Witness Name: Iain Lawrie

Statement No.: M3/APM/01

Exhibits:

Dated: 25/08/23

UK COVID-19 INQUIRY

WITNESS STATEMENT OF [Iain Lawrie]

I, [Iain Lawrie], will say as follows: -

1. **Professor Iain Lawrie**

I, Professor Iain Lawrie worked as a Consultant in Palliative Medicine at North Manchester General Hospital, part of Manchester University Hospitals NHS Foundation Trust, before, during and after the COVID pandemic. I was President of the Association for Palliative Medicine of Great Britain and Ireland (APM) from March 2019 to March 2021, then President Support of the same organisation. I was also a member of Council of the Royal College of Physicians (RCP) as well as a Councillor Trustee of the RCP.

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.

Generalist palliative care

6 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.

Specialist palliative care

7 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.

Impact on community palliative care (care in the usual place of residence)

9 Many community SPC teams supporting patients were a lot busier than previously as they attempted to support patients with life-limiting illnesses to stay at home and avoid the need to be admitted to health or social care facilities. This was partly to support patient preference, as more patients preferred to stay away from hospitals which they saw as places where they may catch COVID-19. It was also to support the national agenda of reducing pressure on hospital in-patient beds. ONS data has been used to explore place of death in England and Wales from 7th March to May 15th 2020 (INQ000239714). This revealed spikes in deaths at home and in care homes consistent with the increased activity of community SPC teams.

10 Many community SPC teams changed their way of working to include more telephone or video support for patients. This was required to support the increased numbers of patients dying at home, and also due to infection control concerns. Many hospices and community SPC teams were not prioritised for the provision of PPE in the first surge and had to make difficult decisions about weighing the benefits of seeing patients face-to-face with potentially putting staff at risk of infection. Some teams planned their days to see non-COVID-19 patients first before reviewing patients with COVID-19 to reduce the risk of cross-infection.

11 The combined impact of staff shielding, sickness absence, lack of PPE and patient and family concerns about health professionals visiting their homes due to fear of contracting COVID-19 placed an enormous strain on an already under-resourced specialty.

Impact on hospice in-patient units

12 Most hospices in the UK are predominantly charitably funded, with much of their income coming from sales from hospice shops and other fundraising activities. During the COVID-19 pandemic, this income was reduced significantly and there was a subsequent risk of destabilising these services. Emergency funding was put in place by the UK government which prevented services from closing and allowed hospices to continue to support patients in both hospice and community settings.

13 Hospice in-patient units were typically running with lower bed occupancy due to patients wanting to stay at home due to fear about entering healthcare settings and the fact that visiting from family and friends while in an in-patient / care setting would either not be permitted or, at best, be severely limited. In addition, many patients admitted to hospice in-patient units are admitted from hospitals. In the COVID-19 surges, especially the first one, patients in hospitals were mostly there because of COVID-19 infection. Those dying did so rapidly and as a result of their rapid deterioration, there was often no opportunity to transfer them to a hospice for their last days of life. A study using data from the ONS reviewed all deaths in England and Wales from March 7th 2020 to May 15th 2020 (INQ000239714). Hospice deaths fell by 20% from the start to the end of the study period.

14 Early in the pandemic many hospices lacked access to PPE as they were treated equivalent to care homes rather than hospitals and no clear routes of supply were put in place at an early stage. This meant that hospices were often unable to safely care for patients with COVID-19 infections. Hospice and community SPC teams also suffered from staff shortages (sickness absence and redeployment to other posts as a result of the pandemic) as well as PPE shortages.

Impact on patient / family experiences

15 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.

16 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.

Changing activity through the pandemic

17 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.

18 **Funerals:** There were significant delays in being able to arrange funerals both during and after the COVID-19 pandemic for understandable reasons (e.g. delay in death certification and registration, reduced cemetery and crematorium capacity, etc). Delays in being able to arrange funerals and restrictions on the number of people able to attend funeral ceremonies have had a significant impact on the usual process of grieving for many individuals and continues to have an impact.

Impact on staff

19 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 very angry family members; they often were expected 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 burned out.

Palliative and end of life care COVID guidelines

20 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.

21 Professor Iain Lawrie, President of the APM at the time of the start of the COVID-19 pandemic, created national COVID palliative care guidelines in consultation with several national / international palliative care experts within a few days of the UK national 'lockdown' (INQ000239715; INQ000239716; INQ000239717; INQ000239704; INQ000239705). These guidelines were often discussed and formulated in late evenings and overnight and were amended twice weekly throughout the first phase of the pandemic. The collaboration of these experts was key to ensuring the publication of initial national palliative care guidance relating to COVID-19.

22 The COVID-19 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-19 and those close to them. The guidance covered information about COVID-19, 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.

23 Professor Lawrie was a member of the NHS England COVID End of Life Group that met weekly / twice-weekly / more often during the first phase of the COVID pandemic together with representatives from many other national medical and social care organisations and medical Royal Colleges. Professor Lawrie and Dr 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.

24 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.

Palliative Care COVID cross-Royal College Group

25 Professor Lawrie, as President of the APM, was invited to be a member of the Royal College of General Practitioners (RCGP) Group addressing the pandemic. The group included colleagues from across the medical, social care and voluntary care sectors. This group, which met weekly and then bi-weekly in the evening throughout the pandemic, was instrumental in informing RCP, RCGP and other responses and guidelines relative to the pandemic.

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

26 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 and was distressing for patients, those close to them and NHS staff.

27 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.

28 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.

29 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.

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

31 Learning identified by the APM from the COVID pandemic

a) SPC and hospice services 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 as the skills they would bring cover a very wide spectrum outwith that often considered in NHS 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, therefore restricting the care that could be provided.

d) Care shifted during the pandemic from in-patient hospice settings to 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, although possibly not sufficient.

f) The APM and RCGP 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 may 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 as part of usual practice, not only during a time of crisis.

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

j) There was a disproportionate impact on ethnic minority groups during the COVID-19 pandemic for a variety of reasons, highlighting the need for further consideration of faith-appropriate, 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: 29 AUGUST 2023