PROPOSED RECOMMENDATIONS

ON BEHALF OF (1) GRO-A (2) ROB JAMES (3) GRO-A (4) GRO-A

("THE SAUNDERS CPs")

SUBMISSIONS

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1. These brief submissions identify the recommendations that the Saunders CPs seek, and provide brief reasons in support of them.

2. Further, the Saunders CPs invite the Chair to consider the findings and recommendations of earlier Inquiries, including the *Mid – Staff Inquiry*, in deciding what recommendations ought to be made. In particular, they should be reviewed to determine whether anything can be learnt, and whether any recommendations should be restated, or their implementation reviewed. Without follow up there is risk that Inquiries into medical accidents/catastrophes operate in silos, sometimes repeating the substance of earlier recommendations without any review or assessment of their implementation, effectiveness or value.

3. It is accepted, of course, that the events leading to the *Mid-Staff Inquiry*, and other earlier Inquiries, were very different from the events that are the subject of this Inquiry, and covered different periods of time. Nevertheless, there must be some review of earlier reports if there are not to be gaps in learning. Which recommendations were implemented and which not, and the effectiveness of those

that were implemented are important questions for understanding what recommendations might be appropriate following conclusion of this Inquiry.

4. Similar follow up will be required in the case of recommendations made in this Inquiry.

A. Learning

Recommendation 1:

5. **Education and learning:** An account of the circumstances in which men, women and children treated by the NHS were given infected blood and infected blood products, in particular since 1970, and this Inquiry's ultimate findings in respect of the same, should be embedded in the training of medical and health practitioners (including GPs, hospital doctor, nurses and specialist haemophilia clinicians).

6. The Saunders CPs submit that lessons must be learnt from the catastrophic events that are the subject of this Inquiry. Learning from these events cannot be presumed (see, Powell, *"Learning from NHS Inquiries: Comparing the Recommendations of the Ely, Bristol and Mid Staffordshire Inquiries"* (2019) Political Quarterly, 1-9).

7. Further, there must be compulsory training of medical healthcare professionals on haemophilia, co-morbidities and the impact of age. This should form part of continuing professional development ("CPD"). This is because, as this Inquiry has revealed, knowledge of the impact of haemophilia, infection and co-morbidities is limited among practitioners, affecting the quality of care.

B. Health Care

Recommendation 2

8. **Psychological support:** Arrangements should be made for the provision of psychological / counselling support for those infected and affected, without limit of time. The impact on those affected by these events has been profoundly distressing and, in some cases, has resulted in mental ill-health.

9. Whatever the nature and extent of the trauma, for many it has, too, been exacerbated by the experience of taking part, and/or following, this Inquiry. It cannot be assumed therefore that mental distress or mental ill- health is a matter of historic concern only.

10. In the case of infected haemophiliacs, the Inquiry might consider recommending that this support be provided through haemophilia centres so as to make its availability apparent and accessible.

Recommendation 3

11. **Free access to health and social care for life and for all conditions, including for end- of-life care:** There should be access to health and social care for life in respect of all medical conditions, including end- of-life care, whether or not related to the infection/s. Further, those infected should qualify for free prescriptions and therapeutic aids, again whether related to the infection or not, and they should be added therefore to the list of persons who are currently entitled to free prescriptions whether or not the prescriptions relate to the qualifying condition.

12. These arrangements could be modelled on the Irish scheme (Health (Amendment) Act 1996), as follows:

> "(2) A health board shall make available without charge to persons who, in the opinion of the chief executive officer of the board, have contracted hepatitis C directly or indirectly from the use of Human Immunoglobulin-Anti-D or the receipt within the State of another blood product or a blood transfusion and to persons of such other classes (if any) as may be prescribed

(a) general practitioner medical and surgical services, in relation to all medical conditions, provided by registered medical practitioners … chosen by the persons,

(b) drugs, medicines and medical surgical appliances,

(c) the nursing service specified in section 60 of the Act of 1970 [home nursing],

(d) the service specified in section 61 of the Act of 1970 [home help],

(e) dental, ophthalmic and aural treatment and dental, optical and aural appliances,

(f) counselling services in respect of hepatitis C, and

(g) such other services as may be prescribed."

