Witness Name: Andrew Steven Lockey

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Exhibits: 33

Dated: 13 November 2023

UK COVID-19 INQUIRY

WITNESS STATEMENT OF ANDREW STEVEN LOCKEY

- I, Professor Andrew Steven Lockey MBE, of Resuscitation Council UK, First Floor, 60-62 Margaret Street, London, W1W 8TF, will say as follows:
- I am President of Resuscitation Council UK (registered charity number 1168914). I was appointed to this role in December 2021, having previously held the position of Vice President from December 2019.
- I am also a Consultant in Emergency Medicine at Calderdale and Huddersfield NHS
 Trust, having been appointed in April 2002 I&S).
- 3. I write this statement in response to the letter from the Inquiry dated 7 July 2023 in request for evidence under Rule 9 of the Inquiry Rules 2006.

Introduction

4. Resuscitation Council UK (RCUK) is a Charitable Incorporated Organisation dedicated to saving lives by developing guidelines, influencing policy, delivering courses, and supporting innovative research. Over the past forty years, RCUK has become a global leader in the resuscitation field for the UK and recognised globally for its contribution to improving the care of critically unwell people, and cultivating a community of healthcare professionals who share our passion for saving lives through evidence-based resuscitation practice. Our guidelines, courses, and quality standards serve as a foundation for their education and practice. We are working towards the day when everyone in the country possesses the skills needed to save a life.

- 5. Our core membership comprises specialist clinical and academic experts recognised as international leaders in resuscitation. They play vital leadership roles with the International Liaison Committee on Resuscitation (ILCOR) and the European Resuscitation Council (ERC), which scrutinise published scientific evidence on an international scale. Our wider membership includes over 15,000 specialist healthcare volunteers who provide training to over 150,000 members of the UK healthcare sector every year to an internationally recognised standard.
- 6. As the organisation responsible for issuing resuscitation practice guidelines and standards for the healthcare sector throughout the UK, our guidelines development process is conducted to the highest standards. Our guidelines are developed through extensive processes of reviewing existing and emerging research evidence, both nationally and internationally. The process for development of these guidelines is accredited by the National Institute for Health and Care Excellence (NICE), follows best practice for guideline development, and the guidelines are implemented across the National Health Service (NHS), social care, and the community.
- 7. We are committed to improving outcomes for cardiac arrest patients by ensuring that more individuals arrive at hospital with the best chances of survival and that following our standards and guidelines ensures that they receive proper care during their recovery. In parallel with this, we advocate for robust processes to respect the right of individuals who do not want CPR if they die so that their wishes are met.

Cardiopulmonary Resuscitation (CPR)

- 8. CPR is used in healthcare settings, where appropriate, when the patient has a cardiac arrest, defined by the absence of normal breathing and/or signs of life. Unlike a heart attack where the heart continues to pump and the individual remains conscious, cardiac arrest occurs when the heart stops pumping, and the patient loses consciousness. Usually, the cardiac arrest in an adult is due to a heart or circulation problem, whereas in children it is more often caused by a lung or breathing problem. A cardiac arrest is the ultimate medical emergency and, in the absence of CPR, the patient will not survive.
- Currently, the UK adult out-of-hospital cardiac arrest (OHCA) survival rate to hospital discharge is 8%. For patients having a cardiac arrest in-hospital, the survival rate to hospital discharge is 23%.

- 10. The basis of effective CPR is the combination of administering chest compressions and delivering rescue breaths. This is supplemented in the hospital setting by additional key skills provided by a specific expert team (often called the Cardiac Arrest Team) who will be mobilised to attend the patient when a cardiac arrest call is made. These skills include delivering interventions such as advanced airway management, defibrillation, and using resuscitation drugs, alongside key leadership skills in managing the cardiac arrest team, looking after the patient, and being able to diagnose and treat underlying conditions, which may include reversible problems.
- 11. The underpinning principles for CPR are the same for all patients, although certain variations exist in different age groups. These include, but are not limited to, differences in chest compression to ventilation ratios and drug dosages between adults, children and newborns, and the relevance of early defibrillation in adults and to a lesser extent children (almost always irrelevant in the newborn child).
- 12. In adults, chest compression only CPR may be sufficient in the first instance, but rescue breaths in addition to chest compressions are particularly important for children and babies on all occasions. The role of CPR in adults is to buy time until definitive interventions most likely to save a life, e.g., defibrillation and airway management can be instigated.
- 13. CPR in adults will often cause rib fractures (70% of patients resuscitated from OHCA), but if the patient survives the cardiac arrest, these are treatable, as may be the identifiable causes of cardiac arrest, along with underlying or additional health problems. If CPR is instigated despite a valid advance care plan, ReSPECT plan, or DNACPR (see paragraphs 55 68) then there is nonetheless a risk that a patient may be resuscitated to a quality of life that they may not have wanted or reasonably expected prior to the event.

