SCOTTISH COVID BEREAVED

IMPACT / INEQUALITY STATEMENT

MODULE 2

WHO THE SCOTTISH COVID BEREAVED REPRESENT AND HOW AND WHY THE GROUP WAS ESTABLISHED

1. Scottish members originally started out as part of the Facebook Group Covid Bereaved Families For Justice (CBFFJ) which was formed 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 sub group 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 the latter half of 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 too, 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 we have focused our activities mainly in Scotland, due to the absence of anyone else doing it, we have participated in actions with the original CBFFJ Group in its efforts

to get a UK Inquiry. We are also 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 feel we cannot do one without the other.

6. We are a group of like minded bereaved individuals with a common goal of not wanting our loved ones deaths to have been in vain and for lessons to be learnt to stop others having to go through what we have been through. We also feel that sharing our experiences, both good and bad, will be of great help to both Inquiries in assisting them to establish what really happened.

7. Although our group came about because of bereavement we within the group have members dealing with other consequences of the pandemic ranging from traumatised healthcare workers, teachers who had to buy their own disinfectant to keep classrooms safe and using their own money to feed pupils, to those dealing with long covid to those dealing with the financial consequences of the pandemic and other issues too.

8. In addition to the political and media activity outlined in #1 through our work with our Group eg. we set up groups to support those who were bereaved by Care Homes and through Nosocomial Infection, we have identified consistent areas of concern amongst our Members which we have shared, albeit verbally, with the First Minister, Deputy First Minister and the Health Secretary when we met with them. A full list of those questions/issues is attached at Appendix 1.

9. For example we flagged up the fact that Nosocomial deaths were in the region of 25% compared with Care Home deaths at 9%.

10. We also raised issues about Covid Symptoms consistently being restricted to the three cardinal ones, namely temperature, persistent cough and loss of sense of taste or smell whether you were dealing with 111 or On-line testing criteria. The Scottish Health Secretary confirmed to us in December 2021 that the UKHSA were responsible for the symptom profile and would not, at that stage, change it. A clear example of the Devolved Nations having to follow the UK lead.

11. We offer mutual support through our closed Facebook Group. Also through the formation of regular zoom meetings discussing both the current situation with regard to the Inquiries and also having group meetings for people just to share their stories and to ask for help if they need it, just so they know they are not alone.

12. We also proposed that the Lord Advocate and the Crown Office and Procurator Fiscal Service (COPFS), who were investigating Care Home deaths due to covid, should also consider Nosocomial Deaths.

HOW BEREAVEMENT DURING COVID-19 AFFECTED THOSE WITHIN OUR GROUP

13. In addition to the natural consequences of bereavement those within our group feel that their grief was compounded by the restrictions in place.

14. Many of our group members were unable to be with their loved ones at the end of their lives and the thought of their loved one dying alone is something that continues to haunt them.

15. As time goes on, our members have more and more questions about how and why this was allowed to happen. Indeed, a number of our members wonder whether the restrictions on visiting their loved ones was as a result of an inadequate PPE supply.

16. Our members are aggrieved that it appears that guidance relating to visiting and attendance at end of life was not consistently applied across health boards but also within hospitals and even across different wards within the same hospital.

17. We have members who have reported that some of the guidance was simply nonsensical, for example, not being allowed to visit their terminally ill relative in hospital as they were advised the hospital was not letting anyone in who was not a patient. However, after their loved one's death, they were then advised by the same hospital that they would require to attend at the hospital in person to collect the death certificate. Examples such as this have added to the grief and frustration felt by our group members.

18. The situation with regards to end of life care and the subsequent bereavement has caused significant trauma to our members.

19. Indeed, many feel a sense of anger and guilt about the standard of care their loved one received before their death and there are some that feel their loved one's death could have been prevented. Many also feel ongoing guilt that they were unable to advocate for their loved one when they needed this.

20. We have heard accounts from members who have advised that they were told by hospitals that they had to choose between being present at end of life with their loved one or attending at their loved one's funeral, due to clinicians misunderstanding guidance on isolation rules.

21. Due to guidance and the consequent restrictions placed on individuals, the usual grieving process was unable to occur. For example, relatives were unable to see their loved one after their death, which was particularly painful for those who had not been able to be present at end of life of their loved one.

22. Additionally, members have reported not being allowed to provide clothing for their loved one to be laid to rest in, leading them to feel that their loved ones were dealt with in an inhumane and undignified manner. These are important details that have caused our group members on-going distress.

23. The grieving process was also impacted due to their being restrictions on funerals and memorial services. Families were not allowed to be together to provide comfort and support to each other. Religious observances were often unable to be followed. All adding to the trauma experienced by families in these circumstances.

24. These farewell rituals are vital at a time of loss and their absence resulted in traumatic experiences because family members were prevented from properly saying goodbye to their loved one.

