Witness Name: Scottish Covid Bereaved
Statement No.: 1
Exhibits: 13
Dated: 05/10/2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF JUDITH KILBEE OF SCOTTISH COVID BEREAVED

I, Judith Kilbee, make this statement on behalf of Scottish Covid Bereaved (SCB). The information and examples contained within this statement have come from my discussions with members of the SCB, statements that members have provided to the legal team and I have also included some examples from my own personal experiences.

History, Purpose and Aims of Scottish Covid Bereaved

1. The Scottish members of our group originally started out as part of the group Covid Bereaved Families For Justice UK (CBFFJ) which was formed on Facebook in June 2020. Following our meeting with The First Minister, Nicola Sturgeon, in March 2021 it became clear we needed to be an autonomous group/branch within CBFFJ organisation, especially after it became a Limited Company with directors without informing the membership. At that stage we became a subgroup of CBFFJ but arranged all of our lobbying and press activity ourselves. Following a clear difference between our group approach on several major topics and that of the main CBFFJ group we formally severed our connection with them in September 2022 and became a completely separate group, namely Scottish Covid Bereaved.

2. Given the very nature of our Group and that we have come about as a consequence of bereavement as a result of the various responses made by both

the UK Government and the Scottish Government we have highlighted issues after the fact rather than prior to the decision making.

3. Since our first press article in July 2020 with the BBC (on Care Homes) we have had a consistent and positive press presence via TV, Radio, Newspapers and social media mainly in, but not limited to, Scotland.

4. Our political campaign, ultimately leading to the formation of the Scottish Public Inquiry, began in September 2020 with the then Scottish Labour Leader asking a question on our behalf at FMQs. Since then, various questions have been asked on behalf of members by politicians from all political parties.

5. Whilst our activities have been mainly in Scotland, in the absence of anyone else doing it, we have participated in actions with the original CBFFJ Group in its efforts to secure a UK Inquiry. We are very conscious of the overlap in both Pandemic Planning and the actual handling of the pandemic between the UK Government and the devolved Nations. We feel it is especially important to be knowledgeable about the whole process to assist the Inquiry in identifying areas where the original Pandemic Planning fell short not only in Scotland but in the UK as a whole and we believe we cannot do one without the other.

6. We are a group of bereaved individuals united in a common goal. We do not want our loved ones' deaths to have been in vain. We want lessons to be learnt to stop others having to go through what we have been through. We also believe that by sharing our experiences, both good and bad, we will assist both Inquiries in their establishing what really happened, and therefore further assist both Inquiries in arriving at their conclusions, recommendations and lessons to be learned for future pandemic planning.

GENERAL POINTS

7. Scottish Covid Bereaved (SCB) acknowledge that staff in care settings were in an unprecedented situation and the majority did their best to look after those in their care, however, there is a distinct lack of understanding around the different types of residential care settings with the terms Care Homes and Nursing Homes used interchangeably. Care home staff can provide personal care, washing, dressing

and feeding support, activities and socialisation but have no medical or nursing training and therefore when a resident needs medical or nursing care the home will be reliant on visiting GPs and/or admission to hospital.

8. A Nursing home will provide the same services as a care home but with oversight of staff who are registered or qualified nursing staff, providing 24-hour nursing oversight. This distinction is particularly relevant for Module 6 as Nursing homes should have been better placed to support residents in their familiar setting and have a greater understanding of how to recognise the signs and symptoms of COVID 19, monitor respiratory rate and recognise signs of hypoxia (including 'happy' or 'silent' hypoxia), delirium and dehydration – See sections 2 & 3 of **(JK/01 - INQ000336345).**

9. Nursing homes should also be more familiar with, and able to, implement infection control procedures including correct use of PPE (including how to don and doff and safely manage disposal).

10. Social care appears to have been largely forgotten in the pre pandemic planning and despite widespread media coverage of the impact on care homes in Italy and Spain before COVID 19 hit the U.K. Care homes here were woefully neglected and ill prepared.

11. There are vast differences too, in the application and interpretation of guidance across different care providers, some SCB members with loved ones in Care homes in Scotland with the group head office, and most of their homes based in England, found that the focus was on guidelines from England when Scottish guidance should have been followed. One of our members has said, *'They were the only Scottish care home in the group so when they were getting guidance it was usually English guidance from the head office.'*

12. Many homes are privately owned and were left to source their own PPE with several SCB members reporting homes relying on community support to provide PPE of poor standard and in some cases homemade fabric masks. One of our members has said, *'They were short of PPE. I remember someone had donated*

PPE and the Manager had posted a thanks on Facebook and said if anyone had anymore they would happily accept it.'

SYMPTOMS AND TESTING

13. Testing in the early days of the pandemic was lacking for both residents and staff, inadequate PPE and misinformation around symptoms, with staff looking for the 3 cardinal symptoms. This was despite early evidence of the elderly presenting with a plethora of other symptoms, such as new onset/ worsening confusion and diarrhea – See Page 4 of **(JK/02-INQ000147440).** SCB members have many examples of the lack of understanding of these symptoms and of asymptomatic transmission in care settings which allowed residents to mix freely so long as they did not have a cough or fever.

14. One of our members stated that, on April 13th 2020, when the Nursing Home GP rang to say that her late mother was unwell with a cough and that she thought she might have covid, she (the GP) advised that she knew a few of the Nursing home residents had tested positive for COVID 19 but that at that time Public Health could not advise which residents. Knowing which of her patients had tested positive for COVID would have helped that GP provide care to her patients and Nursing home staff with regards to IPC measures.

