Witness Name: Sarah Cox

Statement No.: M3/APM/01

Exhibits:

Dated: 25/08/23

UK COVID-19 INQUIRY

WITNESS STATEMENT OF [Sarah Cox]

I, [Sarah Cox], will say as follows: -

1. **Dr Sarah Cox**

   I, Dr Sarah Cox worked as a consultant in Palliative Medicine at Chelsea and Westminster NHS Foundation Trust before, during and after the COVID pandemic. I was chair of the joint specialty committee (JSC) for Palliative Medicine; a joint committee of the Association for Palliative Medicine (APM) and the Royal College of Physicians (RCP) from November 2016 to November 2020. I was Vice President of the APM from March 2021 to March 2023. I have been President of the APM since March 2023.

2. **The Association for Palliative Medicine of Great Britain and Ireland (APM)**

   The Association for Palliative Medicine of Great Britain and Ireland (APM) is one of the world's largest representative bodies of medical and other healthcare professionals practicing or interested in palliative care, with a membership of over 1,200. Members are individuals who specialise in caring for people with a potentially life-limiting illness, including those at the end of their lives.

Palliative care prior to the Covid-19 pandemic

3. **In 2004, the National Institute of Clinical Excellence defined** Palliative care as: "The active, holistic care of patients with an advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments."

4. The specialty supports and manages people with both cancer and non-cancer diagnoses, as well as those who may be receiving potentially curative treatment but who have significant needs amenable to palliative care intervention. The core of palliative care is the importance of maintaining quality of life and supporting people to live as well as they can for as long as they can. Holistic, patient- and family-centred care, as well as management of pain and other symptoms and provision of psychological, social and spiritual support, is paramount.

5. Palliative care is provided to individuals based on need regardless of diagnosis, age, background or location. Palliative care is delivered in hospital settings and hospices (specialist palliative care units), but also in community settings (in the patient's usual place of residence which could be their home, a care home, a prison, the street, etc). Patients may require palliative care at different stages of their illness. They may need help with pain or other symptoms while undergoing active treatments for their underlying condition such as cancer or heart failure, when prognosis may be measured in years. They may need support for themselves and those close to them at the end of their lives when prognosis may be measured in weeks or days.

6 **Generalist palliative care**

Generalist palliative care is delivered by all healthcare professionals working with patients with a potentially life-limiting illness, including those at the end of their lives. This includes General Practitioners, District Nurses and hospital-based doctors, nurses of all grades and allied healthcare professionals.

7 **Specialist palliative care**

Specialist Palliative Care (SPC) is provided by clinicians (doctors, specialist nurses and specialist allied healthcare professionals) dedicated to and expert in palliative and end-of-life care, usually for patients with the most complex symptoms and / or circumstances.

8 The charity Sue Ryder commissioned a report on demand for and funding of SPC services which was published in February 2021 (INQ000239703) It found that SPC services were under-resourced nationally pre-COVID-19 with only 37% of hospice services funded through the National Health Service (NHS) and the remainder relying on charitable donations. Even with this charitable funding, according to the report, a significant proportion of dying patients (between 25% and 40%) are unable to access SPC due to a lack of provision. Before the COVID pandemic there was evidence of unwarranted variation in the provision of SPC services in the United Kingdom. Public Health England produced an atlas of variation for palliative and end of life care in England in 2018 (INQ000239710). There was evidence of increased need and issues with access to services for people with income deprivation, people of ethnic minority, LGBT individuals, people with learning difficulties, the homeless and the prison population. A study published in 2020 using population based information from the Office of National Statistics (ONS) showed wide variation in access to hospice inpatient services across England (INQ000239711). The further away from a hospice patients lived, the less likely they were to die there.

9 How and why the provision of palliative care changed as a result of the COVID pandemic.

Variation in impact over time and geographically

10 The impact of the COVID-19 pandemic on palliative care provision across England varied over time and geographically. The geographical variations mean that it is difficult for the APM to represent the experience of all palliative care services as being the same, especially during the first surge. We present the experiences of our own services and from published information.

11 From March 2020 many UK palliative care services (both specialist and generalist) were very rapidly overwhelmed. This is evidenced in a survey of palliative care services between April and July 2020 which was multinational but with a majority of responses from the UK (INQ000239712). Challenges with staffing were reported, with 77% of services having staff with suspected or confirmed COVID infection, and services reporting that the availability of volunteers to support clinical services had plummeted. Home and hospital SPC team activity increased but hospice admission reduced, partly due to patients choosing to stay at home rather than risk admission and infection. Other changes identified in this study include;

- A surge in the numbers of patients referred to SPC services leading to a switch from proactive to reactive care to manage demand
- The need for rapid development of guidelines and educational material
- Training and support for other health care professionals
- Increase in virtual working with 84% of SPC services reporting this type of support for patients
- Support from SPC services for patients having non-invasive ventilation withdrawn at the end of life

12 For subsequent COVID-19 surges this geographical variation was not seen to such a degree across the UK, possibly as a result of COVID being established over a wider geography. Vaccination led to a further change from spring 2021 with dramatically reduced numbers of patients seriously ill with COVID-19 and many fewer dying patients.