25. Following on from the funeral, the impact of restrictions continued and resulted in feelings of loneliness and despair due to families and friends not being allowed to be together,

providing very much needed comfort and support. One of our members has said, *'You do not realise how powerful a hug is until you are deprived of one'*

26. There are also situations where the loss of a loved one has resulted in loss of income causing great financial strain. This has impacted whole families and in some instances people have lost their homes.

27. Members have explained that their grieving process has been prolonged due to not having the usual routines to follow after someone dies. The grieving process has been more challenging for them due to lack of support and resources to assist with coping. We understand that a number of our group members are now suffering from PTSD as a result. This has not been helped by there being constant triggering reminders of covid and covid deaths in the media.

28. It is clear that dealing with bereavement during a pandemic has been an extremely traumatic and devastating experience for our group members and the impact of this on them will never leave them.

INDIVIDUAL SUMMARIES OF GROUP MEMBER'S EXPERIENCES

29. Many of the individuals within our group have been affected as a result of pre-existing inequalities. Our group members have given a number of accounts which illustrate some of their experiences of this and the impact of these inequalities.

Later Life & Ageism Inequalities

Social exclusion and isolation due to lockdown

30. "When lockdowns started in care homes two of the first people to made redundant by the care home my Mum was in was the activities coordinators. Residents were confined to their rooms for several weeks, with meals being served in their rooms. There were no activities and there was no contact."

31. *"My mum, who eventually died of Covid 19, suffered terribly during the first lockdown. She lived alone and didn't see another person for weeks. She spent her final months almost entirely alone before succumbing to Covid-19 in February 2021."*

32. *"I feel that my mother was getting more and more nervous going into the second lockdown. I feel the Government were on TV every day talking about all these different things and there was no equality for her as an elderly lady. The elderly were not considered. It was a case of 'keep away from the elderly and vulnerable to protect them' meanwhile other people were in and out of each other's bubbles and houses. There was no consideration for the elderly. I feel they were just numbers. My mum caught covid and died in the hospital. Lockdown played a big part in terms of the mental health of the elderly. They were to isolate because they were vulnerable or of an older age. Which played a big part in the mental decline of the elderly. They tried to put my mum on anti-depressants, but she wasn't depressed, she was just anxious."*

33. *"I feel there were inequalities to the elderly due to their age. They were left in hospitals and care homes and we as their family had no option of taking them home. I think the Government knew it was going to be more than the 2–3-week situation they told us and if they knew we were going to be in lockdown for a few weeks then why weren't we given the option to take our loved ones home with us, we were also in lockdown at home and could have been together."*

34. *"I would argue that this was, in many cases worse for those residing in care homes as they had no physical access to loved ones who were not permitted entry. For those living in their own homes, although clearly very challenging indeed there was a possibility to be supported and to see family via the "support bubble" mechanism."*

35. *"My mother expressed loneliness and my father exhibited symptoms of depression such as loss of interest in prior activities due to their social exclusion and isolation."*

The clinical management of those with pre-existing chronic diseases or awaiting treatment for long term conditions that are more prevalent among the elderly

36. *"I suspect his pre-existing condition, particularly when he became covid positive, was not effectively taken into account."*

37. *"Once he was admitted to hospital, there was a lack of appreciation that they were treating a vulnerable patient with dementia, unable to advocate for himself. Did they risk assess this and how to best administer oxygen and medication to a distressed and confused patient? Did they liaise fully with other hospitals where he had been a patient? Was he left alone on admittance and how long for? During a long-awaited phone call from a Dr on 13th January, I had to advise him of Dad's dementia, and was then told there would be no more treatment given at this point.*

38. *Finally, was my Father given a true chance to survive Covid-19? No vaccination, a delay in diagnosis, inadequate early treatment and a delay in giving him access to specialist care. This all compounded with a potential lack of understanding of how to treat a patient with dementia contributes to a chaotic picture of negligence and an absence of a clear patient plan. Add to that the gap in family communications at a crucial point in his treatment."*

39. *"My mother's shoulder surgery was put on hold, and additionally she did not receive the physical therapy she should have had for her hip."*

Reduced access to formal care services for those not resident in a care home

40. *"This is in relation to medication and health check reviews not happening by GP Practices, each year (or more if required) I would take my Da to the doctors to discuss medication and clinical observations were done this enabling any changes to his repeat medication. No proactive medicine and indeed difficulty in accessing reactive intervention. Whilst in hospital in Jan 21 a small but concerning lump was found during a chest CT. Both he and I were told not sure when we will be able to assess further due to pandemic."*

41. *"Mum had no choice but to go into a care home because of the NHS funding criteria. One of her carers became pregnant. There was no funding to pay for her to go on maternity leave, and to employ a carer during her maternity leave because we were using Self Directed Support funding. If she had been employed by an agency or the NHS this would*

have been covered. This was very unfair. Mum went from having an excellent team of carers who knew her very well and provided 7 hours of care a day to a care home where she was mainly left on her own."