15. Many care homes continued to admit new residents from hospitals or return those who had been in hospital for other treatment without testing. As they were without the 3 cardinal symptoms, they were not isolated in the home and some later developed symptoms and tested positive for covid **(JK/02-INQ000147440).**

16. One SCB member wanted a loved one to be returned from hospital to the family home where they had access to oxygen and continuous support and supervision, this was not allowed and they were transferred instead to a care home where they caught covid, had no access to oxygen and subsequently died.

17. There are also further examples of those in SCB who had relatives who were discharged from hospital into care homes, untested, despite still requiring hospital care. One of our members has explained, *'Around 26th or 27th March mum was*

discharged back to the care home with oxygen as her levels still weren't great. She had a cough which was thought to be a symptom of the chest infection. She wasn't tested for covid before she was discharged.'

18. Another member has explained, *'I discovered though Public Health Scotland data released on 1/10/2024 that 9 patients had been discharged to this care home between 1/3/2020 and 31/5/2020, 5 of whom were not tested and at least 1 had tested positive. 11% of the 45 beds were occupied by untested discharged patients between 1/3/2020 and 21/4/2020. My dad's first symptoms were on 25/4/2020. There were 8 deaths from Covid-19 in the first 3 months of the pandemic in this home, 2 of which were my parents.'*

19. In October 2020, the Scottish Health Minister at the time, Jeane Freeman, stated that a Public Health Scotland (PHS) report **(JK/03-INQ000147514)** had shown no harm resulting from discharges into care homes. The report, dated 28th October 2020, which discusses discharge from NHS Scotland hospitals to care homes between 1st March and 31st May 2020, states at page 42, *"The overall interpretation is similar to the previous analysis. The analysis does not find statistical evidence that hospital discharges of any kind were associated with care home outbreaks."*

20. At the time, members of the SCB were in disbelief that this statement had been made. Indeed, the report was subsequently revised and reissued in April 2021 **(JK/03-INQ000147514).** The conclusion on page 48 now says, *"Considering the results from the adjusted model, we do not find any statistically significant association between hospital discharge of any type and the occurrence of a care home outbreak,* ***but cannot rule out a small effect."***

21. The SCB welcome the updating of this report with confirmation that a link cannot be ruled out, however, would question the statistical analysis as a whole contained in this report.

22. SCB members feel strongly that the UK Government and the devolved administrations made decisions to discharge patients from hospitals into care homes without properly considering and assessing the devastating impact of this decision on residents and staff in the care sector. Some of our members wonder if

financial gain and /or incentives have played a part in homes accepting these transfers?

ISOLATION

23. The manner in which the guidance on isolation was interpreted and implemented by homes varied hugely. Some members feel their loved ones were left in their room, neglected, and in some cases, left to die alone.

24. One member has explained, '*About 3 days after my mother went into the home (12th April 2020) all residents were confined to their rooms as there had been an outbreak of covid in the home.'* Another member has said, *'If the nursing staff had said to me that my mum was at the end of her life and was dying I would not have left the care home. I would not have left my mum to die alone.'*

25. There are also members who have witnessed isolation not being adhered to where loved ones were looked after in corridors or communal areas. One member has explained, *'I got a message to say that it was better to "isolate" dad in the lounge as he was mobile and sociable and he could and would get up and move around. I explained that dad would be at greater risk as he would be exposed to a much greater viral load given that the lounge was the hub of the building. He wouldn't be afforded the same protection as the other residents who were being isolated in their rooms.'*

26. At the beginning of the pandemic families did not want to visit their relatives inside care homes. They were initially very keen to protect their vulnerable relatives and allow them to be what they thought was properly isolated and protected within their homes. However, this feeling changed for those families who experienced a prolonged period of isolation from their relatives in care homes. They witnessed the impact of isolation and cognitive decline of their loved ones, causing distress for both resident and relatives.

27. It is important to recognise that staff went home after work and went about their normal routine outside of working hours and this therefore impacted on the effectiveness of isolation within the home.

28. Some members of the SCB feel that had homes considered alternatives to the "no visitors" approach, such as allowing one named person per resident to attend during the pandemic, who was tested and wearing full PPE, this would have improved the mental wellbeing of the resident concerned. They could have also supported the care home staff by assisting in the washing, dressing and general care for that resident. It is difficult to see how this could be seen as a higher risk than that of existing staff coming and going and when agency staff were working across several care homes.

29. One member has said, '*The impact of not being able to hold my parents hands, hug them, be close to them had a massive affect on them and myself. They both isolated for 2 weeks when they entered the home. After that I got window visits. Initially I could just pop to the window when I was out with the dog. Video calls were difficult as they struggled with technology and I can only assume there wasn't enough staff to sit in their room with them while we were chatting to them. These video calls had to be booked. Sometimes when I phoned there wasn't any iPad's left or the staff didn't have time to take one to their room. Their room was right at the back of the building in an extension and the Wi-Fi signal was terrible.*'

30. Another member further explained her traumatic experience following the death of her father in the same home her mother remained as a resident, she has said, '*I had to telephone or shout up to my mother on floor up on an outdoor balcony. I was offered an end of life visit with my mother, however after I phoned my brothers I discovered she died before I could leave my house (about 25 miles away) on 20/5/2020. I collected my father's possessions later on the same day. I stood in the car park and a staff member (in PPE, as described) put the box in my car boot. She expressed sympathies and described the pressure staff were under coping with an outbreak but could not say about the extent of this, or discuss hospital discharges.*'

PERSONAL PROTECTIVE EQUIPMENT (PPE)

31. There are numerous examples within our group of PPE not being used by staff, being used incorrectly and also being disposed of in an unsafe manner.