Impact on palliative care in hospitals

13 In the first pandemic some hospitals very quickly became overwhelmed by patients very unwell with COVID-19. Hospital SPC teams also became overwhelmed with the number of patients that were needing their support (INQ000239712). In many hospitals, SPC team staff increased their hours, with some individuals working six-day weeks. Many teams started a seven-day medical and nursing face-to-face service. Staff sickness with COVID-19 and shielding placed even greater pressures on staffing and service provision, but the response of staff was both astonishing and humbling. The RCP produced a report in August 2021 which examined the care of patients through retrospective case note reviews (INQ000239713). The input of specialist palliative care teams was seen as contributing to excellent care and supporting rapid recognition of the end of life. Around 90% of centres commented that end of life care was of a very high standard. There was a recognition in the report that when end of life care was not done well it had a significant impact on the patient and family. The lack of sufficient SPC staff to provide care may have contributed to these gaps.

14 Hospital SPC teams were mostly providing symptom control and terminal care for patients sick with COVID-19 during the surges, possibly because patients with non-COVID-related illnesses tended to avoid hospital admission.

15 Patients with COVID-19 in the first two major surges experienced breathlessness, cough and anxiety/agitation as their main symptoms which vary slightly from what SPC teams

would normally see. Patients were dying very quickly following hospital admission, often within 12-24 hours, and this required very rapid responsiveness from palliative teams, including frequent calls to see multiple dying patients in the Emergency Department. There was little opportunity to transfer patients home or to a hospice because they were deteriorating much too quickly.

16 SPC teams in hospitals developed local guidance for non-specialist teams to resource them to provide symptom control for patients the SPC team did not have time to review themselves. Local palliative care networks were also created for sharing best practice.

17 Once the use of non-invasive ventilation (NIV) increased in the hospital, SPC teams were also learning to support patients with medication to help them tolerate the NIV masks, and also to provide symptom control when NIV failed, in order to allow patients to take off the NIV mask without distress at the end of life.

18 During the first COVID-19 surge hospital SPC teams often supported their generalist colleagues in having early conversations with patients admitted with COVID-19 about what treatment might and might not be helpful. Agreeing these treatment escalation plans at an early stage in the admission made appropriate treatment more likely in the event of sudden deterioration.

19 Hospital SPC teams provided emotional support to patients and those close to them and often had a role in supporting effective communication with relatives who could not visit the dying patient. Many family members became distressed and sometimes angry because they could not see what was happening and therefore struggled to understand what was happening to their relative. SPC teams were often asked to support other teams in addressing the emotional distress and anger of relatives.

20 Hospital SPC teams had a significant role to play in providing emotional support to hospital staff. This was especially important in the first year of the pandemic before staff health and wellbeing services were introduced / enhanced. In the surges in March/April 2020 and early 2021, there were many very distressing situations in hospital where staff needed immediate support, empathy and reassurance from the SPC team.

21 There was a challenge in learning quickly enough what was required to support COVID-19 patients and those close to them. There was also a lot of fear in hospitals around supporting patients with COVID-19 and the personal risk to staff and their families. Rules around Personal Protective Equipment (PPE) were unclear and rapidly changing and this increased uncertainty and fear.

22 Outside of the COVID-19 surges there were impacts on outpatient services, with many patients preferring telephone or video appointments. However, the frequently complex conversations and symptom / holistic assessments that form part of palliative care outpatient appointments can be inferior in these forms compared to face-to-face consultations.

Impact on hospice-based day-treatment facilities

23 Hospice day-care or day treatment facilities were mostly closed during the COVID-19 pandemic resulting in a complete lack of often essential therapy and support services for patients and those close to them. This had an inevitable impact on those caring for palliative patients at home, as the opportunity for regular, restorative breaks from caring was lost.

Impact on patient / family experiences

24 There were not enough specialist staff to see all of the patients that required SPC input and specialist management and support during the COVID-19 surges and this will inevitably have resulted in gaps in care for some.