42. "My Mother-in-law had been diagnosed with Alzheimer's and was receiving care at home. *We always used to get my mother in laws shopping and we weren't even able to do that for her. We think my mother-in-law must have told the carers she was concerned about her grandson who was feeling poorly, and the next thing we know the carers were refusing to go see her because they said we were going to give them covid. Nobody had covid. They said they would do a phone call to her every day, but she could tell you anything over the phone, you can't tell if she's actually okay through the phone. Can't prompt whether or not she needs medication or not through a phone call."*

43. *"My Mum was 80 and not in good health, with heart and lung conditions. She was unable to get a GP to come out to visit her. They either phoned her or just gave her antibiotics. We ended up phoning NHS24 several times and a doctor would come out. Two of those times, she ended up in hospital, the 2nd time contracting covid. I honestly believe she would not have ended up in hospital had her own GP taken the time to visit and seen her face to face."*

Digital exclusion where no access or unable to operate digital devices leading to difficulty maintaining connections with family, friends and community supports

44. "Social isolation during first lockdown and for months thereafter - difficult to communicate with someone who is deaf by 'phone/video call or through a window/microphone system."

45. "The first day I got to see her, then two days later they shut down and I didn't get to see her. I was keeping in touch with her by phone, but she was getting upset when we were on the phone. I then found out that some of the residents were having window contact and we were never offered that. She was there for a while and we never got to see her.

46. She then went to this other care home; we booked a time on the iPad to speak to her and then when we phoned to have our FaceTime call the person said someone else was using *the iPad and we would need to buy my mum one to speak to her. But we couldn't buy her an iPad because she wouldn't know how to or be able to use it."*

47. *"My dad was 104 yrs. old when he died of Covid-19. He had lived with myself and my family for 27 years. Unfortunately due to his dementia and becoming a falls risk we were struggling to keep him safe at home and were advised that he required 24-hour care. He went into a local nursing home on the 27th of February 2020 where he settled well. He still recognised family and friends. Two weeks later the home locked down. We tried to Skype but my dad was hard of hearing and didn't understand the technology. His family called him every day again that was a struggle. I had been my father's voice for years and spent several hours a day with him in the home until it lockdown. Then just like that our human rights were denied, we no longer had a voice. I could drop off cards, letters and his favourite treats but couldn't wave to him through a window incase it upset him."*

48. *"My grandpa also had a laptop sent in, and when myself and family asked if someone could show my grandpa how to video call we were told yes, someone would show him but this never happened so my family and I never once had the chance to see my grandpa after he was admitted to hospital or before he passed. He passed away alone, when he was a family orientated man, we don't know as a family what went on behind the scenes."*

49. *"The care home did not have any WIFI, so we were unable to contact Mum via facetime. We couldn't use the telephone as Mum couldn't use it and she also didn't recognise our voices due to her dementia, although she always recognised our faces. We wrote letters to Mum and asked the staff to read them to her, but the care home could never confirm if this happened. We set up a website with family pictures and videos so Mum could see what was happening in the family, but the care home never accessed it to show her."*

50. *"Although we tried to have family gatherings via zoom, she struggled with the technology and wasn't always able to join us."*

51. *"He was completely dependent on staff for access to technology. I have no memory of getting a FaceTime call from him."*

52. *"Elderly people wouldn't have had that app to let them know if they had been around anybody testing positive, they weren't able to facetime or video call, even in the hospital they weren't allowed to video call."*

53. *"We did get a FaceTime call with my mum, but she didn't get it, she didn't understand it. My mum died very early on into lockdown so I didn't have a lot of time with her."*

54. *"I was informed that the health board had sanctioned one way system mobile phones. This meant that I could never directly contact the clinical area for any updates. I had to wait on one call from the consultant and one call from the nurse on duty. On my husband's last day this strategy was still utilised causing extreme pain and distress. I didn't actually hear from any clinicians from this time until 14 hours later to tell me that my husband had gone into multi organ failure and nothing could be done. Who gave permission for his strategy and what was the rationale behind it."*

55. *"One point I still can't get my head around is my mum's so called care home did not have facetime or any other way of contact during lockdown when most other care homes had a way of seeing their loved ones. The grief, anger and all the rollercoaster thoughts in my mind I will never come to terms with to the day I die and how my poor wee mum was treated."*

56. *"They tried virtual communications via small handheld devices but Mum had neither the vision nor hearing capacity to benefit from those means."*

57. *"When mum was in hospital we could not speak to her direct as she could not work a mobile. Staff did not have time to pass on messages to her each time I called. I asked for an iPad video call but was told that they only had 1 iPad which was for staff use. When i kept pushing (having written to the health board) they then said she didn't want to do it (by this time she had covid and was seriously ill). It was extremely frustrating not to be able to see her or speak to her especially when she was basically dying. A member of nursing staff (friend of family) managed to help us by doing a video call with her, which although distressing we could see exactly how she was both mentally and physically."*

58. *“We saw on tv in some care homes I pads being used to help the older people in touch with their relatives during lockdown. My mum had no access to a phone to talk to us. When she was first diagnosed with Covid on 17 January 2021 we were told she was still able to talk and was holding her own for a week.*