Overview

- 14. As set out in further detail below, RCUK published statements and guidelines for managing in-hospital cardiac arrests throughout the pandemic encompassing adult, paediatric, and newborn resuscitation events. Between March and September 2020 in particular, there was a continuous and concentrated effort to review emerging evidence, evaluate its significance, and to publish updated guidelines.
- 15. Throughout the relevant period, we collaborated with various Royal Colleges and societies, including the Royal Colleges of Physicians, Anaesthetists, Paediatrics, Psychiatry, General Practice, and Emergency Medicine, along with the Intensive Care Society, the College of Paramedics, and the Faculty for Intensive Care Medicine. All materials for publication were shared for consultation and agreement with those bodies and any subsequent changes were reviewed by the relevant college or society before being posted on our website. We also had representation on the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) to advise on the guidance produced for NHS Ambulance Trusts.
- 16. To ensure widespread dissemination, we recognised the importance of directly communicating the updated guidance, algorithms, and statements to the healthcare community in relation to practice for patients with COVID requiring resuscitation. This included contacting resuscitation departments within NHS Hospital Trusts and private hospital settings across the four nations of the UK to offer advice, feedback, and support. We regularly updated 'Frequently Asked Questions' (FAQs) on our website to inform NHS Trusts and other organisations. Additionally, an amended version of the RCUK Immediate Life Support (ILS) course was developed to support those working in the Nightingale Hospitals.
- 17. Finally, we established global collaborations with national resuscitation councils around the world, such as Canada, North America, South America, Europe, Southern Africa, Asia, Australia, and New Zealand. Valuable insights were gained from regions where the effects of the pandemic preceded us, in particular China and Italy. These included the review of a case series report published in April 2020 [AL/9 INQ000251679] of 136 adult patients with COVID who had an in-hospital cardiac arrest (see paragraph 30

below), and direct communication with Italian colleagues specialising in Intensive Care Medicine about what to expect from the pandemic as their initial experience in Italy preceded the impact in the United Kingdom. We also shared our own experience and expertise to benefit the international community during these challenging times.

Chest compressions as Aerosol Generating Procedures

- 18. In the initial stages of the pandemic, it became rapidly clear that COVID-19 was not behaving in the same way as with seasonal influenza. We would normally have expected the elderly, infirm, and those with compromise of their immune systems to be primarily affected. On the contrary, fatalities were occurring in people of all ages and levels of health, including healthcare workers. Whilst our guidance already contained recommendations to mitigate risks to the rescuer, we realised that this would need to be particularly emphasised in our COVID guidelines.
- 19. We recommended, therefore, the use of Aerosol Generating Procedure Personal Protective Equipment (AGP PPE) for healthcare workers administering chest compressions throughout the pandemic to safeguard their health. AGP PPE was defined as the combination of a filtering face mask (FFP3 respirator), long sleeved fluid repellent disposable gown, eye protection, and gloves. This differs from Respiratory Protective Equipment (RPE), defined as filtering face piece (FFP3 respirator) only. Our guidelines were consistent with those produced by other international organisations such as American Heart Association, European Resuscitation Council, Australian Resuscitation Council, World Health Organization, and others.
- 20. Our guidance in place for patients of all ages immediately prior to the pandemic prioritised an approach designed to predict any deterioration in health and to prevent cardiac arrest where possible. Most patients having an in-hospital cardiac arrest would therefore already be cared for by healthcare staff either wearing appropriate PPE or with immediate access to it. In particular, we recommended that AGP PPE should be immediately available in areas of the hospital where high risk or confirmed cases of COVID were cohorted to minimise any delays to emergency patient care.

Timeline for CPR Guidelines for the relevant period

- 21. In March 2020, the then President of RCUK (Professor Jonathan Wyllie) convened and subsequently chaired an Expert Working Group (EWG) to review our existing guidance. I was a member of the EWG from its inception. The EWG considered the progression of the pandemic, and the aim was to be proactive as well as reactive to the situation. This group comprised core members of RCUK who have international clinical and research expertise in cardiac arrest management across all age ranges (newborn, paediatric, and adult).
- 22. The group included representatives from the ILCOR Expert Review Group, who commissioned Warwick Evidence (a NICE Technology Appraisal Report Team) in March 2020 to undertake a review of risk to rescuers from attempting resuscitation during COVID-19. This resulted in a recommendation from ILCOR in May 2020 [AL/1 INQ000251647] that chest compressions and CPR have the potential to generate aerosols.
- 23. Our aim throughout the pandemic was to maintain consistency of messaging and only change guidance if evidence indicated a need to do so. The EWG met regularly on a virtual basis throughout the pandemic, reviewing the existing and emerging evidence from around the world as well as undertaking direct communication with colleagues involved in resuscitation in Australia, New Zealand, United States, and Europe.
- 24. We published our first statements on 4 March 2020 for the in-hospital setting that covered adult [AL/2 INQ000251658] and paediatric [AL/3 INQ000251669] resuscitation. These statements reinforced the basic principles of infection prevention and control and provided links to the guidance available from the Department of Health and Social Care (DHSC) and Public Health England (PHE), Public Health Wales, Health Protection Scotland, and the Department of Health Northern Ireland. At this stage, the guidance from PHE stated that any healthcare workers interacting with a COVID patient should wear respiratory protective equipment (RPE), defined as a filtering face piece (FFP3 respirator). We emphasised the importance of early recognition and prevention of patient deterioration. We recommended prioritisation of defibrillation attempts and full AGP PPE for healthcare workers during CPR to safeguard their health as well as the patient.