13. Additionally, like the Irish scheme, those infected should be given priority appointments for clinical assessment.[1]

Recommendation 4

14. **Priority treatment:** Some of the Saunders CPs seek a recommendation that those who have contracted HIV or HCV (or both) as a result of infected blood should be prioritised for medical treatment.

15. Unlike other medical accidents, the events surrounding and following infection by blood and blood products are so extraordinary that they require an extraordinary response. Over a period of decades those thousands given infected blood experienced (i) the transmission of infection without information concerning risk and consent (ii) an absence of transparency and cover up around the catastrophe (iii) brutal treatment by the state and (iv) an absence of support, treatment and care by the state and the bodies who might have been expected to provide it.

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[1] *"Information guide to HSE Primary care and hospital services to persons. Who contracted hepatitis C through the administration within the state of contaminated blood or blood products: arrangements for the provision of services 2020"* p8.

16. That requires a unique, effective and robust response. This response should include priority treatment from the NHS. An example of such prioritising can be found in the "Armed Forces Covenant"[2] which provides that: "Veterans receive their healthcare from the NHS, and should receive priority treatment where it relates to a condition which results from their service in the armed forces, subject to clinical need. Those injured in service, whether physically or mentally, should be cared for in a way which reflects the Nation's moral obligation to them…". The imperatives for prioritising are no less compelling here given the devasting impact on the lives of those infected as a result of gross state failures.

Recommendation 5

17. **Old age:** A review into the needs of those infected as they age, including the need for bespoke health care and the need for social care, should be undertaken.

18. Those who were infected and who have survived well-beyond the age expected have increasingly complex needs. Provision must be made to accommodate and meet those needs. This can only be successfully achieved by a thorough review of needs and the putting in place structures and services targeted at them.

C. Systems

Recommendation 6

19. **Risk Management:** An oversight body should be established (or the task should be allocated to an existing body) to record, review and act upon incidences of medical treatment and therapies where evidence is indicative of harm. This should operate as an "early warning system" (a subject, again, addressed by the *Mid-Staff Report*).

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[2] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/49469/the_armed_forces_covenant.pdf, p.6.

20. There was no mechanism for spotting early warning signs during the period in the 1970s, 80s and 90s[3] at the dates of the events that this Inquiry is concerned with. The difficulty of spotting signs was aggravated by the disparate and fractured nature of the relevant services, and local delegation. Steps need to be taken to ensure that the risk of this occurring again is ameliorated.

21. **Haemophilia Centres:** There should be a detailed review of the functioning and effectiveness of, and the development of a strategy for, haemophilia centres. The role of such centres is changing, and a review of what is presently being audited is required. This must ensure that that the auditing systems are adequate and cover, for example, the different needs of older people with haemophilia, current or historic viral infections and younger people without viral infections.

Recommendation 7

22. **Hepatitis treatment:** HCV testing should be promoted to ensure that those who are unaware that they have been infected with HCV (a problem identified during the course of the Inquiry so far) can access treatment quickly. The availability of testing should be widely publicised and made available for all those who request it.

Recommendation 8

23. **Pharma:** The role of the pharmaceutical companies has been, disappointingly, only superficially considered in this Inquiry[4] but it is apparent that they bear significant responsibility for the commercialising of blood and blood products and the sourcing and distribution of infected blood. There must be a review of the regulatory arrangements in place. They must ensure that products are not sourced from people with vulnerabilities (through poverty or otherwise) for commercial gain. This means having in place an effective regulatory system and enforceable standards.

D. Support

[3] At least until the establishment of the Serious Hazards of Transfusion (SHOT).
[4] The Saunders CPs will be writing to the Inquiry separately about this matter.

Recommendation 9

24. **Advocacy support:** An advocacy scheme should be introduced allowing for the provision of advocates for those infected. A theme running through this Inquiry is the extent to which information was denied to those infected and affected at each stage – infection, diagnosis, prognosis, cause of the infections and treatment. In part this has been because of the efforts of a number of bodies to obscure what actually happened.