59. *We got a ‘granny phone’ easy to use - to call us and handed into the ward. However, she was unable to use it. She needed the support of nurses to be able to call us or receive a call. This only happened once when a nurse happened to be in with her and answered the call and passed to our mum.”*

60. *“The location of my parents’ house has always been a problem, in terms of poor mobile phone/TV reception, with various providers citing coverage of their postcode as the cause. Even now, I can’t always get a mobile phone reception in the house. In other words, their hands were tied to the broadband (etc.) providers, in terms of what they provided to the area (pretty inadequate, in this case). It was difficult to show my mum and dad how to Facetime, when we weren’t physically next to them, guiding them step-by-step. Although always quick on the uptake (once shown), as everyone knows, it is always easier face-to-face. To an extent, this excluded them, digitally.”*

61. *“Once hospitalized, both parents were unable to maintain connections with family, friends, and community supports. They owned smartphones but couldn’t operate them.”*

Age often used to categorise and divide people which leads to harm and has serious consequences for people’s health, wellbeing and human rights

62. *“The inadequate communication and total lack of humanity shown by the care home I felt, was because of Mum's age and because she had a DNR in place. Both these factors in my opinion were influential in her being left to die basically. Whilst I have no evidence that this is what they did. It’s purely my observations, given the timings of their calls, the tone of their calls and my observations from the short access visitation I was granted when I demanded to see her, left me in no doubt this was their decision.”*

63. *“This was sadly obvious in the lack of care and intervention on confirmation of COVID positive for my Da. No treatment incomplete DNA CPR and very poor palliative care. From*

first sedation to last breath was plus 48hrs. Several times he woke in terrible distress (I was present) several times I was told he would not survive intervention.. My Da was asymptomatic on day 3. After an assisted fall he came breathless it was assumed to be covid pneumonia. But his pain he told me was in his shoulder. Chest X-ray comments query broken clavicle. Da was 80 and marvelous at 5:30pm we were chatting for over 40 mins on the phone. He was including the nurse in our conversation (I then met that exact nurse who told me he was a fantastic guy who made them all smile) he was in pain but waiting on pain relief and an air mattress. Just before midnight end of life care had began. Nobody noticed the comments about the possible fracture. They didn't even check the DNA CPR was signed properly they said he's 80 he will be dead in the morning. What then followed was 48plus hours of torture."

64. *"As an older person, with dementia, dad (along with all the others in the same situation) was clearly disproportionately affected by the measures imposed due to the pandemic. He was deprived of family life and any real contact with us- dinner at our house, trips out with carers - both the private ones who would take him out and from the home. And, of course, the speed at which a DNR was requested by the home is a big concern. I get the impression this was applied in a blanket move, but hopefully the inquiry will shed more light on this."*

65. *"I feel my Dad was subject to Ageism whilst suffering from Covid. He was in hospital for 4 weeks, and was in the High Dependency Unit. I spoke to a nurse who said that that was as far as his care will go. They didn't want to put him in Intensive Care or ventilate him due to his age. Now my Dad was a strong man, he may have been 83 when he passed but he was still strong. He had just finished installing a new shower room for me and built a wall in my brother's garden. He was a very fit and able man. The hospital never gave him a chance because of his age. Don't get me wrong, all the staff were lovely but nonetheless Ageist"*

66. *"My son was 31 years old when he was finally taken into hospital for the first time on day 5 of covid. He was young & asthmatic and his diagnosis was worsening Covid & Exacerbation Asthma but he was sent home. He was still deteriorating on Day 8 of having covid and went to assessment unit, but again was sent home. Why was this? Was it*

because he was young and they thought he would survive. This was a big mistake. The clinicians reasoning was, "we followed protocol and guidelines."

67. *"Age used to categorise people and triage access to services was a reality, it was often stated that people in care homes were in the last year or so of life. There was no attempt to look at the quality of life pre covid and no understanding of the person as they were often not seen by any medical person known to them. If elderly were able to access hospital care they were measured on a frailty score yet this was when they already had covid rather than informed by their function when well."*

68. *"Perhaps we should be highlighting the inequalities between those who managed to die in a hospital bed - compared to the death old people left to die in care homes were experiencing at the height of the Covid pandemic?*

69. *So many old people were denied a hospital bed due to the blanket use of DNRs being placed on them. Government guidelines stated it was not envisaged that residents within care homes would be admitted to hospitals - instead, they would continue their care within the care home setting.*

70. *Sadly, we now know that many of these old people were left to die a terrible death. Windows in their rooms were not allowed to be opened, no fans were allowed into rooms to help ease the suffering of those with extremely high temperatures. No suctioning of airways to help clear mucus and help these poor souls to actually breath.*

71. *All of these measures were apparently put in place to help prevent further cross contamination by aspiration or by fans, open windows etc. allowing airborne virus particles to spread further within the care home.*

72. *No doctors or nurses were visiting these patients. Many of these old people were residents in "care homes" which obviously differs significantly from "nursing homes" in that care homes have no qualified nursing staff. Therefore, the care for the seriously ill and dying was passed onto care home staff to try to manage. Whilst kind and well meaning, care home staff often lacked the experience or knowledge needed to deal with end of life care.*

This huge responsibility should not have been placed on the shoulders of those with little or no medical background.