32. We understand from our members that some care homes didn't have PPE available for staff due to the cost of this. One of our members has explained, *'The carer had no PPE on, nothing at all. I asked her if they had any PPE yet and she said that the boss was refusing to buy it because it costs so much money.'*

33. Other examples within SCB include members being sent videos clearly showing staff not wearing PPE, despite claiming that this was always used. One member has said, '*There was a video on Facebook of the staff doing oops upside your head. They were sitting on the floor. They weren't social distancing. They weren't wearing masks either.'*

34. There are members who noted that poor quality PPE was being used in homes. One member explained, '*We were given a mask, gloves and an apron to put on. They were very thin and of a very poor quality. My brother is a big guy. When he tried to put the gloves on his hand went right through it.'*

35. Another member has explained that at times even when PPE was being worn, they witnessed it not being worn properly, *'When the staff were speaking, they would pull their masks down to speak. There was just a general lack of understanding. There wasn't any more bins or waste bags made available. We left our used PPE lying in dad's room toilet.'*

36. The process of donning and doffing PPE was also not conducted correctly with several SCB members reporting witnessing staff going from room to room without changing PPE. One member has stated, '*Staff definitely weren't changing their PPE going in and out of rooms.'*

37. Another member explained regarding PPE, *'From the start of lockdown, March 2020, the management hid the PPE & the staff were limited to 3 masks per 12 hour shift. This practice didn't change until the first positive case in October 2020. Face shields were always restricted. These were to be wiped down and reused.'*

38. SCB members with loved ones cared for at home have also reported that carers had both inadequate knowledge of infection prevention in community settings and experienced difficulty accessing PPE.

INFECTION PREVENTION AND CONTROL

39. A care setting, unlike a hospital will have significantly less experience of infection prevention and control. The SCB have examples of care staff who also undertook cleaning duties and believe that cleaning guidelines were not followed appropriately with many members expressing shock at the lack of basic hygiene in homes when allowed in to see relatives.

40. One member has said, *'My Dad, despite having covid, was being looked after in the lounge of the home and taking himself to and from the toilet. When he became unwell and unsteady on his feet, I was informed that staff were now accompanying him. I questioned why this hadn't been happening up to this point given that Dad would be touching handrails and door handles. Staff should have been ensuring correct hand washing and cleaning of the room and handrails particularly given that staff used the same facilities.*

41. Another issue that has been raised by members is the sharing of equipment in homes. This should not have been happening. One member has stated, *'I saw my dad walking with a walking frame and then saw a picture of him in a wheelchair, neither of which belonged to him. I question whether decontamination of these items was being adhered to, there shouldn't have been sharing of equipment.'*

42. Another member has explained, in March 2020, her mother mentioned in a telephone call (that home being in lockdown) that residents in the shared dining room in her Nursing Home were coughing. The member contacted the home to

express her extreme concern about residents mixing freely in that way. Irrespective of whether information about asymptomatic transmission had been given to the home, experience with previous outbreaks of influenza and norovirus should have dictated risk assessments and IPC measures, which, at the very least, should have been isolation of residents with symptoms such as a cough and cessation of communal dining.

43. Some members report witnessing refurbishment of homes during lockdown with decorators and workmen coming and going in the home without wearing PPE. One member explained, *'The home was being refurbished when it was locked down so there were workmen in and out.'* Another has said, *'One of the carer's husbands went into the care home during lockdown to decorate the lounge. Just another example of someone who was non-essential.'*

44. There were also instances where carers were seen not washing hands when entering or leaving a resident's room, the most basic of IPC. One member has explained that her late father told her, *'He said ... there was no hand washing before and after carrying out his care in the room.'*

45. Albeit before lockdown, but when covid dangers were well known, there was an example of a resident blowing out birthday cake candles and the cake then being shared with every resident. This is something that was common practice in residential settings pre covid, however at this stage it was well known about aerosol spread and even though the care home wasn't locked down at this time, they should have known better.

TIMING AND CLARITY OF VISITING GUIDANCE

46. Despite guidance being generally considered to be universal across Scotland, interpretation of this guidance varied from region to region and care home to care home. Indeed, it seemed that visiting was ultimately at the discretion of the care home. It is understood that each care home had to ensure that they had the staff to support visiting procedures and also they had to give consideration to footfall in

the care home grounds. However, communication on this from care homes was not consistent **(JK/04-INQ000224524 and Page 2 of JK/05-INQ000147441).**

47. One member has explained, *'Visit information was unclear and ever changing throughout the pandemic. The rules were applied uniformly throughout Scotland, no matter what level of risk the area was under. For example the Highlands was low risk for most of the pandemic but still stopped visiting in all care homes. Care homes were able to interpret visiting guidance themselves, leading to differences between care homes even in the same area. The visiting guidance did not take account of the impact on resident's health, especially mental health, which was even worse for people with conditions such as dementia. The average length of stay in a care home is 2 years, so the impact on residents and their families was huge.'*

48. Communication was not consistent; one member was not made aware of "window visits" as an option and missed out on these for many months. This member has explained, '*Our family were excluded and unaware of window visits between March 2020 and June 2020. It is unknown how this information was communicated to families, but we were not included and missed out on these crucial visits for months. It was distressing to discover that we had missed out on window visits for months.'*

49. With regards to window visits, where these were allowed, they had to be pre-arranged. This was to allow footfall in the grounds to be managed and staff support to be provided for residents. The availability and frequency of window visits was determined by the individual home. Also, due to travel restrictions these were only possible for families who lived near the care home. Where a resident did not have a room on the ground floor window visits were not an option. Window visits where residents had sight or hearing problems were ineffective if the resident could not hear or see properly.

