

Witness Name: James Sanderson

Statement No: WITN7274001

Exhibits: WITN7274002-WITN7274003

Dated: 1 November 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JAMES SANDERSON

I, JAMES SANDERSON, will say as follows:-

Section 1: Introduction

1. I am James Sanderson (GRO-C 1974) and I am based at NHS England at Wellington House. 133-155 Waterloo Rd. London. SE1 8UG.
2. I am currently the Director of Community Health and Personalised Care at NHS England, leading on a range of programmes that are supporting people to have greater choice and control over their health and wellbeing.
3. I joined NHS England in late 2015 (prior to this I was the Chief Executive and Accounting Officer for the Independent Living Fund) as its Operations Director and Chief Operating Officer/Deputy CEO, before becoming Chief Executive Officer.

4. As Director of Community Health and Personalised Care, I oversee a series of programmes including palliative and end of life care, community health services, the implementation of the comprehensive model for personalised care, and anticipatory care
5. I am not a member of any committee, association, party, society or group relevant to the Inquiry's Terms of Reference.
6. I make this statement to respond to the questions raised by the Infected Blood Inquiry (IBI) sent to NHS England and addressed to me via a Rule 9 request dated 16 September 2022.

Section 2: Palliative Care

The inquiry has received evidence (both written (EXPG0000043) and oral (INQY1000190) from a group of experts in palliative care in advanced liver disease. One of the issues raised by the group was the variable access to both palliative and end-of-life care for those with advanced liver disease. What if any plans are there in place to tackle this inequality?

7. Specifically, NHS England has recently commissioned Hampshire and Isle of Wight Integrated Care System to support the reduction of inequity of provision of palliative and end of life care for people with advanced liver disease, by developing an evidence based toolkit for the commissioning and implementation of an integrated care bundle that can be applied at an Integrated Care System (ICS) level. The Advanced Liver Disease Palliative Care Project (due for completion in March 2023) aims to develop an evidence based toolkit by:
 - a. Describing the core components (e.g. early identification, advance care planning, multi-disciplinary teams) of an ideal

integrated care approach for addressing the palliative and end of life care needs of people with advanced liver disease

- b. Drawing on existing evidence (recognising that there may be limited data available) to model the clinical and cost effectiveness of such an approach.
 - c. Developing a sample business case that sets out an evidence based case for change and description of the core components of such an integrated care approach, the resources needed and standardised quality and outcome measures that should be used prospectively to drive forward future improvements.
8. The project is being undertaken by a group of multi-centre specialists, led by Dr Mark Wright of University Hospitals Southampton NHS Trust, and in conjunction with colleagues from the British Association for the Study of the Liver national special interest group on palliative medicine in advanced liver disease (chaired by Dr Ben Hudson).
9. More broadly, NHS England has invested in, and supported work to improve, palliative and end of life care for people experiencing homelessness. This work is in recognition of the high rates of most long term conditions, including advanced liver disease, amongst people experiencing homelessness, along with variable access to palliative and end of life care.

Please outline any plans as to how the palliative care system (particularly for those with advanced liver disease) might be improved in England.

10. Palliative and end of life care is delivered by, and across a range of, local and national statutory and voluntary organisations. Collaborative and integrated working across all of these is fundamental to improving

palliative and end of life care in England, including for people with advanced liver disease.

11. The National Palliative and End of Life Care Partnership is a broad partnership of national organisations (including NHS England), across the statutory and voluntary sectors, with a deep commitment to improving palliative and end of life care in England. This commitment to high-quality personalised palliative and end of life care is set out in the refreshed Ambitions Framework 2021-2026 published by National Palliative End of Life Care Partnership (**WITN7274002**). This Framework has been signed by Professor Bee Wee of NHS England as the co-chair of the Ambitions Partnership. It outlines the Partnership's vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England. This emphasises the important role all organisations have in improving people's palliative and end of life care.
12. As a member of the National Palliative and End of Life Care Partnership, NHS England is also committed to supporting the transformation of palliative and end of life care services. Aligned to the Long Term Plan (**WITN7274003**) and Ambitions Framework, NHS England's Palliative and End of Life Care Team has developed a strategic delivery plan which prioritises improving access, quality, and sustainability (this plan is an internal document to the Palliative and end of life Care Team which is not a published document).
13. As outlined in the evidence submitted for the purposes of the inquiry, access and quality are of particular interest when considering people with advanced liver disease, acknowledging the need to address the inequalities that can occur for this cohort in these areas.