- 25. In response to a request on 25 March 2020 from the "CRASH officer" for the Nightingale hospitals, we published an amended Immediate Life Support (ILS) course to fulfil the training requirements for those returning to practice or changing clinical practice to work in the Nightingale hospitals. This enabled staff to attain knowledge and skills in resuscitation practice via a shortened course with the use of e-learning to supplement the manual. The course was ready for launch on 30 March 2020 with the London Nightingale Hospital opening on 3 April 2020.
- 26. On 27 March 2020, the New and Emerging Respiratory Virus Threats Advisory Group (NERVTAG) stated that "chest compression and defibrillation per se are not AGP" [AL/4 INQ000220132] and this was swiftly followed the same day by a statement from PHE that aligned itself with this stance [AL/5 INQ000251675]. The EWG felt that this appraisal focused purely on the theoretical science of AGPs, without appropriate consideration of the clinical realities of conducting repeated chest compressions as part of a resuscitation attempt.
- 27. We produced a statement [AL/6 INQ000251676] on 28 March 2020 in response to the PHE statement. We reaffirmed our commitment to the safety of both healthcare staff and patients and the desire to work with PHE and NHS England (NHSE) to enable the delivery of safe, high-quality care during those exceptional times.
- 28. On 3 April 2020, representatives of the EWG had a virtual meeting with Dr Hopkins (Deputy Director, National Infection Service) and members of her team from PHE. I was unable to attend as I was on clinical duty that day. I was subsequently informed by colleagues who attended that concerns were raised by PHE in that meeting about the potential delay to commencing CPR because of the need to don PPE. PHE also raised concerns about the lack of evidence for compressions being AGP and, therefore, requiring AGP PPE.
- 29. After the meeting, we had email communication [AL/7 INQ000251677] with an attached document [AL/8 INQ000251678] from a Consultant Microbiologist and Consultant Virologist and Infectious Diseases Physician who had been part of the PHE team at the meeting. They confirmed that transmission of SARS-CoV2 (the novel coronavirus that causes COVID-19) was accepted to be predominantly via respiratory droplets. They conceded that in an incident such as resuscitation, whether or not there is an AGP, there will be significant respiratory droplet production.

- 30. We scrutinised the initial evidence emerging from China including a case series report published in April 2020 [AL/9 INQ000251679] of 136 adult patients with COVID who had an in-hospital cardiac arrest. All patients received full standard cardiac arrest management by staff in full PPE. Despite this, only one patient survived with a favourable neurological outcome; this patient presented with a cardiac rhythm amenable to defibrillation. The vast majority (>95%) did not have such a rhythm.
- 31. We wrote to Dr Hopkins on 6 April 2020 [AL/10 INQ000251648] with our response to the concerns raised by PHE at the meeting on 3 April 2020. We stated that, "in the time to assess, call for help, attach a defibrillator, and deliver up to 3 shocks, it is entirely possible for the team to arrive or upgrade to full PPE with FFP3 mask". We emphasised this in an updated statement dated 15 April 2020 [AL/06 INQ000251676].
- 32. In addition, we were cognisant of the review of deaths in NHS staff published in the Health Science Journal on 22 April 2020 [AL/12 INQ000251650] which showed that a considerable number of health and social care workers were dying in the initial stages of the pandemic. Those working in high-risk specialty areas of anaesthesia and intensive care, the only area where AGP PPE was mandatory at the time, were under-represented among these data suggesting an increased and effective level of protection.
- 33. Based on emerging contemporaneous evidence, our adult guidelines were therefore created to prioritise patient survival by amending them to include swift delivery of up to three defibrillation attempts, which could be achieved without the need for AGP levels of PPE. These guidelines were consistent with international guidelines, produced by the American Heart Association, European Resuscitation Council, Australian Resuscitation Council, and others.
- 34. Paediatric guidance recognised the importance of ventilations during CPR in this population, so guidelines were created to emphasise the importance of the awareness of signs of deterioration in children and placing them in suitable environments so that healthcare workers were alert and adequately prepared to deliver immediate CPR with AGP PPE. Little change was needed to the newborn guidelines, other than adaptations for the COVID status, known or unknown, of the mother at birth.
- 35. In April 2020, we published infographics and flowcharts for adults, non-acute hospital settings, and information for use in the delivery suite for both mother and baby.