50. There are examples in the group of relatives being told they could not wave through the window but they did so anyway and were distressed to see their loved one looking unkept and in a dirty room.

51. Where a resident was able to see family and vice versa this may have offered comfort to both parties however residents with cognitive issues may have been distressed that their loved ones were not coming inside to see them. For loved ones seeing their relative and not being able to comfort them with any physical contact was stressful.

52. One member has explained, '*As I lived beyond the allowed travel zone, I was not able to see Dad via a window visit but had a family member who did so as they lived locally. Following the window visit I was sent a photograph taken from inside the home, looking towards the family at the window. This photograph was very distressing as it showed a staff member standing next to Dad and wearing no PPE whatsoever and in a long-sleeved shirt buttoned at the wrist, this was despite having been sent the PPE guidance stating that PPE would be worn at all times in communal areas. A later photo shared from a window visit, this time from the family looking in at Dad, showed a shocking deterioration in my Dad's condition, so much so that I took one look at it, burst into tears and said to my husband "Dad is dying".*'

53. Another member has confirmed her experience of window visits as follows, *'Window visits lasted no more than 30 minutes. They took place once per week, but when there were lockdowns in the care home for norovirus for example, they didn't happen every week. Window visits made communication difficult, partly because of the difficulty hearing, but also in seeing. There was a lot of reflection on the glass. In one awful window visit Mum had been given a whole apple to eat. After eating the apple she proceeded to start eating the core which she started choking on. Fortunately, I was able to open the latch on the window and climb in to help her. There was no way we could raise the alarm, other than calling the main care home number, which often didn't get answered.'*

54. Another member has explained regarding window visits, *'The Care Home did not have window visits as such, but when outdoor visits were allowed (very cold in Scotland) they also set up a visiting 'pod' , I think in late Spring 2020. These were essentially a 'window' in the sense that the resident remained in the lounge and a section of the lounge nearest the garden was sectioned off by plexiglass and communication was by two way microphone. This was extremely frustrating for my stepfather as, on many occasions, the mike was not working well and as he was*

hard of hearing, he could see us, but not hear us, which was upsetting. Visitors were often required to wear a mask, even in the pod, which did not help communication. I think the visit was 30-40 minutes and I think the resident was permitted two visits per week.'

55. A further member has explained, '*From mid-June I visited around 3 x weekly via the window. These visits were short lived however on 13/07/20 I received a communication from the care home advising further supports for visits were being offered including visiting at the door of the lounge. The wording in this email turned out to be contradictory as I was notified at my next visit that I was permitted 1 x visit per week for 30 minutes and the other visits were stopped. Another relative later told me that this restriction was not placed on her family. I queried these discrepancies and inconsistencies by email but the care home merely stated they were following Scottish guidelines.*

Visits were also impacted by clusters of infections in our area so there did not appear to be clear guidelines. Another relative was permitted an outdoor visit to the care home to see her mum on 19/11/20 only 4 days after my mum's death after she tested positive on 14/11/20. The care inspectorate wrote that this may have been an essential visit but I know categorically that this was not the case so different rules seemed to apply.

I believe we should have benefited from essential visits but this didn't happen. I have learned that I was excluded from updates and family emails and I have no explanation why this would happen.'

56. Another member has explained, *'Regarding window visits these were restricted to 1 x nominated person . I was required to wear a face mask throughout. Window visits were stopped altogether when there was the first covid outbreak from 11/10/20 and were never resumed. My mum died on 15/11/20 after being routinely tested on 14/11/20. I could not communicate properly due to being in the other side of a window and wearing a mask. Each visit was heartbreaking but at least I could be close to my mum.'*

57. One member has also explained her experience with visiting / communication with her parents who both resided in a care home together, saying, *'Visiting was suspended on 11/3/2020. Following my father's death on 3/5/2020 I visited a couple of times and stood in the car park. My mother suffered from deafness, found speech challenging following a stroke and needed staff to push her in a wheelchair. Communication was best by telephone. Before his death I could FaceTime my dad and also speak to mum, but she couldn't use it independently. When dad died I had to ask a staff member to sit with her so I could tell her of his death and be sure she would hear. I can still hear her cries and I am so sorry for what I asked the staff member, who volunteered to be there with her, to do.'*

STAFFING

58. There were issues with staffing levels in many homes due to staff shielding or suffering from Covid symptoms. Those who remained often continued to work due to staff shortages. There are examples of staff knowingly going into work, against all guidance, despite having "cold" symptoms and testing to prove it wasn't covid, only to find they had a positive test.

59. One of our members has explained, *'there were carers going into the home with covid symptoms and not being sent home because they were so short staffed.'* Another member has explained, *'We got [a] WhatsApp … telling us that the Manager had tested positive for covid. Apparently, he had mild symptoms that felt like a cold so he went into the care home. He went and got tested the next day to prove he didn't have covid and it came back positive.'*

60. Agency and staff from other homes in the care home groups were often drafted in to staff the homes and in some cases from across the border and from covid hotspots, without testing or isolation periods, before starting work.

RESIDENTS ACCESS TO HEALTHCARE PROFESSIONAL SUPPORT

61. Many SCB members feel that because their loved ones were in a residential care setting, they were denied access to medical professionals and supportive care such as oxygen and fluids which may have been lifesaving.

