

151. One of the key issues I raised throughout this period was in relation to care partner guidance.

Care Partner Guidance

152. On 22 September 2020, the Department of Health published care partner guidance, endorsed by the NI Executive. This was intended to assist those with essential care partners, to lessen the detrimental impacts of lockdown, and was therefore also introduced to respect human rights of residents and their families. This background and purpose were expressly noted in the guidance and in supplementary documentation published in September and November 2020. Despite this, the care partner guidance was not complied with by many care home providers across the jurisdiction in 2020, despite them being given 6 weeks to implement it. I am also aware from my work with NICBFFJ that many individuals and families who should have benefitted from the operation of this guidance were not informed about or made aware of it.

153. Once the guidance had been published I did my best to ensure that my mummy's care home, and other care homes, would implement it. This was a significant focus of my engagement with individuals and entities throughout this period.

154. I engaged with I&S by emailing their regional manager to advise of the guidance and ask about their arrangements for implementation in September 2020. I received effectively a holding response which advised they were engaging with the Trusts and DOH and awaiting further guidance on implementation. This did not make sense to me.

155. I therefore emailed SHSCT Director of OPPC as well as the Health Minister's Office, to seek information about whether additional guidance was being provided for care partners despite the government guidance already issued, and (as far as I could see) it being clear on the role and responsibilities of care partners. I also sought a timeline for implementation of the guidance. I followed this up with FSHC themselves, but also sought information from the care home manager, as well as Doug Beattie MLA (who submitted a written question to the

Minister on the issue), the COPNI, and the office of the Minister for Health.

156. During this period I attended a Carers' Reference Forum organized by the SHSCT and raised concerns about continued visiting restrictions and the failure to implement the guidance. I also attended Virtual Stakeholder Event (remotely) on the Impact of COVID-19 on care homes hosted by Stormont NI Assembly in mid-October 2020.

157. In early October 2020 I corresponded further with the offices of the Chief Nursing Officer and Chief Social Work Officer in relation to the failure to implement the guidance. Initially I raised my concerns and the concerns of other families that were part of our Support group (Relatives Dementia Care Group) in writing. The CNO's office replied to put me in touch with the Patient and Client Council (PCC), and I was ultimately invited to a virtual involvement session on "Çare Partners" with the DOH took place on Friday 23rd Oct 2020 1pm facilitated by the PCC. We followed this up by providing feedback and seeking details of further sessions.

158. During October and November 2020 I attended a series of meetings with PCC, HSCB, PHA, DOH, RQIA and families that were desperate to bring an end to what we described was draconian measures. I also continued to engage in written communication with the SHSCT, Doug Beattie and the Minister for Health's office on the issue. Many families felt our call for change was falling on deaf ears. I believe this was understandable, given that the care partner guidance was not being implemented despite all of our efforts. Some families resultingly became disengaged.

159. In mid-November 2020 I understand that the CNO and CSWO held a number of virtual sessions with independent health care providers and circulated supplementary information on care partners to Trusts and care home providers.

I also understand a number of care homes attended workshop with Trusts, PHA and DOH regarding care partner guidance on 16 November 2020. This was approximately two months after care partner guidance was published. My mummy's care home had still not implemented the guidance.

160. On 21 November 2020 a campaign event for families was held at I&S which I attended along with other families who wanted the loneliness, isolation and visiting restrictions to end in care homes. An online petition to raise awareness of the care partner role and the plight for care home residents was created. A song (''You Stood By My Side (mind)'' was written and produced for the I&S event.

161. Around this time, I received a response to a subject access request which I had submitted, which revealed that Trust staff had undertaken a number of internet searches about me and the campaign for implementing care partner guidance to be implemented, and visiting to restart in care homes. The response included an email from my mummy's care home to the Trust to ask them whether they were going to respond to a media article which mentioned the campaign. This suggested that the Trust staff were fully aware of the issues regarding the visiting ban in care homes for myself and many other families, and were more concerned about criticism from me in media articles than they were about ensuring access to care homes for care partners.