25 Visiting restrictions in hospitals, hospices and care homes had a huge impact on patients and those close to them. Relatives of dying patients could not be with them or know what their experience was. SPC teams tried to support patients in the absence of families, as did other health and social care staff. Initially, the telephone was the major tool for communicating with relatives of patients. Video meetings / calls became more common when internet-connected tablets became available, but this was too late for the first surge. The use of new technology was also difficult for certain groups, especially those who were older, those with language barriers and those with learning difficulties. It was also challenging to use such technology with patients who had certain specific diagnoses that would impact their communication abilities and those using NIV masks. Visiting restrictions in place at varying times during the pandemic have made the course of bereavement more difficult for many relatives. SPC teams with bereavement services tried to address this impact at the time of the pandemic, and are continuing to do so. Some hospital teams set up dedicated bereavement services to offer support.

26 Changing activity through the pandemic

In the spring and summer of 2021, many hospital SPC teams saw a reduction in numbers of referrals and a reduction in deaths of their 'usual' patient cohort. This may have been because the patients who would have been admitted in these months had already died in the COVID-19 surges. From April 2022 there were an increase in referrals to SPC services and an increase in the number of hospital deaths. This may be because of the impact of the COVID-19 pandemic on the health of the general population and the lack of usual healthcare in 2020-2022.

The provision of palliative care to patients in acute hospitals at risk of death or dying and not suitable for escalation to Intensive Care Units on Covid-19 wards.

Lack of palliative care resources

27 Lack of resources in SPC teams was the biggest issue in supporting these patients in a hospital. Some teams were able to increase face-to-face availability of the team to seven days a week. This had to be provided through existing staff members increasing their working hours, with some working six-day weeks. Funding was available for this through government COVID-19 funding to the NHS. Post-pandemic this additional funding is no longer available although significant unmet need for SPC remains in many teams.

Impact on staff

28 SPC staff were at the centre of the pandemic response and as a result carry their own forms of emotional damage. They were involved in difficult treatment; decisions they stayed with numerous dying patients in place of their families; they supported patients in respiratory distress; they supported emotional and sometimes angry family members;, and they often had to 'police' visiting restrictions through dialogue with distressed families; and they tried to support colleagues often at the point of physical and emotional exhaustion. Many felt that they were not able to provide the care they wished to and many are left even now feeling burnt out.

Guidance, protocols and guidelines relating to palliative care produced during this period.

Palliative and end of life care COVID guidelines

29 The APM was approached to contribute to the national response to COVID-19 within 2-3 days of the announcement by the Government of a national 'lock-down' as it was recognised that end-of-life care services would be key to providing care.

30 National COVID palliative care guidelines were first written in March 2020 and updated through the pandemic with the last update produced in January 2021 by Professor Lawrie and Dr Cox. They presented the most up to date guidance about addressing palliative and end of life care needs of patients with COVID and their families. The guidance covered information about COVID, symptom control, clinical decision-making, supporting withdrawal of non-invasive ventilation in patients at the end of life, remote communication with families and care after death for patients and families.

31 Professor Lawrie and Dr Sarah Cox, on behalf of the APM contributed as specialty experts to a number of other guidelines relating to palliative care, general practice and other specialties, including:

- *Coronavirus (COVID-19): reuse of medicines in a care home or hospice* (Department of Health and Social Care) (INQ000239706)This document outlined how certain medications, sometimes prescribed for other patients, could be re-used in a safe way under specific circumstances.
- *COVID-19 rapid guideline NG163: Managing symptoms (including at the end of life) in the community* (NICE) (INQ000239707) This document outlined management of the common symptoms experienced by patients with COVID and key aspects of care planning.
- *Priority medicines for palliative and end of life care during a pandemic* (cross-Royal College coalition) (INQ000239708). It was recognised that, during the pandemic, additional demands for certain medicines may occur. This document outlined those medications regarded as being essential for providing effective end of life care symptom control during this period and alternatives that could be used should the first line medication be unavailable.

32 With the Royal College of Physicians (RCP) Dr Cox and the APM updated their guidance “Acute Care Resource; End-of-Life Care in the Acute Care setting to include guidance around supporting patients with COVID-19 at the end of life. This guidance had been published in February 2020 to support hospital doctors to provide excellent care at the end of life to their patients (INQ000239709). An addendum was written in February 2021 to cover guidance on care of the dying patient with COVID-19 in hospital (INQ000239718).

33 Dr Cox and the APM also supported the RCP with guidance on COVID-19 preparedness, modelling what palliative care services could be provided in cases of progressively more challenged staffing numbers.

34 The APM adapted its website to provide clear guidance, resources and web-links for both patients and healthcare professionals. These included guidance on clinical issues, symptom control, infection control, communication and staff resilience.

Communication between palliative care practitioners and palliative care patients or their families.