62. If oxygen can be provided to people with conditions such as Chronic Obstructive Pulmonary Disease living in the community, why was this simple life saving measure denied to those in care settings?

63. Some members believe that staff were ill equipped to identify signs of anything outside of the 3 cardinal symptoms for covid. There are examples of conversations with 111 where staff stated that residents were not distressed, failing to identify and report signs of respiratory distress.

64. There are members of the SCB who had loved ones that were sent to hospital and then reported them being described as dehydrated upon arrival and, in some cases, "neglected." One member explained, '*They told me when mum was away in the ambulance and said to make my way as soon as possible to the hospital. My taxi drove in behind the ambulance. When I first saw my mum I said 'Dr, is that my mum, no way is that my mum'. The Dr's words were 'that wee lady has been neglected'.'*

65. Even when seen by a doctor staff failed to ask for guidance and despite being asked to monitor respiratory rate one SCB member only learned after their loved one died that staff did not know how to do this. It is clear that training and preparation of care staff was seriously overlooked. Medical staff should have ensured staff were able to follow any instructions given.

66. One member has explained, *'If I had known they didn't know how to measure respiratory rate as requested by the covid team I could have talked them through it and directed them to YouTube videos etc. Policies where they are in place are pointless if they cannot be implemented through lack of knowledge or training.'*

67. SCB members understand that GPs were often not visiting care and nursing homes and access to support was via 999 or 111. Members have reported 999

teams declining to attend and in cases where they did so, often defaulting to diagnosis of a urinary tract or chest infection, despite residents being known to have covid.

68. 111 were known to actively block access to hospital with one example where they actually stated *"we don't take Covid positive residents to hospital, order the end-of-life pack".* This was despite local hospital occupancy sitting at only 55% and a recent statement in the local press from the medical director of the health board stating that there were absolutely no barriers to residents with covid accessing hospital care.

69. Some members report begging for loved ones to go to hospital yet being denied any supportive care or oxygen. With 111 making such a statement it is not surprising that members feel their loved ones were given no chance to fight covid and that they watched them gradually decline and die.

70. There are members of the SCB who have questioned whether care and nursing home managers may have, after calling 111 and repeatedly getting this answer, perhaps decided there was no point in continuing to call 111 to be told the same thing and so resigned themselves to losing residents.

71. It has been explained by a member, *'after the care home manager was told by 111 we don't take covid positive patients from care homes to hospital, I contacted 111 directly to confirm if this is the correct policy. It was subsequently confirmed that this was not correct policy. I communicated this to the care home manager who was relieved. The manager explained that this gave him hope that he could still get help for residents unwell with covid. The concern here is that were there managers in homes who were given this incorrect information by 111 who then decided there would be no point calling them again about other residents.'*

72. One member has explained that when her late father was ill and covid positive, *'They called an ambulance as his oxygen levels were dropping and he didn't seem well. The ambulance came and they decided to treat him for a UTI and just order antibiotics and were not minded to take him to hospital. I believe there were times when covid positive residents were being labelled as having a chest infection or*

UTI as this meant they could be treated where they were and didn't have to go to hospital.'

73. There are also many SCB members who felt that relatives appeared to rally and then decline rapidly. In some cases, this meant that end of life medications, which needed to be prescribed by medical staff, were not received in time and therefore loved ones died without medications to alleviate their suffering. One member has explained their experience of this saying, '*My mum didn't receive end of life drugs or end of life care it was just terrible, it was horrendous.'*

74. Another member has explained, *'I got a call from the A&E department to say that mum was very ill and they didn't think she was going to make it. Her oxygen was down and she was very dehydrated. They were going to put a drip in. When she was hydrated she seemed to rally round.'*

75. In some cases, "Hospital at Home" services were brought into homes to deliver IV Fluids and oxygen. With robust pre-pandemic planning could this have been provided more widely in care and nursing homes to meet the needs of residents?

76. One member said their loved one was not being taken to hospital in case they caught covid but also that if they did have covid they wouldn't be taken anywhere anyway in case they passed it on.

77. SCB members feel that GP's often left care homes to their own devices and some care homes were refusing entry to medical staff.

78. With little or no GP attendance, few Inspections of services, and no relatives going in to see what was happening, **(JK/06-INQ000515941)** members are left feeling traumatised by the way their loved ones died. They are left wondering if they could have been saved. Some died alone, many were dehydrated and in one case, where an inspection did take place, a service was found to be understaffed with residents left to die alone in their rooms without any water. One of our members has said, *'My mum passed away a couple of hours after my visit, still in her chair, alone and without any medical intervention or assistance which could have improved her comfort in her final hours.'* Another member explained of their late

father, *'He wasn't given any care. He was just left to die. He wasn't given a chance. I think it was a case of because he is elderly they weren't going to treat him.'*

79. One member has explained that their loved one's care home refused access to a medical professional, *'There were also further restrictions imposed on my mum as I phoned the doctor to report end of life concerns after noticing how ill my mum looked during a Skype call. The Doctor sent a nurse to assess my mum and obtain urgent bloods on 12/11/20 and the nurse was refused access by care home. The health board has confirmed that the nurse was refused access to my mum. We have no explanation for their decision.'*

80. SCB members feel their loved ones were denied access to treatment because of their age and address and some feel their loved ones were victims of euthanasia. They have asked, where was the so called "protective ring" claimed by the UK health secretary at the time?