73. *Therefore, surely the biggest inequality these old people suffered was the inequality of the standard of end of life care they received - compared to the medical care given to Covid patients who died in a hospital bed?*

74. *These old people deserved help to allow them leave this world and die with peace and with dignity. Having their pain properly managed at the end and having medical staff to help them pass away peacefully would appear to be something which was sadly denied to so many.*

75. *Why was this tragic inequality allowed to happen when we had a Nightingale hospital sitting empty? I hope the inquiry might shine some light on this tragic inequality of care for the dying and hopefully this disgraceful inhumane treatment of elderly people is never repeated in the future."*

76. *"Was my 28-year-old son discriminated against when he called our health service for advice/help on his ninth day of illness & isolation with Covid symptoms? He was told to wait another day, the day he died from a blood clot and Covid. Why was he told to wait another day? At that time in late Dec 2020, what criteria did you have to meet to be given medical attention? Was priority being given to another age group or something else? A few days later after Andrew had passed away at his home, we were told in person that our health service professionals knew of instances of young patients developing fatal blood clots caused by Covid."*

77. *"I do agree that the class of people or should I say, peoples status in society had a lot to do with how they were treated, and if you got to live, or just die. No one has the right to call end of life on anyone within hours of being diagnosed with Covid, and then refuse food and water. I would not expect an animal to be treated this way . But to do this to another human is unforgivable. Something I will never forget."*

78. *"The human rights of older people were not taken into account and they were seems as expendable, with their vulnerabilities and need for shielding totally ignored because of the type of accommodation they lived in."*

The stereotyping and de-valuing of older dependent people leading to a longstanding failure to invest adequately, and historic underfunding in the provision of social care services, including care homes

79. *"The care home had no budget for activities and events - there is no ringfenced funding for food or activities in the care home funding, there are just some guidelines. There are also no criteria for staffing levels. During the Covid outbreak in the care home the Care Inspectorate did an unannounced visit. The home was so short staffed that people were bed bound and not even having basic care such as hydration. They issued an immediate safety notice."*

80. *"During lockdown staff drafted in from the sports centre and the ice rink to replace staff . At start of pandemic 9 patients transferred from hospital to my mum's care home and 7 were untested."*

81. *"My father twice suffered a failed discharge from hospital as he was too ill to go home. He needed more hospital care but did not receive it. Home care was not prioritized for my father; it was not put into place although both the family and the family doctor requested it. This failure of the care system to adequately provide for my father caused my mother extreme distress. Ultimately, it cost both of them their lives."*

Failure to identify high risk groups of older people during the pandemic – those living in deprived areas, ethnic minority older people, those living in care homes or awaiting discharge in hospital and frontline / keyworkers

82. *"I felt why was my elderly dad who had been in hospital nearly a month sent home on the day he tested positive to his elderly wife who they knew would be a high risk to catch covid still sent home, they said hand washing would be adequate yet my mum contacted covid and I lost both of them in a 8 day period. I still find this difficult. I worked through covid in*

care sector and I made sure I followed protocol in my job and outside of work. I protected them both and the NHS let me down."

83. *"When my mum caught Covid-19, in Jan 21, she had still not been invited for a vaccination. By contrast, her younger brother in Derbyshire had received his first jag weeks before my mum caught the virus. My mother in law and other relatives who were younger than my mum were being called up for theirs, when she appears to have been entirely overlooked."*

84. *"Police were not considered front line workers and police forces were one of the last groups to receive PPE. Police were also prejudiced again when it came to the vaccination delivery."*

85. *"Generic discrimination in the sense of the ' Herd immunity' policy Feb/March 2020 in Scotland and also clearing hospital beds & discharging known/ possible covid cases the care /nursing homes. In their Nursing home, the GP did not visit after lock-down - therefore possibly inferior care for these elderly patients."*

86. *"Those living in care homes were in the highest risk groups. Yet both NHS England and NHS Scotland decided that care homes were the ideal places to put "bed blockers", many of whom had been exposed to Covid, some of whom were known to have Covid, without testing and without adequate guidance on how such people were effectively to be held in isolation."*

87. *"My 86 year old father was discharged from hospital and sent home to my 83 year old mother although it was known he had been exposed to Covid in the hospital ward and had not yet received the results of his Covid test. As a result of this exposure, both my father and my mother died, and my high-risk sister, high risk brother-in-law, and their three young adult children all contracted Covid. My sister was later diagnosed with Long Covid and retired from her 30-plus year Civil Service career on health grounds."*

LGBTQ+ Inequalities

Lockdown and social distancing magnified vulnerabilities for LGBTQ+ people who already have higher rates of depression, anxiety, suicidal ideation and self-harm compared to heterosexual and cisgender populations