- 36. On 17 April 2020, the EWG met to consider the shortages of PPE reported in the media and its impact on our guidance. Our guidance already contained recommendations that AGP PPE should be immediately available in areas of the hospital where high risk or confirmed cases of COVID were cohorted to minimise any delays to patient care. We published an updated statement on 20 April 2020 [AL/13 INQ000251651] in which we reaffirmed that our principal focus was to balance the potential for positive outcomes for patients with the safety of healthcare professionals. Our guidance remained unchanged and was consistent with international best practice issued by organisations such as the World Health Organisation (WHO), ILCOR, the European Centre for Disease Control (ECDC), and ERC.
- 37. During this period, we offered to work with NERVTAG and PHE to a unified goal of prioritising patient and healthcare worker safety. In addition to the letter sent to Dr Hopkins on 6 April 2020, we wrote to Professor Horby (Chair of NERVTAG) on 17 April 2020 [AL/14 INQ000251652] offering to help with the NERVTAG review of the issue of chest compressions as an AGP. We also sent a joint letter on 23 April 2020 to Mr Selbie (Chief Executive of PHE) co-signed by the British Medical Association (BMA), Royal College of Nursing (RCN), and the Hospital Consultants and Specialists Association (HCSA) [AL/15 INQ000097926]. We were concerned about the confusion and worry that divergent guidance would produce to the healthcare sector as well as the increased risk to healthcare staff. We asked for a precautionary approach that would either classify CPR as an AGP or note the lack of definitive evidence and support the expert guidance published by RCUK as a professional consensus.
- 38. On 24 April 2020, NERVTAG released a consensus statement [AL/16 INQ000384631] saying that "the scientific evidence base is extremely weak and heavily confounded by an inability to separate out specific procedures performed as part of CPR". They cited a systematic review from 2012 relating to the SARS infection that had found that "chest compressions and defibrillation were not significantly associated with an increased risk of SARS infection". They went on to state that "it is biologically plausible that chest compressions could generate an aerosol, but only in the same way that an exhalation breath would do". They concluded that they did not consider chest compressions to be associated with significantly increased risk of transmission of acute respiratory infections.

- 39. As a result of the NERVTAG review and, in response to our letter the previous day, PHE confirmed on 24 April 2020 that they would not be adding chest compressions to the list of AGPs. They did, however, further amend their guidance on 27 April 2020 to state the following: "we understand that healthcare organisations may choose to advise their clinical staff to wear FFP3 respirators, gowns, eye protection and gloves when performing chest compressions, but we strongly advise that there is no potential delay in delivering life-saving intervention" [AL/17 INQ000257949].
- 40. RCUK stated on 28 April 2020 that "we welcome the fact that PHE's guidance of 27 April 2020 now aligns with that of RCUK inasmuch as it allows Trusts to opt for AGP levels of PPE if they consider this appropriate to best ensure healthcare professional safety" [AL/18 INQ000251656]. We also stated that NERVTAG's appraisal had focused purely on the theoretical science of AGPs "without appropriate consideration of the clinical realities of conducting repeated chest compressions as part of a resuscitation attempt".
- 41. During May 2020, the EWG continued to review evidence and practice, along with the course of the pandemic. Minor amendments were made to our published documents to ensure they linked to the most up to date source of information.
- 42. On 4 June 2020, we published joint scenarios along with the Royal College of Paediatrics and Child Health (RCPCH) with FAQs for general principles and actions for paediatric resuscitation events [AL/19 – INQ000251657]. On 8 June 2020, the newborn algorithm was published to support guidance already in circulation [AL/20 – INQ000251659].
- 43. The 'National Guidance for the Remobilisation of Services within all Health and Care Settings throughout the United Kingdom' was published by PHE on 21 August 2020

 [AL/21 INQ000299582] This set out pathways for High, Medium, and Low risk categories. Of note, the additional paragraph inserted in the PHE guidance from 27 April 2020 that had allowed Trusts to opt for AGP levels of PPE was deleted for this and subsequent iterations.
- 44. We updated our position statement on 21 September 2020 [AL/22 INQ000251661] to recommend that COVID-19 algorithms, including the use of AGP PPE, should continue to be used for patients allocated to the High and Medium risk categories. For patients