COMMUNICATION WITH RESIDENTS AND THEIR LOVED ONES ABOUT THE RESIDENT'S CONDITION AND TREATMENT

81. The majority of SCB members who had a loved one residing in a care home during the pandemic feel that communication from care homes was extremely poor. As most members could not visit their loved ones in person, they relied on communication from the care homes in order to be kept up to date with their relative's condition. This then also contributed to miscommunication in relation to DNACPR. Some members have reported being advised that their loved one had passed away without having been told that they were unwell or receiving end of life care.

82. One member explained, *'The last call I received from the care home was from a member of staff (I swear she said she was the cleaner) was at 01:15 on Wednesday 23rd December 2020 telling me Mum had passed away. We were never called prior to this to advise it was end of life.'* Another member explained, *'I*

got a phone call a few days later (16th May 2020) to say that dad had passed away. It was quite a shock as we hadn't been contacted to say he had deteriorated.'

83. There is particular concern about the apparent blanket issuing of DNACPR instructions by GPs looking after some care homes where it appears that all residents had DNACPRs in place without any consultation or explanation with the individuals and /or their families including those who were acting as Power of Attorney. There was also a concern that where a DNACPR was in place for individuals this was interpreted as no escalation of care or active treatment.

84. Given the lack of normal oversight of care homes by medical professionals, the lack of external scrutiny by visitors / family / inspectors and GPs and lack of training some members consider that staff in care homes may well have misinterpreted DNACPR as meaning no treatment.

85. Despite there being a Scotland-wide policy in existence by way of the "DNACPR Integrated Adult Policy Decision Making and Communication" document, issued by the Scottish Government, there seems to have been both a lack of consistency in applying this across both the country and individual care providers. In some instances, there seemed to be little or no apparent adherence whatsoever, giving rise to concerns that a blanket approach to issuing DNACPRs may have been taken.

86. It is worth quoting from the afore mentioned document which reflects the Scottish Governments position: - "The aim of CPR is to restore spontaneous breathing and circulation in a way that is sustainable for that patient. As with any treatment, CPR should only be offered if there is a clear expectation that its aim can be achieved. Where it is clear that CPR would not be successful (i.e. would not achieve sustainable spontaneous breathing and circulation) it should not be offered. There is a common lay-public misconception, possibly fueled by media coverage, that CPR is always a potential life-saving treatment and that patients always have the right to be offered this treatment. Where it is clear in advance that CPR would not be successful it is essential that the information that CPR cannot be offered is clearly and sensitively shared with patients unless it is judged that the conversation

would cause physical or psychological harm. Where a patient lacks capacity to engage with this conversation, relatives/relevant others (those close to the patient) must be informed without delay where this is practicable and appropriate. A clinical decision that CPR would not work should be sensitively explained as part of a wider person-centered conversation about the patient's goals of care in the context of their current illness, and realistic expectation about future deterioration and dying."

87. With regards to the issue of blanket DNACPR, from the point of view of individual members much of this information is anecdotal. However, we can confirm this was the general belief with the following documents (NB we are referring to Scotland only).

a. On 9th April 2020 Patrick Harvie MSP raised a question in the Scottish Parliament about apparent blanket DNACPR forms being issued. Nicola Sturgeon MSP First Minister responded by saying this should not happen in this way **(JK/07-INQ000515946)**

b. Nicola Sturgeon also addressed the issue that care home residents contracting the virus (again on a blanket basis) are not being taken to hospital. She said if hospital is right for that individual then that is where they should go **(JK/07-INQ000515946)**

c. We also understand that the Scottish Labour leader Richard Leonard MSP raised the same issue in First Ministers Questions on or about 20th/21st April 2020. We have been unable to find the transcript but attach a copy of an article from the Scotsman confirming this **(JK/08-INQ000515950)**

d. Dr Donald Macaskill CEO of Scottish Care also referred to this in his statement to the UK Inquiry dated 11th July 2023, see paras 69 and 70 **(JK/04-INQ000224524).**

e. In the Scottish Covid Inquiry the Central Scotland Care Home group also referred to this in their Organisational Witness Statement dated 14th January 2024 (SCI-WT0423-000001) in paras 82 and 83. **(JK/09-INQ000515949).**

f. On 15th May 2020 the Scottish Government issued v3 of National Clinical and Practice Guidance for Adult Care Homes in Scotland during the

COVID-19 Pandemic and in Section 6 about DNACPR paragraph 6.1 specifically states "There should never be a blanket approach to completing these forms." **(JK/10-INQ000515948).**

g. Additionally, there is the BMJ report of 3 December 2020 entitled "Some care home residents may have died because of blanket DNR orders, says regulator" which is self-explanatory. However, this report relates to England only, as do the CQC reports it refers to. That said we believe it reflects the position across the UK, including in Scotland **(JK/11-INQ000509835).**

88. There is also some concern about the way the Clinical Frailty Scale (CFS) is being used to assess what, if any, treatment is appropriate for the older individual **(JK/12-INQ000515942).** It is also suggested in the Treatment Escalation Plan (TELP) that the CFS may help in reaching a decision. The concern here is that neither of these two documents state on them that the CFS should be based on how the individual was two weeks ago (See the "HOW?" Section on Page 3 of the CFS Guidance issued by the Specialised Clinical Frailty Network.). There is further guidance available also explaining the 2 weeks prior requirement, but it is in separate documents which were not issued to all those required to complete the CFS. Therefore, no discussion was had with others, especially family members, as to how that individual was prior to Covid.