35 One of the most significant challenges that hospitals and hospices had to manage throughout the pandemic was the issue of visiting, which has already been widely commented on in the national press. Hospital staff were often provided with unclear, conflicting and constantly-changing guidance regarding visiting for patients who were at or nearing the end of their lives, with little senior support, meaning that they had to both interpret, and apply guidance on an individual basis. This aspect of end of life care was often 'delegated' to SPC teams.

36 Visiting was one of the most contentious issues for patients and their relatives at the end of life during the pandemic and resulted in conflict, complaints and, at some times, both verbal and physical aggression directed towards NHS staff. While this is understandable given the emotions involved in such situations, more clear, consistent and supported guidance from senior national NHS figures may have been useful. The psychological trauma of having to deal with situations relating to visiting during the pandemic remains real with many NHS staff and may need to be further addressed.

37 Communication with patients' families and those close to them was extremely difficult during the pandemic and not an issue that the NHS was prepared for. Communication with families at the end of life can be a challenge when meeting face-to-face as this is a very emotional time for all concerned. With visiting restrictions and the fear and uncertainty among families with COVID-19, this was extremely challenging. Many in-patient units set up daily telephone calls to a nominated person close to the patient but these were difficult to maintain due to challenges with staffing. SPC teams offered guidance to generalist colleagues on sensitive communication by telephone. Internet-connected tablets for video-calls did become available in some hospitals for Intensive Care Units (ICU) and then for other wards but were not available in early COVID-19 surges and the systems were not always easy for staff or families to use.

38 Communication was exceptionally difficult / severely impaired with patients, their families and those close to them at the end of life as a result of the necessity to wear facemasks, visors and other PPE during each consultation or visit. This had a significant impact on building relationships and rapport with patients and those close to them, and as a result affected the level and quality of communication, trust, and rapport that could be established.

39 Communication guides were collated by the APM and made available on their website.

Inequality and the provision of palliative care during the Covid-19 pandemic.

40 An online survey of 277 UK SPC team leads carried out after the first COVID surge in 2020 identified issues related to inequality (INQ000239719). Firstly, relatives of patients from ethnic minority groups were disproportionately impacted by restricted visiting practices. Families struggled when they were unable to fulfil religious and culturally prescribed responsibilities. Some families believe that there should be large numbers of people present to support care or decision making at the end of life but the restricted visiting made this impossible. Secondly, communication challenges were exacerbated if families did not have English as their first language. Telephone interpreters were used but services reported issues with availability and effectiveness with these services. Access to all faith leaders was restricted but where faith leaders were high risk for infection this was even more of an issue. There were unmet religious and faith needs especially for Muslim or Jewish patients where there are important rituals at the end of life that family or members of their religious community would normally perform. In some areas, SPC teams received training in faith-based procedures after the death of a patient and carried out such duties until a community faith-based, COVID-19-compliant solution was found. This created additional strain for NHS staff but was hugely appreciated by local faith communities. Further work in this area would be a positive outcome of the pandemic. Rapid burial was difficult because of delays in death certification and registration due to the high number of deaths. Some SPC services reported that certain cultures and communities were mistrustful of attempts to discuss advance care planning or ceilings of treatment. There were some reports of general mistrust of healthcare services where families felt treatment was being rationed. The report identifies that SPC services need to offer care relevant to the patient and that this may vary for different populations.

41 Learning identified by the APM from the COVID pandemic

a) SPC and hospice services have had essential, front-line roles during COVID-19 but they felt overlooked. It is essential that palliative care is included as an essential part of any pandemic planning.

b) SPC services are under-resourced and appropriate resourcing outside pandemic times will be needed for an adequate response in a future pandemic.

c) Access to PPE was variable, with hospices and community teams reporting they could not access essential supplies early on in the pandemic.

d) Care shifted during the pandemic from in-patient hospice settings into hospital and community settings.

e) The availability of charitable funding for hospices (63% of their funding) was significantly reduced, and emergency funding from Government was essential to their continued survival.

f) SPC services were able to respond with rapid changes, adopting innovative practices and through international collaborative working.

g) Services developed more contact through telephone and video consultations and this has continued to some degree as a hybrid model of a new approach to care. These sorts of virtual consultation models will be essential parts of care in future pandemics but cannot replace face-face consultations.

h) Early discussions with patients about what treatments would be helpful should their condition deteriorate support the appropriate delivery of care and should be encouraged.

i) Improved training in palliative and end of life care for generalist healthcare professionals will support better care including during a pandemic.

j) There was a disproportionate impact on ethnic minority groups, highlighting the need for equitable care.

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: _______25/08/23__________________________