162. On 7 December 2020 I also received correspondence from Professor Charlotte McArdle, CNO, who acknowledged my correspondences dated 15 and 17 November 2020 ''*in which you sought further clarification over the visiting guidance in relation to care homes in Northern Ireland during the COVID-19 crisis, in particular the concept of care partners. I would also like to acknowledge your correspondence of 29 September 2020, 14 and 29 October 2020, and 5 November 2020 to which the Department of Health Private Office was either in direct receipt of or copied into*.'' This

demonstrated the extent to which I had engaged with the CNO to seek answers and implementation of the guidance.

163. Prof McArdle's correspondence stated:

> *"Care homes are actively encouraged to adhere to all aspects of the revised visiting guidelines including the introduction of care partners. However, it is important to note that for the safety of visitors, residents and staff, the Care Home Manager is responsible for making decisions regarding permitting visitors into the home on a day to day basis. This decision will be based on a risk assessment of the environment and rely on the ability to ensure social distancing and safety of residents, staff, visitors and care partners. The expectation is that care homes continue to work to facilitate a range of visiting options in accordance with the detail of the visiting guidance aligned with the Alert Level relevant at the particular time and the care home's individual circumstances.*
>
> *The Department recognises the care partner role as being of critical importance to the health and wellbeing of care home residents. Whilst it is acknowledged that the concept may be challenging for some care homes to implement whilst mitigating the transmission of COVID-19, where there are difficulties in progressing the role, Health and Social Care Trusts have been asked to support care homes to seek a solution as a matter of urgency."*

164. This appeared to me to be suggesting that there was nothing the CNO or the Department could do if a care home simply chose not to implement care partner guidance. This effectively suggested that the guidance was optional, as opposed to setting out guidance which required to be implemented in order to protect and respect the fundamental rights of residents, and to protect their health and life. This suggested a failure to acknowledge in practice (as opposed to paying lip-service to) the real detriment caused to the health and lives of residents who were reliant on care partners, but who had suffered under a blanket ban on visits from those partners for, at this point, nine months, with no apparent end in sight.

165. I continued to engaged with the SHSCT and FSHC throughout December to

seek implementation of care partner guidance. I also discussed this with care home management. In particular I sought details of when I would be permitted to visit as a care partner. On 11 December 2020 I received a response from [redacted] care home Manager ([redacted]) that stated *''Unfortunately we are having to suspend visiting on a temporary basis as per Public Health advise this morning, due to receiving positive COVID-19 results, from Whole Home testing 09.12.2020. At this moment in time I am not in receipt of all results – and I can confirm that I do not have your Mummy's result yet, but we will inform you as soon as we do. We will be in touch as soon as we can regarding the care partner role.''*

166. This was the fourth outbreak in my mummy's care home, and had occurred a number of months after care partner guidance was introduced, but before my mummy was able to benefit from it in practice. When I enquired if the outbreak was actually in my Mummy's east wing dementia unit, the SHSCT replied on 15 December 2020 *'the East Wing is affected by the outbreak.'*

167. I contacted a number of individuals/entities given my concerns about this further outbreak. This included the MLA Doug Beattie. I also emailed CNO and CSWO, copying in officials in the DOH. I raised concerns about Christmas fast approaching and that care partners had still not been implemented in my mother's care home. I also requested my email be forwarded to Dr Michael McBride CMO. At this stage my focus was still on care partner guidance as I had been told that no test result had been received for my mummy, and was never informed that she had tested positive in the home. I therefore assumed she had not contracted covid during this outbreak.

Summary of Experience July-December 2020

168. The care partner Guidance was not implemented for thousands of others across NI, despite the efforts and support of bereaved groups (which have now effectively formed NICBFFJ), and their engagement with senior politicians and

officials in the jurisdiction. When families sought to establish (via the Patient Client Council Engagement platform) why care partner Guidance was not being implemented, we were told that '*guidance is just guidance.*' I do not believe that this was a correct analysis of the legal effect of the document, particularly in circumstances where it was produced in order to ensure that fundamental human rights were respected, however this answer also demonstrated that failure of those in authority to properly ensure that these measures were implemented in practice. Additionally, when I was part of the PHA/DOH Task & Finish group, which was set up in relation to normalized visiting in care homes, I provided feedback on the guidance and was advised via email by a DOH official that '*the pathway is guidance, not law.*'

169. In the absence of in-person visits I was restricted to window visits and, on occasion, supervised and social distanced visits in the front foyer of the care home, to see my mother, aside from the brief period she had spent in hospital. This was difficult, and was particularly bad when the weather was terrible. The feeling that this was demeaning and unnecessary was brought home to me by the fact that I had been able to visit my mother so much when she had been in hospital. When she was in the care home, during window visits, I was unable to wipe her nose if she sneezed. I not only felt powerless to help her, it was also clear that, as she had dementia, she did not understand what was happening.