89. With regards to DNACPR one of our members has explained her experience of this with her Father who was in a care home, *'My dad's DNR was signed on 30/10/2020. A day after he was admitted. One was also given to my mum. I had POA for my parents. This was in their notes. Both DNRs were signed without consulting myself. It was during a conversation with a nurse that I found out. I asked her if my dad would go to ICU & she said no as he had a DNR.*

This was the first I'd heard of this. I was stunned, angry, upset, hurt that a doctor had made such a decision without consulting me. He didn't know my dad. He'd only just met him, if he even met him at all. A consultant cannot & should not be able to make a decision like that without having all the facts. Facts only the family can give him. During one phone call with a nurse she asked if my dad was spoon fed at the home. I was literally gob-smacked. I informed her my dad only moved

into the nursing home 8 weeks earlier to be with my mum. He was fully mobile and self-sufficient.

I requested a phone call with the consultant. I never received this. Instead, one of his team phoned me a few days later and agreed that I should have been consulted. The nurse who I found out from also said the same. I'll never understand or accept signing DNRs so liberally was the right thing to do. Nobody should chose who deserves to be treated and who doesn't. There is no doubt that the decision was made due to the fact my dad was admitted from a nursing home and his age.'

90. Another member has explained regarding the issue of DNACPR, *'There was a Key Information Summary added to my mum's medical records without family knowledge or consent stating "not for admission to hospital, preferred place of death and care to be care home". The Key Information Summary logged by the nurse impacted seriously on my mum's care. My mum did not receive any medical care before her death. Family had agreed on DNACPR but our understanding of this term was if my mum's heart stopped due to cardiac arrest she would not be given CPR . This did not mean that we did not want our mum to receive any medical care.'*

GENERAL COMMUNICATION

91. SCB members experienced communication issues at every level. There was a plethora of guidance directed at care settings from numerous sources. Some members found that guidance from within Scotland was not followed by care groups based in England, who tended to follow English guidance, which added to the stress and confusion of members. If guidance from one central point with short and direct daily updates had been available from the outset this may have aided adherence and avoided confusion for staff.

92. One member has explained that the care home their relative was resident in was the only one in Scotland owned by a I&S This member reported that questions were asked by families of relatives about the PPE

guidance. They wanted to know whether the home was following their own guidance and/or local guidance. The response was that they were following the care home group guidance.

93. In a particular care home there was a resident who was exhibiting covid symptoms and was generally unwell. The care home manager was told by a local council that only carers get tested. The manager contacted the Care Inspectorate by phone as he was struggling to get a test. The phone was not answered. Scottish Government had stated on 15th April 2020 that all symptomatic residents would be tested yet the manager was unaware of this change until the Scottish Government position was shared by concerned family members.

94. This home did not seem to be aware of guidance in Scotland, and brought additional staff from I&S which was a covid hotspot at the time, despite this being against travel restrictions. This was also in conflict with PHS guidance on staff movement between homes in the locality.

95. Many SCB members also reported a lack of ability to get through to homes by phone. There were also instances of members only hearing about covid in the home their loved one was living in by reading it in the local newspaper. One of our members has said, *'The Home did not inform us before the story broke in the newspaper. They confirmed that some residents and staff had tested positive for covid.'*

96. There was also misinformation communicated around availability of hospital admission **(JK/07-INQ000515946)** as demonstrated by SCB members experiences of 111. One member explained, *'according to the health board there was no barrier to covid positive care home residents going into hospital (there had been a newspaper report days earlier where the health board Medical Director stated this). At that time hospital capacity was at 45% so there was no reason dad couldn't go to hospital. I asked them [NHS 111] why they were giving out the wrong advice and not following local guidance. The covid team agreed that dad wasn't end of life. They said that every case is evaluated and there is no blanket approach to not take care home residents to hospital. [NHS] 111 was telling people quite the opposite.'*

97. Where face time visits were an option, many residents could not access these due to lack of equipment. There were also instances of internet and phones being "down" and of the facility to facetime being removed due to risk of cross infection when using the same phone or iPad in the home.

98. SCB members had the experience of videos being shared which, whilst undoubtedly were well intentioned and sent to comfort families, were extremely distressing, to see a loved one "performing" for the camera whilst looking very grey and unwell. Seeing these videos while being unable to visit them was extremely traumatic.

99. One member explained, *'We got another video of dad on 6th May. He used to be able to recite long poems and sing etc, but he couldn't even co-ordinate to clap his hands. The video was sent to try and reassure us, but it did nothing of the sort. It showed how unwell dad was.'* Another member stated, *'They held a sign behind my dad and made him hold a guitar. Dad's sign said, 'let me entertain you.' He was clearly unwell and unhappy in the picture. I was disgusted at it.'*

CHANGES TO THE REGULATORY INSPECTION WITHIN THE ADULT SOCIAL CARE SECTOR

100. In the early part of the Pandemic there were no routine physical inspections of care homes by the care Inspectorate, this, along with the lack of GP visits and inability of families to visit due to lockdown restrictions meant that the usual checks and balances were missing **(JK/13-INQ000320180).**

101. Care Inspectorate documentation indicates that the decision to pause physical inspections was on the advice of Public Health Scotland **(See Page 30 of Exhibit JK/13 - INQ000320180).** Members have reported that when inspections resumed later in 2020 there were significant concerns identified, many of which members have highlighted in their accounts. These concerns are also documented in the Care Inspectorate's own report.