- allocated to the Low-Risk category, we advocated standard pre-COVID algorithms but that healthcare workers should still wear a minimum of Type II fluid resistant surgical mask, eye protection, disposable gloves, and an apron.
- 45. In December 2020, we published guidance for anaphylaxis in vaccination settings [AL/23 INQ000251662], with minor updates on 4 January 2021. This was written in conjunction with the British Society for Allergy and Clinical immunology (BSACI) and partners in the Department of Health and Social Care (DHSC), PHE, and the Medicines and Healthcare product Regulatory Agency (MHRA). This guidance was widely disseminated to all vaccination clinics ready for the vaccination roll out in January 2021. Further amendments to clarify the approach in community settings without access to oxygen cylinders were made on 10 August 2021.
- 46. The following months were spent reviewing evidence and speaking with clinical colleagues from around the world to gauge the course of the pandemic and evaluate our response to it. No changes were made to the requirements for PPE or the algorithms as healthcare settings were risk assessing their response and moving towards a staged approach to the care of the suspected or confirmed COVID-19 patient.
- 47. Minor updates (predominantly branding) were made in October 2021 to the algorithms for adult, paediatric, and newborn resuscitation.
- 48. The EWG next met in January 2022 to review our position on COVID-19. We were aware of the rise in the Omicron variant, and the positive effects of the vaccination programme. We noted that the UK Health Security Agency (UKHSA) had updated its guidance on 17 January 2022 to reflect the change in isolation period in hospitals from 14 to 10 days for cases and contacts of cases of COVID-19. We also noted an international scoping report on AGP listings which stated that 13 countries or international bodies (WHO, ECDC) other than the UK considered CPR as a high risk for AGP. We concluded that there was no evidence to suggest that we should change our quidance.
- 49. On 5 April 2022, the EWG reviewed recently published evidence from the USA that suggested that COVID-19 was predominantly transmitted via the aerosol route as opposed to direct contact and via fomites. Our guidance was amended on 5 April 2022 to prioritise protection against the aerosol route of infection [AL/24 INQ000251663]. We stated that "we continue to recommend the use of FFP3 masks or respirators during

- AGPs associated with resuscitation when treating a patient with suspected or confirmed COVID-19. The donning of other aspects of AGP PPE should not lead to a delay in patient treatment".
- 50. The EWG next met on 21 April 2022. At this meeting we discussed the preliminary findings from the Bristol Aerosol Research Centre that were due to be presented at the European Resuscitation Council conference indicating that chest compressions are probably an AGP.
- 51. We were aware that the PHE statement regarding the NERVTAG review and consensus that CPR was not an AGP was withdrawn on 27 May 2022. Our guidance remained consistent throughout the pandemic in that we believed CPR to be an AGP, so our position was unchanged because of this withdrawal.
- 52. NHSE produced a statement on 9 June 2022 [AL/25 INQ000130583] in which they reviewed a range of procedures currently on the UK AGP list for association with AGP. As chest compressions were not on that list, they were not included in the review. A recommendation was made, however, to remove advanced airway manoeuvres from the UK AGP list.
- 53. At the end of June 2022, the EWG met and made the decision to revert to pre-COVID resuscitation guidelines for all age groups. This decision was made on the balance of risks given that most healthcare workers were now immunised thus reducing the risk to the rescuer. An updated statement was produced on 10 August 2022 to this effect [AL/26 INQ000251665].
- 54. In November 2023, the Bristol Aerosol Research Centre group published their research findings in Anaesthesia journal [AL/34 INQ000339577]. The article, titled 'A Quantitative Evaluation of Aerosol Generation during Cardiopulmonary Resuscitation', found that "a substantial rise in aerosol . . . occurred with cardiac defibrillation and chest compressions". The authors concluded that "multiple components of cardiopulmonary resuscitation generate high concentrations of respiratory aerosol". They recommended that "airborne transmission precautions are warranted in the setting of high-risk pathogens, until the airway is secured with an airway device and breathing system with a filter".

Decisions and Care Planning during the relevant period (1 March 2020 to 28 June 2022)

Overview

- 55. There are numerous terms used for advance care planning, which can on occasion cause confusion. To address this, we have endeavoured to define them below. A detailed description is provided for the ReSPECT process. RCUK does not have any authority or governance over any specific alternative processes to ReSPECT and we have therefore provided descriptions of them, where we are able, to provide context. It should be noted therefore that we are unable to provide detailed description of these alternative processes, and we have indicated where descriptions are provided to the best of our ability and knowledge.
- 56. An <u>advance care plan</u> is an umbrella term for any document in which an individual records, in advance, what matters to them, and their preferences, priorities, and decisions about future care and treatment. They can include details about the preferred place of death, treatments, or types of care that would be desired or should be avoided and can also include non-medical preferences such as music that might be desired in the last hours of life.
- 57. Advance care plans are very varied and can, therefore, be completed in many ways; depending on context they can be instigated by the patient or by a clinician.
- 58. The only kind of advance care plan which is legally binding in England is an Advance Decision to Refuse Treatment (ADRT), commonly known as a Living Will. This document is instigated by the individual and must be signed and dated by the individual to whom it refers and witnessed. It is legally binding if it complies with the Mental Capacity Act, is valid, and applies to the situation.
- 59. A <u>DNACPR</u> (Do Not Attempt Cardiopulmonary Resuscitation) notice is an instruction advising clinicians not to attempt CPR if the individual's heart stops. DNACPR notices are usually red bordered and are held at the front of a patient's notes for easy identification in an emergency. The function of a DNACPR notice is to ensure that unwanted or inappropriate (defined as extremely unlikely to be successful or not achieving an outcome that the patient would want) CPR is not attempted. The notice can be used in any number of settings: in hospital, in the community, and in a care home. Ideally the notice travels with the patient.