170. The lack of rationality surrounding these visits was also frequently demonstrated in other ways. In or around 7 November 2020, a notice appeared in all windows in the care home stating something to the effect that the windows that separated residents and their loved ones were required to remain closed otherwise the visit would be classed as a close contact or face to face visit. This did not make sense at all to me. The windows being open allowed fresh air to circulate, and ensured the visit was more like an outdoor visit. Open windows

were also often necessary for visits to be effective, as closed windows made it more difficult to communicate. It also appeared to have been suggested that Public Health had advised the care home to close all the windows. I personally contacted Public Health, as well the Trust and a variety of other entities, to query this. My husband was told by the PHA that they did not speak with members of the public, however they also informally advised that there had been no advice to the effect described. The care home also responded in an unsatisfactory way after I raised concerns about this notice.

My Mummy Contracts Covid

171. On 23 December 2020 (the day after we buried my mother-in-law who had been battling cancer during the pandemic), I received a phone call from one of the nurses in my mother's care home who advised 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 i I&S a Hospital. The Doctor spoke to me about a DNR which I wasn't happy with and explained I would need to speak with my family as I was one of six children. If I recall correctly, this was Dr I&S (A&E at I&S on 23 Dec 2020).

172. My mother was transferred to the Covid ward on Christmas Eve, 24 December 2020. I thought my Mum was going to recover after receiving some treatment. She spent approximately 2 weeks on the Covid ward, and I was thankfully able to spend time with her during her stay after challenging the SHSCT visiting policies. My mum sadly passed away on 4 January 2021.

Engagement with Individuals/Entities from January 2021 onwards

173. After my mother passed away, I continued to engage with those in authority and attend meetings on behalf of others in order to highlight issues around care homes.

174. Prior to, and during the pandemic, I was a Memory Services/Older Persons Representative with the SHSCT. Quarterly meetings were held where I raised concerns on behalf of families who were restricted from visiting in care homes and PPE concerns.

175. In February an engagement platform for concerned families was launched, and I attended with families who continued to face issues around care homes facilitating care partner access. In March a specific care partner engagement platform was set up, with the launch attended by myself, other families and a regional representative from the Trust and RQIA.

176. In March I also sat on the 'Visting with Care – A Pathway' Working group established by PHA. This was set up to develop a pathway back to normal visiting regime.

177. In May 2021 I and other families attended a meeting with Health Minister Swann. Discussed were issues of time constraints on care partner arrangements, reluctance/failure of care homes to follow DOH guidance, the validity and reliability of data collected by individual Trusts and RQIA. The absence of HSCT care management and care reviews for families and residents and the use of anti-psychotic drugs in care homes. I followed this up with an email exchange with Minister Swann.

178. I continued to engage with the Trust, the COPNI, the NI Human Rights Commission, and to send and receive FOI requests about issues of relevance to care home access. I also continued to attend campaign events, such as a further event at I&S in November 2021 which I had organized along with other families, and subsequent events.

Later Disclosure that Covid was the Cause of Mum's Hospital Admission

179. It was not until some months after my Mum's death that I learned from ambulance records that my Mum was "*suspected COVID*" when being admitted to I&S. This was shocking for me to read, as I had not been told that at the time or since by the care home.

180. Given that the ambulance staff were told that Covid was suspected, there is no good reason not to tell me that this was the reason, or at least part of the reason, for the hospital admission. As a lead member of the NICBFFJ, I am one of the many family members who have proactively fought and 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. From my own personal experience, and the learned experience of our group, I know that there was at times an apparently deliberate failure to provide adequate information to family members in such circumstances. Poor record keeping has also caused difficulties for families who have sought to seek answers subsequently.

181. It should also be noted that the efforts of many of our members to obtain the medical notes of their loved ones have not been successful and it is claimed that notes, or sections of notes, are lost or otherwise irretrievable.