102. Members have asked how many lives might have been saved if inspections had been in place throughout the pandemic and these were able to properly identify issues and support and train staff appropriately? SCB members consider that an inspector wearing full PPE would not have been a significant risk and could have identified areas of concern in homes in a timely manner.

103. One member has explained that they had communications from the care home confirming that the care home had, 'weekly support from our Inspector, who telephones every Tuesday.' However, members consider what was required were in person inspections to ensure care homes were operating appropriately in the circumstances and most importantly to identify where there were areas of concern that could then have been addressed. **(JK/06-INQ000515941)**

SCB FORMAL ENGAGEMENT WITH THE SCOTTISH GOVERNMENT

104. Virtual Meeting with First Minister March 2021

Questions asked relating to care sector -

- How, at a time when there was said to be a "protective ring" around care homes and WHO was repeatedly stating "Test Test Test" does the Government justify sending untested hospital patients into care homes full of vulnerable people?
- We all saw the scenes on the news from Italy and Spain depicting the COVID devastation in care homes. Why was the "lead" time we had in Scotland not capitalised on to provide infection control and PPE training and support in care homes?
- Why did no one appear to consider the distinction between care and nursing homes? Without nursing input many care homes would not have an understanding of covid symptoms and infection control yet they were left to cope with no care inspectorate visits, no GP visits and no relatives visiting, where were the checks and balances?

- 111 was the route for help for care homes concerned about residents yet when calling 111 to request help for covid positive residents the default position was "we don't take Covid positive patients to hospital, order the end of life pack" Is it any wonder so many care home residents died? If you are a manager of a care home are you going to keep calling time after time if this is the response you receive?
- People died without relatives around them, without prolonged antibiotics and iv fluids or the simple basic human right of oxygen to help them breathe. Done in the name of protecting the NHS -is this not their NHS too and the one they have contributed to throughout their lives?
- Given that most residents enter care services due to a need to be cared for and protected as vulnerable members of society, why were they less able to access medical help than those in their own homes?

105. Various Meetings with Deputy First Minister and Health Secretary 17 August 2021-24 November 2021

Questions asked relevant to care sector –

- We had various meetings during this time. We discussed the commitment to the Scottish Public Inquiry and the DFM invited the family representatives to maintain contact with officials and we would be involved in setting the ToR and discussing the scope for the Scottish Inquiry as we requested.

- We raised again symptoms and testing criteria - received formal reply on 23 December 2021 after chasing response that UKHSA would not change the criteria at that time.

- We also raised lack of Bereavement Counselling especially for those bereaved when strict social distancing measures were in place including, but not limited to, number restrictions at funerals, inability to be at loved ones side at death, inability to gather as friends and families for mutual support, inability to even have a hug from friends and some family.

LESSONS LEARNED

Care Settings

106. There should be greater understanding and clarity around types of care settings, umbrella terms such as Nursing homes or Care homes are often used with apparently little or no acknowledgement or understanding of the differing types of care each can provide.

107. In future pandemics, the training and support of staff in each setting should be tailored to ensure they are able to meet the changing needs of residents in their care.

Training of staff

108. Staff in care settings must be trained to identify, record and report Oxygen levels, respiratory rate, signs of dehydration and of respiratory distress and if requested to monitor these by a clinician speak out without fear when they don't feel equipped to do so. Medical staff and triage functions such as 111 should also ensure that staff are understanding of and confident in their ability to follow such instructions.

109. Many SCB members watched helplessly as loved ones deteriorated day by day with little or no supportive care. Some relatives then realised, after witnessing a long unsupported, painful decline and distressing death, that staff were unable to monitor residents as requested nor to report accurately to triage teams which, if addressed may have saved lives.

Infection Control

110. Infection control training should be embedded routinely in all care settings. This should be updated frequently and unannounced inspections undertaken as is the case in the NHS with findings shared and addressed.

111. The provision of PPE alone is not enough. In future, supply and quality of PPE should be consistent and plentiful with steps taken to ensure staff know how to correctly don and doff PPE and dispose of it correctly.

112. Roles within care settings should be clearly defined, SCB members experienced staff undertaking both caring, cleaning and even cooking responsibilities.

113. Knowledge of COVID -19 as an airborne pathogen was known early in the pandemic yet the understanding of this was not always as it should have been with examples of residents blowing out birthday cake candles after which the cake was shared with all residents.

114. Any pre pandemic planning in the future should take into account different settings, knowledge and experience. The Care Sector should be fully integrated into pandemic planning with training needs assessed and addressed.

Equity of Care

115. Whilst it was stated there was a "protective ring" around care homes this was patently not the case, people with COPD residing in their own homes could access oxygen yet those in a "care" setting were often denied not only the supportive care they needed but in many cases the ability to access any medical care at all.

Consistency of Guidelines and Messaging

116. Care home groups with facilities across the UK may have had to contend with numerous differing guidelines at a time making understanding and adherence even more challenging. Consistency of guidelines and messaging in future pandemics could prevent unnecessary stress for relatives and avoidable deaths.

Isolation of Residents

117. Isolation of residents was important in avoiding the spread of covid 19 and in future pandemics we must look at better ways of achieving this. Where people were decanted from hospital into care homes, isolation was paramount and we know from our examples that this did not happen. Footfall through residential settings should be minimised and this should include changing staff shift patterns and dedicating staff to particular areas of a home. In the case of residents struggling with isolation, such as those with dementia, thought must be given on how to achieve this safely, for example, one named person wearing full PPE per

resident should be considered to support their wellbeing while isolated within the home.

Statement of Truth

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

Signed: Personal Data

Dated: 19th November 2024