- 60. DNACPR notices are most frequently instigated because the clinicians looking after the patient do not think that CPR would be successful or believe that CPR has a high chance of leading to a condition that the patient would not value. They can be instigated at a patient's request, but this is rare. Following the Court of Appeal decision of *Tracey* v *Cambridge University Hospital NHS Foundation Trust & Others* [2014] EWCA Civ 822 all such notices must be discussed with the patient, or where they lack capacity, those close to them. They are signed by the clinician and not by the patient.
- 61. <u>ReSPECT</u> (Recommended Summary Plan for Emergency Care and Treatment) is an emergency care and treatment plan developed by RCUK which complements the advance care planning process. It is a process *incorporating* the recommendation whether or not to attempt CPR alongside establishing a shared understanding between the patient and the clinician about wider goals of treatment. Its key functions are to:
 - a. facilitate shared understanding between the clinician and the patient about which treatments (including CPR) would and would not be of benefit to that particular patient, given their condition and outcomes.
 - b. provide instruction to clinicians in an emergency, when the patient lacks capacity, about what the goals of treatment should be, and which treatments are and are not recommended. Note that the ReSPECT form can also document that a patient should be *for* attempted CPR.
 - c. be used in any number of settings: in hospital, in the community and in a care home. Ideally the form travels with the patient.
- 62. The <u>ReSPECT</u> process is undertaken between the clinician and the patient to establish shared understanding about:
 - a. current diagnoses and conditions
 - b. wider goals of care
 - c. preferred patient outcomes, and
 - d. clinical recommendations for which treatments (including CPR) would be likely to get the patient to their preferred outcomes.
- 63. The first part of the current form **[AL/27 INQ000251666]** is written in the patient's voice; namely "Shared understanding of my health and current condition", and "What matters to me in decisions about my treatment and care in an emergency" (alongside prompts to record details of other advance care planning documents or legal welfare

proxies). The next part of the form, including "Clinical recommendations for emergency care and treatment", is written by the clinician in discussion with the patient. The reverse side of the form includes space to document capacity (the assessment of whether the patient can understand, weigh, retain, and communicate the specific recommendations being discussed at the time the ReSPECT process is undertaken), who was involved in the discussion, and emergency contact details.

- 64. ReSPECT can be instigated in hospitals, care homes, or in the community by the primary care provider. They are signed by the clinician and can be countersigned by the patient or others who were involved in the discussion if they wish, but this is not required; the option for patient and other signatures was introduced in Version 3 (see paragraph 76) following patient feedback.
- 65. Neither a <u>DNACPR</u> notice, nor a <u>ReSPECT</u> form is legally binding. They are both standardised forms which document clinical recommendations for an emergency where a patient lacks capacity to be involved in decision making.
- 66. In theory, a <u>DNACPR</u> notice should have no impact on decisions regarding other treatments such as escalation of care or treatment; it is intended solely to guide clinicians in the event of a cardiac arrest. However, there is evidence that DNACPR notices can often be conflated with a signal that a patient is approaching the end of their life, or that comfort should be prioritised. It can be misunderstood by clinicians to mean that other potentially beneficial treatments should be withheld. DNACPR notices can therefore have an unintended negative impact on decisions regarding treatment of the patient such as escalation of care.
- 67. It was primarily in response to these concerns that the ReSPECT process was conceived and designed by a group of stakeholders, and subsequently introduced by RCUK in December 2016. ReSPECT contextualises the CPR recommendation within overall goals of care, making sure that clinicians and patients agree on what the priority of treatment should be: "Prioritise extending life" OR "Balance extending life with comfort and valued outcomes" OR "Prioritise comfort". There is an open text box in which recommendations can be made about specific treatments or escalations. This is to ensure that there is no conflation between a DNACPR recommendation and not having escalation of treatment. It is perfectly reasonable, for example, to recommend that someone should be considered for full escalation of treatment, including intensive care treatment, but not for attempted CPR. The ReSPECT process, therefore, leads to

- explicit documentation of recommendations about escalation of treatment and care, which should be in line with the patient's values and preferred outcomes.
- 68. ReSPECT was developed with patient, carer, and family feedback. This feedback was collated and discussed among the ReSPECT expert working group (consisting of clinicians from primary and secondary care, paediatrics, neonates, ambulance service, out of hours, ReSPECT leads, and a patient representative).

Coverage of adoption of the ReSPECT process in the UK

- 69. The ReSPECT process has been adopted in different ways, with most regions coordinating system-wide integration, and others adopting it in a more organic fashion.
- 70. At the beginning of 2020, all ambulance trusts were familiar with ReSPECT, in anticipation of its adoption throughout the UK.
- 71. At the beginning of 2020, adoption had commenced in five of the seven regions (as defined by NHSE) in England. Coverage increased in these regions (East of England, Midlands, North East and Yorkshire, South East, and South West) throughout the relevant period. The two English regions that did not adopt ReSPECT at any stage during the relevant period were the North West (except for Manchester) and London, as they had alternative processes in place.
- 72. At the beginning of 2020, one out of fourteen Health Boards in Scotland (Forth Valley) had adopted the ReSPECT process. This increased to four Health Boards (Forth Valley, Lanarkshire, Tayside, and Western Isles) by 2022. We do not have details of what the alternative local processes were in place during this time, but we believe that most areas not using ReSPECT used a simple DNACPR form alongside local advance care planning documents.
- 73. Throughout the relevant period, there was no adoption of the ReSPECT process in Northern Ireland and Wales. Northern Ireland used a simple DNACPR form without ancillary forms. To the best of our knowledge, Wales had a variety of forms including a simple DNACPR form, a Treatment Escalation Plan for hospitals, and an advanced care planning document for use within the community setting. We do not have sufficient knowledge of the forms used in Wales to comment upon the material differences between those arrangements and the ReSPECT process.