88. *"Specifically, referring to the impact that covid has had on my son who started transitioning from female to male around February/ March 2021. My son only came to us re this just after his brother passed away from covid. He applied to change his name and had to wait 10 months to do this. He as having to explain himself which was wrong. I don't have to justify who I am so he shouldn't have to either. I phoned up and spoke to a manager. This delay was due to the impact of covid on such services. He was referred to a gender clinic. These services have all been impacted as a result of covid. They are only currently working on referrals from May/ June 2019. This is the waiting list prior to covid. Nothing happened during covid as it was not seen as an essential service. My son's mental health was really suffering so he has gone private. He is paying for his own hormones and medication. He has saved up to have the surgery. He is waiting an appointment and should have the surgery by the end of the year. He had been attending CAMHS mental health services for around 6 to 7 months. This was during covid via video call. He was referred here prior to announcing he was transitioning. He is still on the waiting list at the gender clinic. His mental health is really bad and mood very low. The process with the NHS is too slow and covid has impacted on this."*

Ethnic Minorities Inequalities

Lack of trust/ engagement with healthcare services due to previous unsatisfactory treatment/ experiences and higher risk of serious illness and mortality due to pre-existing social and economic inequalities

89. *"My husband's family is from Bahrain and he was a practicing Muslim. It was known that ethnic minority groups were disproportionately affected by Covid – 19 from a very early stage in the pandemic. What did they do to address this? On the day my husband was admitted to hospital, he was not that unwell. A doctor called me in the evening to say that if he deteriorated, they would not escalate him to intensive care. If they knew that my husband was at a higher risk of dying, why was more not done to help him? Why did they*

give up on him on the first day? I want to know what was done to help people from ethnic minority backgrounds after it became clear they were disproportionately affected. After he died, we also had real difficulty in obtaining his death certificate. Muslims are supposed to be buried within 24 hours of passing away. It took far longer for us, we called multiple times and nothing happened. We eventually found out the death certificate had been signed but had not been taken to the morgue. It was a week after his death before we got the certificate. My husband's funeral was delayed significantly from when his culture and religion specifies it should have been."

<u>Child Health Inequalities</u>

<u>Major disruptions to the services that safeguard children, that look out for them, their health, education and wellbeing and offer services, support and guidance</u>

90. *"At the same time as my mother and father passing away, I had a 16-year-old granddaughter who tried to commit suicide. She became so overwhelmed with the disruption to her online learning and trying to do exams online and not being able to go out and socialise and do the things that she wanted to do as a young girl, that she tried to take her own life. Thankfully she was found and taken straight to hospital. The help she received was an online website given to her by her friends mum, and she was put on anti-depressants at the age of 16."*

91. *"I have grandchildren who were affected by the loss of their nana. There was no mental health services available to them and the schools were closed as well. It wasn't until they got back to school that things started to get better. The older grandchild was able to access a counsellor through his school who provided him with counselling."*

92. *"My son was given predicted grades in s5 that affected his choice of uni. Due to home learning and lack of any support his predicted grades were affected/ lower and by the time he sat his exams in s6 he'd more than enough As to pass the requirements for the university he wanted to go to but due to his predicted grades being lower than this he has had to go to a different uni."*

93. *"My son who has autism received no school leavers follow up and there was no support in place to help support his transition to adulthood"*

94. *"My grandson has also struggled with lockdown and knowing how to be around other people. He has developed ticks and has started to isolate himself in his room due to starting first year and being so anxious."*

95. *"I have a son who is autistic. He likes his own company and it's a struggle with him being in social situations. During lockdown it was fine because we entered his world and were in doors, but now we're struggling with him coming out of lockdown and trying to adjust to life."*

Disability Inequalities

Disproportionate impact of pandemic on the disability community, it exposed, intensified and reinforced pre-existing inequalities

Those with disabilities should have been foreseen to be at higher risk due to intrinsic vulnerability to infection, being in a weakened socio-economic situation and many being dependent on health and social care services which were weakened during the pandemic

Difficulties in adopting self-isolation to reduce the risk of infection, many in close contact with others when receiving care and support in daily activities

96. *"For someone who is visually impaired/blind a number of challenges arose during the pandemic. Firstly, social distancing is very difficult if not impossible as you are not able to see where other people are so you don't know if you are going to close and sadly a lot of people don't think to get out the way. As another CP said Guide Dogs don't understand social distancing. A long cane is slightly more effective as you know if it touches someone you are too close!*

97. *Secondly, visually impaired/blind people use a lot of touch for assisting them. For example, going upstairs they will use the handrail to identify when they are coming to the top or*

bottom. Furniture is touched going round a room to help orientate themselves. If they are in shops and they want to check, they have the right item they have to pick it up and hold it right up to their face to see what it is. If they sit at a table to eat they have to touch all of the area in front of them to identify what is where etc. They can't read warning signs and so on."