14. NHS England's Palliative and End of Life Care Clinical Excellence Workstream focusses on high quality for all, irrespective of condition. Acknowledgement that this is not the case for people with advanced liver disease led to the development and commissioning of the Advanced Liver Disease Palliative Care Project, which is set for completion in March 2023. This project is described in more detail in the answer to Question 2.
15. To support the delivery plan, NHS England has funded the development of seven regional Palliative and End of Life Care Strategic Clinical Networks (PEoLC SCNs). The PEoLC SCNs align with the changes to legislation in the Health and Care Act which promote the responsibility of Integrated Care Boards in commissioning palliative and end of life services to meet local population need, working to support the delivery of accessible, high-quality, sustainable personalised palliative and end of life care for all.
16. This work includes the prioritisation of health inequalities, particularly with regards to improving equitable access to palliative and end of life care services for all. The focus is on identified under-served populations and have made regional funding available via PEoLC SCNs to support the reduction of health inequalities at regional and ICS level.
17. An example is the North West Palliative and End of Life Care Strategic Clinical Network, which has been focussing on delivering activities to address equity and reducing health inequalities in palliative and end of life care across the region. This includes funding to support a population based needs assessment, enabling strategic planning focussed on reducing health inequalities across the North-West. They have also completed a series of successful webinars addressing

issues around health inequalities, as part of their role in supporting quality improvement across footprints and plan to develop a population health workstream approach to Place Based Needs Assessment within their ICSs, as part of their drive for improvement in this area.

18. Extensive work is being undertaken both nationally and regionally to address strategic alignment of palliative and end of life care services for adults across the commissioning pathway. This builds on the opportunity provided in the recent amendment to the Health and Care Act 2022, which has meant that “palliative care services” is now included in the section specifying ICBs’ legal responsibility to commission health services that meet their population needs. NHS England has published statutory guidance¹ to support ICBs in achieving this duty. The guidance contains links to resources and good practice for ICSs when planning locally and working collaboratively with local organisations. A handbook is also in development (to be made available this autumn) which builds on the statutory guidance by providing more detailed practical support to commissioners.

19. In addition NHS England has:

- a. Developed an Accelerated Development Programme (due to begin November 2022) to build a community of practice and develop commissioning mentors. The programme itself will focus on unique features of system integration, arrangements with the charitable sector, funding and contracting, service models, data and intelligence, in the context of palliative and end of life care. It will include collaboration across health and social care, primary, hospital and community care settings,

¹ <https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/>

and statutory and voluntary sector

- b. Developed (due for imminent publication but currently available via the FutureNHS Platform) national service specifications for adult and children and young people's palliative and end of life care. The aim being to promote consistent provision across the country.
- c. Testing of a blended payment approach, with a focus on delivering outcomes

20. Furthermore, NHS England commissioned Hospice UK to develop the Future Vision Programme² in England, which aims to support a collective conversation about sustainable palliative and end of life care in the future and following the COVID-19 pandemic. Through this Hospice UK engaged with over 400 stakeholders from across the palliative and end of life care sector to, resulting in the development of nine strategic principles for sustainability, covering aspects such as hospices understanding their role within ICSs, collaborating with other hospices to reduce duplication and deliver best outcomes for patients, working with commissioners to transform funding and understanding service deliver costs to maximise efficiency.

21. A variety of work is occurring across NHS England and other organisations NHS England works with to improve palliative and end of life care in all settings. This includes:

- a. The National Audit of Care at the End of Life (NACEL)³, a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute hospitals,

² <https://hukstage-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2021-10/hospice-uk-future-vision-programme-discovery-phase-final-report.pdf>

³ <https://www.nhsbenchmarking.nhs.uk/nacel>

community hospitals and mental health inpatient providers in England, Wales and Northern Ireland.

- b. The Enhanced Health in Care Home Framework⁴, focussing on proactive care that is centred on the needs of individual residents, their families and care home staff through a whole-system, collaborative approach.
- c. The development and provision of training and career development such as the End of Life Care for all e-learning programme (e-ELCA⁵), which aims to enhance the training and education of the health and social care workforce so that well-informed high-quality care can be delivered by confident and competent staff and volunteers to support people irrespective of setting.
- d. The Getting to Outstanding programme; a programme led by NHS England's Clinical Excellence workstream to support quality improvement across local systems. Previously, the Getting to Good programme supported improvements in end of life care in NHS Trusts, such that the number of Trusts rated as requires improvement or inadequate by the Care Quality Commission dropped from 92 in 2016 to 24 in 2021, and increased the number rated as outstanding from 19 to 39 in that same time period. The Getting to Outstanding Programme (available through the Future NHS Platform; a membership platform) builds on that by supporting quality improvements across whole systems.
- e. Provision of clinical guidelines and standards⁶ as provided by NICE

⁴ <https://www.england.nhs.uk/publication/enhanced-health-in-care-homes-framework/>

⁵ <https://www.e-lfh.org.uk/programmes/end-of-life-care/>

⁶ <https://www.nice.org.uk/guidance/health-and-social-care-delivery/end-of-life-care>

f. NHS England's Clinical Commissioning workstream is also supporting the following pieces of current work:

- i. Developing training resources for professionals to better identify and address the needs of unpaid carers
- ii. Appreciative inquiry to identify and share learning about improving access to palliative and end of life care for underserved populations
- iii. Discovery project to better understand barriers and facilitators to improving access to palliative and end of life care for those who are most deprived

22. NHS England places significant emphasis on the importance of personalised care (as outlined in the NHS Long Term Plan and Universal Personalised Care⁷) for people at the end of their lives, including personalised care and support planning and access to shared decision-making conversations about treatment and care. Even under extremely pressurised circumstances, these conversations between healthcare professionals and patients are vital. To support this, NHS England, in conjunction with other interested parties, has produced public facing information regarding DNACPR⁸ and Universal Principles for Advance Care Planning⁹. The latter sets out six high level principles for advance care planning in England. It is for the person, those important to them, practitioners and organisations involved in supporting advance care planning conversations and honouring their outcomes in order to deliver the recommendations of the Care Quality Commission's (CQC) report into

⁷ <https://www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/>

⁸ <https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/>

⁹ <https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/>

the use of DNACPR decisions taken during the COVID-19 pandemic.

23. Importantly, the national Palliative and End of Life Care Team has also invested resource in improving how people's wishes, preferences and needs, including those identified through personalised care and support planning (and advance care planning) are recorded and shared. This includes updating the SCCI 1580 standard¹⁰ for palliative and end of life care coordination to ensure that professionals and individuals have access to appropriate information to support decision making for those with palliative care needs and those who are approaching the end of their lives.
24. Finally, NHS England hosts monthly national webinars and disseminates six-weekly bulletins, available to all professionals working in palliative and end of life care, across all settings. These continue to provide an opportunity to share examples of good practice across the sector, as well as bringing professionals together to network and gather feedback and information to support local transformation of services. The national webinars have now had over 4,114 attendees since their inception and the bulletin has over 2,300 subscribers, covering a range of professions and roles in the statutory and VCSE sector, from across England. Both will be used as mechanisms for sharing learning from the Advanced Liver Disease Palliative Care Project once available.

Please provide any comment you consider relevant to the Inquiries Terms of Reference arising from the evidence from the expert group.

¹⁰ <https://prsb2.vercel.app/page/palliative-and-end-of-life-care-information-standard?hsCtaTracking=f03fff77-1ecb-44e3-955b-a56f038c83dd%7C52d83f23-deb4-48a6-99ef-5bd893ec26b6>

25. NHS England recognises the evidence submitted within the written Expert Report at EXPG0000043 ("the Expert Report") and broadly accepts it as a fair reflection of the current situation.
26. The report references the fact that many patients with advanced liver disease do not have an existing relationship with primary care. This consequently exacerbates their diminished access to palliative care, both core and specialist, as primary care provides the bulk of core palliative care, and is the major route of access to specialist palliative care for all patients who need it. The impact of this is seen in the percentage of people with 3 or more emergency admissions in the last 90 days of life (2014-2018) in the figures published by Public Health England¹¹, which was highest for those with advanced liver disease even though the average number of deaths was low, compared to conditions such as cancer or chronic obstructive pulmonary disease.
27. More specifically, with regard to the response to question 11a addressed within the Expert Report, NHS England acknowledges that there is no national consensus on what constitutes a standard model of care for people with advanced liver disease and palliative care needs, which contributes to the variation described. It is in recognition of this that NHS England's Palliative and End of Life Care Team has commissioned Hampshire and Isle of Wight Integrated Care System to undertake the Advanced Liver Disease Palliative Care Project, with one of the expected outputs being a consensus of core components (e.g. early identification, advance care planning, multi-disciplinary teams) of an ideal integrated care approach for addressing the palliative and end of life care needs of people with advanced liver

¹¹ <https://www.gov.uk/government/publications/emergency-admissions-in-the-3-months-before-death/emergency-admissions-in-the-3-months-before-death#underlying-cause-of-death>

disease.

28. Overall, national guidelines and Quality Standard for palliative and end of life care tend not to be condition specific. They are intended to be used for all people with palliative and end of life care needs, regardless of diagnosis. This includes people with advanced liver disease.
29. NHS England also acknowledges the detailed discussion transcribed within the oral evidence at INQY1000190 ("the Expert's Oral Evidence"). The references on pages 93 to 95 of the Expert's Oral Evidence to CQUINs is a reference to the effort to incentivise improvement in palliative care for people with advanced liver disease. As colleagues in the discussion note, CQUINs must be objective and measurable which can create issues when applied to palliative care. It is also worth noting that an aim of NHS England's Advanced Liver Disease Palliative Care Project is to develop standardised quality and outcome measures that could be used prospectively to drive forward future improvements for people with advanced liver disease. This project is expected to conclude in March 2023.

Statement of Truth

I believe that the facts stated in this witness statement are true.

GRO-C

Signed:

Dated: 1 November 2022