- 74. Alternative systems in place during the relevant period included:
 - a simple DNACPR form (e.g., in Portsmouth, Southampton, Wales, and Northern Ireland)
 - b. a simple DNACPR form with a digital 'urgent care plan' accompanying it (e.g., in London). We believe that this was clinician-held, and there were no overall goals of care, so patients were still designated as being 'DNACPR'. The 'Coordinate my Care' plan was used for those approaching their end of life rather than for anyone who wished to undergo advance care planning. This plan did have a section asking individuals for their thoughts in relation to "a CPR attempt"; however, it is unclear if there was a mechanism to document that an individual was 'for cardiopulmonary resuscitation'.
 - c. a DNACPR form with 'Deciding right' materials supporting it (e.g., in the Northeast and Northwest); the 'Deciding right' approach has to the best of our knowledge a series of documents including a simple DNACPR form and an Emergency Health and Care Plan which documents the care needed during and after an anticipated emergency but does not include a CPR decision, and
 - d. a Treatment Escalation Plan, which was clinician led, and which, like ReSPECT, contextualised the CPR recommendation within overall goals of care (e.g., in Devon).
- 75. We believe that the presence of several concurrent forms and processes, as opposed to a nationally standardised process for ascertaining patients' wishes, create risks for patient care. These include:
 - a. problems with acceptance of forms for patients who are away from home, or who live on boundaries between healthcare areas that have separate processes.
 - confusion amongst ambulance clinicians about which form is valid in which setting.
 - c. patients needing more than one form and needing to have repeated conversations about resuscitation causing increased distress.
 - d. clinicians focusing on the DNACPR part of the conversation instead of considering and documenting overall goals of care due to a lack of uniformity of approach.
 - e. barriers to having a national campaign to encourage the discussion of patients' wishes because of a lack of uniformity of approach.

Timeline for ReSPECT

- 76. At the beginning of 2020, Version 2 of the ReSPECT form [AL/28 INQ000251667] was being used. The first formal collation of suggestions for improvements to Version 2 had been circulated to the ReSPECT Expert Working Group (EWG) in July 2019, and work began on synthesising these suggestions and developing a Version 3. This updated version was initially signed off by the ReSPECT EWG in February 2020 with an intention to pilot it in five sites; the Covid pandemic made us re-evaluate this, as clinicians did not have time to participate in a formal evaluation.
- 77. The differences between Version 2 [AL/28 INQ000251667] and Version 3 [AL/27 INQ000251666] were as follows:
 - a. more text instructions were included in the form, to ensure that users understood that the process was based around a conversation, that the form was not legally binding, and that the reasoning for the clinical recommendations should be documented.
 - b. the first three sections of the form were changed to the first person (e.g., "what matters to *me* in decisions about *my* treatment and care in an emergency"), to encourage the individual undertaking the ReSPECT conversation to document their views in their own words, and to give them more agency.
 - c. two boxes ("What I most value" and "what I most fear/wish to avoid") were added to encourage individuals to consider and document these issues. The aim was that clinicians would be guided in an emergency to provide treatments which would be commensurate with the health outcomes that the individual valued, and not provide treatments which were likely to result in health outcomes that the individual feared.
 - d. in Section 4, where previously clinicians had to choose between two options (focus on life sustaining treatment OR focus on symptom control), a third option was added, so that clinicians could reflect more nuanced wishes of the patient. In Version 3 the options are, therefore: prioritise extending life OR balance extending life with comfort and valued outcomes OR prioritise comfort.
 - e. an opportunity for the patient (or others close to them who were involved in the discussion) to sign the form was added.
 - f. two one-page guides were developed: a ReSPECT discussion guide for clinicians, and 'guidance for people with a ReSPECT form'.