98. *"I believe my experience during the pandemic is relevant to the Inquiry's call for further evidence on disability inequality. I have an autoimmune disorder in the highest category of vulnerability to COVID 19 and I was sent a shielding letter from the NHS very early on in the pandemic. I lost my brother in May 2020 and then had to isolate at home to protect myself. I was very scared of catching COVID 19 and was frightened to leave my house and go anywhere. My condition was a disability that prevented me from going out. My fiancé who had had an aneurism when he was 21 was getting blurry vision and refused to go to A & E because "the hospital was rife with COVID 19" and he feared catching it and then infecting me. I begged him to go but he would not risk infecting me with my weakened immune system. He had a second aneurism in 2020 and died. My disability caused him to refuse to seek medical treatment for his blurry vision, which we know now was a warning of the aneurism that he died from. I was told he would have survived if he had received treatment. Had I not had this disorder, he would be here today."*

99. *"My husband was type 2 diabetic & I was receiving chemotherapy & radiotherapy at the time. Neither of us were put onto the shielding list & I can only think this is because we were overlooked. I was told by my surgeon at the time to shield myself but at no time was my husband instructed to do so & because of this he continued working & caught Covid. I remember so many things on TV at the time about certain people being really vulnerable. At no point did I hear that diabetic people, especially type 2, were at great risk when in fact they were at huge risk. This to me is an inequality."*

100. *"'My late cousin, was 70 years old when she died in hospital in August 2021. She had complex, profound learning disabilities. She had cerebral palsy, severe epilepsy and was non-verbal from birth. She was unable to walk and was a wheelchair user, and she required to be fed, was unable to hold a cup or glass and required to be given drinks. She was doubly incontinent and required 24-hour care. Her level of understanding was not possible to assess but she was always able to recognise those close to her, express*

happiness and was always able to let you know if she was unhappy, fed up or angry, and those who knew her well would know if she was in pain.

101. *In March 2020, the care home was 'locked down' and no visitors were allowed to come in. She was unable to understand the situation of the pandemic, lockdown and shielding. She could not understand why my aunt was not coming to see her, spend time with her, play her favourite music, massage her hands, tell her stories and just be there. She demonstrated the anxiety and deep sadness and grief of that sudden loss. She became withdrawn, did not want to get up and into her wheelchair, did not want to engage with the other residents and crucially, she stopped eating and drinking.*

102. *My aunt's only contact was telephone conversations with the care home staff. My aunt was severely visually impaired due to advanced macular degeneration so even if the option of video calls had been offered to my aunt, she wouldn't have been able to see my cousin and it is uncertain what my cousin would have understood. My aunt and my cousin did not see each other for more than a year due to the second lockdown in December 2020 which ran through until 2021 and the additional restrictions that ENABLE put in place.*

103. *Covid 19 was not identified as a cause of death for either my cousin or my aunt. It is my belief that they both died through the indirect consequences of the decisions made by national and local government regarding lockdown and other restrictions. The decisions made by ENABLE were not based on evidence or research and compounded the isolation and grief experienced by their very vulnerable residents and their loved ones."*

104. *"My brother suffered inequalities due to disability. He did not receive the vaccine when requested as he did not qualify due to being aged 56,, even though he was the most clinically vulnerable person in the unit. He wasn't brought outside for fresh air on many occasions and staff used the excuse that they were keeping him safe, but really it was because it was too much hard work for them. This impacted his human contact which he really needed for his mental and physical well-being."*

105. *"My sister had learning difficulties but she was very strong. She had battled through serious illness before, but she came through everything. She fought to be here. When covid hit, she was admitted to hospital with pneumonia initially and then covid. She and*

our family were treated awfully. The nurses did not care for her properly. She had challenging behaviour because of her learning difficulties but it was like they took one look at her and decided they were not going to try and save her. She was not going to be saved if she became seriously unwell and her condition deteriorated. I was allowed to stay with her from Monday to Wednesday until the nurse decided she didn't want me to be there. I was kicked out of the hospital and from that point on I know my sister was basically ignored. On the day I was told to leave, I could hear her screaming but the nurse refused to let me in. When I got the phone call to say my sister's condition had taken a turn for the worse, I went to the hospital and nothing had been cleaned. My sister and her bed had not been cleaned or changed. She was gasping for air and water. I had to get her a drink and it was obvious that she had been asking for water when I wasn't there, and hadn't been getting any. Because of her disability, my sister was completely written off and wasn't given any chance at all. She was put on palliative care and a morphine drip. She was still fighting the next day and they had to double her morphine drip before she eventually passed. She was so strong and I think she could have survived if she was given a chance. Her learning difficulties meant that the healthcare staff just did not even try to help her."

106. "My mum was 84 years old, and had a longterm medical illness that required treatment. She had been diagnosed with Addison's disease at the age of 28 and had been on steroids to manage this illness. Mum required regular medication and in times of illness, trauma, dental work and any type of infection this medication had to be adjusted. Any withdrawal of this treatment or her not receiving her medication would result in an "Addisons crisis" this is a serious medical emergency which always required a stay in hospital. My mum's treatment was withdrawal and this resulted in her falling into a coma. I believe my mum's medical history and her age were factors in the decision to withdraw all treatment. Due to covid and the restrictions in place we did not get to make a decision on my mum's care, I should have said I wasn't happy with the decision. My poor mum never stood a chance, because of a decision made for her by medical staff, she never stood a chance."