182. A further concern is the extent to which information has still not been provided to me. By way of example, as noted above, I had discovered that my mother had been admitted to hospital with suspected Covid after 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. These showed that my mother's care home had specifically advised the 999-emergency operator that the reason for the admission to hospital in ambulance was *'PT query covid'*. However, aspects of these notes are also redacted. It is not clear to me why they would be redacted. That causes me suspicion that there was evidence of Covid in the home among other residents, that this information was redacted, and that this information has been concealed from me, thereby allowing the home to avoid scrutiny for any wider failings.

183. One overarching concern I have had with all of this was not merely the decisions and treatment I have highlighted, but the fact that I and others in a similar position had no one effective to turn to for help. As my account shows, in many instances decision-making was irrational, and extremely detrimental to health and life of those in care homes. Despite this, I approached and engaged frequently with a wide range of individuals and entities, it really highlights how ineffective our system is when families need help. I believe it demonstrated the complete power imbalance between the Department of Health (including its ALB's) and the Care Home Providers within the Independent Health Care Sector. Even when care partner guidance was introduced in September 2020, it was not then followed up and so was not implemented in practice. Throughout its publication, I engaged as much as I physically could with those with power to implement this or those in authority who could ensure implementation. My efforts were unsuccessful despite three months passing between the guidance being published and my mummy contracting covid. In my opinion, this highlights how ineffective our system is when families in need are asking for

help. I believe this demonstrates the power imbalance between DOH and other public bodies, and the care home providers within the independent health care sector.

184. At the start of the pandemic, I contacted RQIA to find out what they were doing, and they advised that they were "supporting the care homes." NICBFFJ believe that support was not sufficient in itself, but regulation and oversight was also required, including real and effective sanctions for failings.

185. The failure of mechanisms and safeguards which people can rely on to hold those in authority to account, and to ensure proper care and treatment for the most vulnerable in society, is I believe a very significant failing, and I and NICBFFJ would urge the inquiry to ensure this receives close scrutiny and that recommendations are made to address this failing.

Conclusion on the case of Ursula Derry

186. NICBFFJ consider that the above case demonstrates a series of systemic failings, including failings in communication, irrational decision-making surrounding visiting in care homes, and overall demonstrating the detrimental consequences for health and life resulting from the draconian visiting restrictions imposed on many people in care homes for unjustifiably extensive periods. It also serves to demonstrate the contrast between the isolation imposed in care homes as compared to hospitals, suggesting a lack of consistency and rationality in the measures imposed.

Broader Concerns on the part of NICBFFJ

187. We have identified thematic concerns above. It also appears to NICBFFJ that these disclose failings in regulation, monitoring and oversight of care homes by the Department and Trusts. The failure to consistently implement care partner guidance is a clear example of such a failing.

188. One concern on the part of NICBFFJ in relation to overall governance is the fact that many care homes are not operated directly by the Trusts, but operate on contract with them. Even though there are conditions in those contracts to ensure "Provider Compliance" obligations, as well as conditions for "Unsatisfactory Performance', it seems these clauses and requirements were not considered or used by those in authority to ensure that care homes were providing the necessary quality of care, were implementing effective infection prevention and control measures, and were respecting human rights of residents, for example, by ensuring implementation of care partner guidance.

189. This is particularly concerning, as many care homes were private entities run for profit but which were effectively state funded, and the conclusions above suggest that there was a failure to monitor public funds in this respect. Many of these care home providers were allowed to self-report throughout the pandemic. As is apparent from the failings identified above, NICBFFJ do not consider that this was acceptable.

190. We would ask the Inquiry to consider and to make recommendations in particular on the extent to which arm's length bodies (ALBs) of the DOH, specifically the Health and Social Care Trusts in NI, appeared to have no power or appetite to make independent care home providers (which are regarded as 'public authorities') follow DOH guidance despite their contractual obligations. We also consider that the systemic failings identified suggest there as a failure on the part of the DOH or Trusts to effectively to monitor and regulate whether or not legal standards, such as Care Standards for Nursing Homes (2015) were being met and complied with.

Statement of Truth

We believe that the facts stated in this witness statement are true. We 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 by:

Signed: PD

Dated: 12/16/2024

DocuSigned by:

Signed: PD

Dated: 12/16/2024