- 78. In March 2020, RCUK became aware of national media reports regarding blanket DNACPR orders, especially in community, residential and care settings. As a result of this media coverage, RCUK received several communications expressing concerns. In response to these enquiries and concerns, and with the concerns of the public particularly in mind, we published a response as part of our FAQ section on our website covering many areas of concerns raised with us [AL/29 INQ000251668]. These included the difference between DNACPR and ReSPECT, the inappropriateness of blanket DNACPRs, who should be contacted to discuss these decisions, the role of the relative in this situation, and the process for how ReSPECT should be implemented including situations where the patient is in a care home.
- 79. During April 2020 we frequently reviewed the evidence and continued discussions on our response and approach. On 8 April 2020 we produced a statement on decision making and family discussions [AL/30 INQ000251670]. The aim of this statement was to provide clarity and reassurance for both staff and patients in the light of the media reports. This was followed by an updated press statement on 9 April 2020 [AL/31 INQ000251671]. This emphasised once again that we do not advocate a blanket approach to decisions on whether or not to attempt to resuscitate individuals in an emergency, irrespective of whether the patients are suspected or confirmed to have COVID-19.
- 80. On 23 April 2020, we released a statement [AL/32 INQ000251672] on the role of the ReSPECT process during COVID-19. This statement aimed to clarify that ReSPECT is a process which creates personalised recommendations for a person's clinical care and treatment in an emergency when they might not be able to communicate this for themselves. It is a non-legally binding process that involves recording the summary of a conversation on a form which in turn belongs to the patient. It requires a conversation between the patient and their clinician and/or legal proxy or close family member. Most importantly, it is not part of a blanket approach to resuscitation and emergency care decisions, and neither is it purely a DNACPR form or Advanced Decision to Refuse Treatment.
- 81. Version 3 was further iterated in July 2020 in response to research conducted at the University of Warwick, and the final Version 3 was launched on 16 September 2020 [AL/27 INQ000251666] alongside an online survey to allow users to feedback on the changes and ensure there were no unintended negative impacts of Version 3. We published an online survey and 813 people (a combination of health and care workers,

- and members of the public) responded positively about Version 3, commenting in particular about the patient-centred approach. No unintended negative impacts were reported.
- 82. We acknowledged and welcomed the publication of the CQC report 'Protect, respect, connect: Decisions about living and dying well during COVID-19', commissioned by DHSC on 18 March 2021 [AL/33 INQ000235492].
- 83. A key action following the publication of this report was the establishment of a Ministerial Oversight Group. As a key stakeholder, we readily accepted the invite to be part of this group and the subsequent conversations to develop the Principles of Advance Care Planning. This was an excellent example of a central governmental process utilising our skills and expertise in partnership for the unified aim of improving processes of care for the UK population.
- 84. The ReSPECT process continues to be adopted in health and social care settings across the UK. We are currently reviewing feedback from users on Version 3 of the form and will update it in light of these. During the pandemic, the drive for using the ReSPECT process primarily came from the acute care settings, but we are now seeing a move to the adoption and use of ReSPECT across community and social care settings.
- 85. We continue to work with clinicians and patients across all ages to ensure that everyone is offered the opportunity to discuss their medical condition and their future preferences should they become too unwell to express their thoughts at the time of any health crisis.

Conclusions and Recommendations

- 86. Resuscitation Council UK is the national body of expertise for cardiac resuscitation practice, and we are always keen to engage with governmental organisations and arm's length bodies to contribute this expertise to national planning. A prime example of this is our partnership with the Ministerial Oversight Group to address concerns over Advance Care Planning.
- 87. We have existing credibility in the healthcare sector in terms of translating evidence into practical guidelines which are understood and accepted by clinical staff. We believe that our guidance throughout the pandemic was clear, consistent, in line with contemporaneous evidence, amended when such evidence emerged to indicate that amendments were required, and that it balanced the prioritisation of patient care with the safety of those treating these patients.
- 88. The ReSPECT process has now been adopted in 5 out of 7 regions of England, 5 out of 14 Health Boards in Scotland (with existing plans for adoption in one additional Health Board, and active consideration from a further 5 Health Boards), and plans are in place to incorporate the ReSPECT process into the Advance Care Policy in Northern Ireland. There are currently no plans to adopt the ReSPECT process in Wales.

89. We recommend:

- a. that, in the eventuality of a future pandemic, processes are put in place early whereby government and arm's length bodies are encouraged to engage with organisations such as RCUK that offer subject matter expertise not immediately available within their own teams.
- b. that when considering issues relating to the health and safety of healthcare workers, government and arm's length bodies should take a precautionary approach when considering levels of risk.
- c. that the ReSPECT process is fully adopted throughout health and social care settings in all four nations of the UK so that there is a standard patient-centred practice with familiar and accessible outcomes available to all, regardless of location or socio-economic situation. The responsibility for this should rest with each nation's governmental department responsible for health and social care, as they work to improve the health and wellbeing of their respective populations,

provide high-quality care, and ensure the provision of appropriate health and

social care services.

d. that everyone has access to conversations with their clinician to explore future

options for treatment and care in an emergency when they may not be able to

voice their own preferences. These conversations should, wherever possible,

happen before they are needed, be communicated to those important to the

person, and documented in a format that is readily accessible and understood by

emergency care providers.

e. the normalising of such conversations in society as a whole, both between

person and clinical team, but also within the family setting to reduce the need for difficult and challenging decisions to be made when a person becomes so unwell

that they cannot voice their preferences.

90. RCUK remains against the use of blanket DNACPR decisions for any patient group.

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: 13 November 2023

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