Gender Inequalities

Significantly more women than men employed in healthcare, care sector including childcare / education sector, so more vulnerable to infection

107. *“My son’s wife worked all through the Covid 19 Pandemic at her place of work. She was a nursery practitioner caring for key worker’s children. She tested positive for covid after receiving a phone call from two work mates in her bubble who had also tested positive. Unknowing to her she had also infected her full family.”*

108. *“My son’s wife worked all through the pandemic in the childcare sector, the Unions asked the FM of Scotland to vaccinate all staff before they return to work and that was rejected and I know that the teachers made clear their feelings on being sent back to work without being vaccinated.”*

Impact on post-natal and ante-natal care affecting women, lack of support from partner/ family before, during and after birth of baby

109. *“In my role as a midwife I felt we couldn't give women the care and support they require throughout pregnancy. It was so busy, so much sickness and women were more often than not alone and very scared.”*

110. *“I was pregnant with my second child when we went into lockdown. I had to go to hospital appointments myself. I had to go to the hospital every few weeks as I had gestational diabetes.*

111. *I had to go in for induction myself, my partner wasn’t allowed to come with me. I also had to labour in the room myself, by the time I got to the labour ward it was only 45 minutes before my baby was born.”*

112. *“It was horrible seeing mums across from you who were struggling and you weren’t able to give them a hug and tell them it would be ok. We were discouraged from talking to each other. You need other people around you when you are a first-time mum, even just having your partner there with you in the hospital.”*

113. *“After lockdown, following the birth of my second child, the support from my CPN vanished. My CPN would phone me but it wasn’t the same as face to face appointments. I had to have a zoom call with my psychiatrist but this didn’t work as I was at home alone with a toddler and a new baby as my husband was working. I couldn’t have a proper conversation.”*

SUMMARY OF REPRESENTATIONS THE GROUP MADE DURING THE PANDEMIC TO CORE POLITICAL AND ADMINISTRATIVE DECISION-MAKERS TO INFLUENCE DECISION-MAKING

Virtual Meeting With First Minister March 2021

Issues Raised Verbally

114. 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?

115. 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?

116. 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?

117. 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?

118. 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?

119. 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?

120. Are we going to have a full and detailed investigation into the pandemic in Scotland so that as many lessons as possible are learnt so that we are far better prepared for any future pandemics?

121. Did trying to go for a uniform U.K. wide approach at the beginning of the pandemic delay an earlier response if Scotland had just gone for it alone?

122. As I see it hospitals cannot prevent patients leaving the wards/buildings, is it worth considering as part of emergency legislation in future planning that should we ever be in another pandemic hospital patients are confined to wards for the duration of their admission?

123. Are we going to have an annual day of remembrance for all those lost to pandemic?

124. Why did the shielding end at the start of August when people were being allowed to go on holiday and no doubt bring variants back into the country, the eat out to help out scheme was started, the schools were returning mid August and the universities shortly after? Surely if there was modelling being carried out it would show this was probably the most dangerous time to stop shielding?

125. The Scottish Government are on record as saying that we were probably 2 to 3 weeks behind England on the path of the virus, the Scottish Government also at times did show they could take decisions they thought correct without the agreement of Westminster, the decisions on wearing face mask is one such instance. If we were indeed behind England and Nicola Sturgeon and Jason Leitch are both on record as saying we had almost eradicated the virus in Scotland in June/July 2020 why did they not take the decision to close air land and sea borders at this time to protect us from further infection and new variants?

126. There is real concern around hospital acquired covid 19 and hospital transmission and yet a member's wife was allowed to walk through the corridors of Hairmyres hospital having tested positive for covid 19 at her leisure without as much as a facemask on. At this time the hospitals were not particularly busy why were you sending covid positive patients home

127. Why were tests not carried out on suspected/known Covid patients and their close contacts, not even in A&E?

128. Symptoms are poorly understood and are not well publicised outside of the usual three : fever, persistent cough and loss of taste and/or smell. More symptoms need to be listed and a public education campaign launched. Will you commit to that?

129. Bereavement Services are overwhelmed. Much more needs to be done to provide Bereavement Counselling. Covid bereavement is not like normal bereavement and is leading to something akin to PTSD in many people if not treated. Will you commit to address this issue urgently.

130. The First Minister committed to having a Scottish Public Inquiry.

Various Meetings With Deputy First Minister and Health Secretary 17 August 2021-24 November 2021

131. 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.

132. 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.

133. We highlighted that nosocomial deaths account for 25% of bereavements within our Group compared with 9% for Care Homes yet it seems to be ignored.

134. We also raised lack of Bereavement Counselling especially for those bereaved when strict social distancing measures were in place including, but not limited to, numbers 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

Signed: Personal Data

Date: 20/09/2023