25. The efforts made by those infected and affected to obtain information and care has been, in many cases, exhausting.

26. An advocacy service would assist those infected in accessing care and information. It would also help ensure that care for infected people with increasingly complex care needs, including as a result of age, is properly coordinated. A national system of advocates should have the role of coordinating the health and social care needs of those infected.

27. This is not a novel idea. There are already a number of specialist statutory independent advocates, such as, independent mental capacity advocates (s.35, Mental Capacity Act 2005), independent mental health advocates (s.130A, Mental Health Act 1983), independent child trafficking advocates (s.48, Modern Slavery Act 2015) and the independent care advocacy service (s.67, Care Act 2014).

28. There would, then, be nothing especially novel about such arrangements. Ireland has introduced an analogous arrangement. The Irish Health Service Executive has appointed a number of hepatitis C liaison officers throughout the country, whose role it is to ensure that persons who have contracted hepatitis C from the administration of blood or blood products receive the services they are eligible for under the terms of the Health (Amendment) Act 1996 (*"Information guide to HSE Primary care and hospital*

services for persons who contracted hepatitis C through the administration within the state of contaminated blood or blood products: arrangements for the provision of services, 2020").[5]

Recommendation 10

29. **Insurance:** An insurance scheme should be introduced, underwritten by the Government. It should provide those infected with an entitlement to purchase (i) life insurance (ii) mortgage protection insurance and (iii) travel insurance, at the same cost as for any other member of the public of the same age.

30. Insurance for those infected with HIV/HCV can be impossible to obtain and where it is secured, endless effort has to be gone through to ensure that exceptions do not apply to the conditions of those who have been infected.

31. Such a scheme could be modelled on the Irish scheme.[6]

E. Apology

Recommendation 11

32. **Apology and vindication:** An apology should be given by the Prime Minister, given the gravity of the wrong, the Secretary of Health for State and the United Kingdom Haemophilia Centre Doctors' Organisations, to those infected and affected. These apologies should include an acknowledgement of the failures of their predecessors.

33. The apologies should identify the wrongs for which the relevant person is apologising, so that it is meaningful. These acknowledged wrongs should include (a)

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[5] Page 5.

[6] *"Information guide to HSE Primary care and hospital services for persons who contracted hepatitis C through the administration within the state of contaminated blood or blood products: arrangements for the provision of services, 2020,"* pp23-24.

the failure of the state to protect those infected from harm (b) the failure to inform people using blood products of the risks of those products (c) the failure to put in place structures that could manage a clear and present viral infection risk (d) the repeated failure to take responsibility for this lack of state protection by denying that it had happened (e) resisting the release of documents, and (f) resisting a meaningful investigation into the events and the evidence.

34. The apologies should also include an acknowledgement of the "vindication" that the infected persons have achieved through this Inquiry; that is, an acknowledgment that in the face of denial and obstruction, the concerns of the Saunders CPs and other CPs repeatedly expressed and rebuffed, were indeed well-founded. They were the victims of gross medical failures and unjustified state denial of the same.

35. The experience of being infected and the events that followed were profoundly destructive and undermining of dignity and autonomy. But the obstruction, denial and cover up that the Saunders CPs and others have experienced has added considerably to their distress. They want the apologies and an acknowledgement that they were right.

F. Follow up

Recommendation 12

36. **Reflection and action:** All health care commissioning, regulatory and ancillary organisations, as well as health service providers, should consider the findings and recommendations in the Inquiry's ultimate report, and decide how to apply them to their own work.

37. **The recommendations:** The Government should commit itself to accepting and implementing the recommendations.

38. **Review and monitoring:** A review and reporting mechanism should be established to review and monitor implementation of the recommendations.

39. This process should be transparent, and a means must be found to hear from the Minister responsible, and those tasked with implementing the recommendations, in a public forum. A report should be published periodically setting out the steps taken to give effect to the recommendations, and their progress.

40. This proposed recommendation reflects, in part, the recommendation made in the *Mid-Staff Inquiry Report*, which revealed many failings similar to those that have emerged in evidence here (including, for example, a lack of candour), as follows:

> All commissioning, service provision regulatory and ancillary organisations in healthcare should consider the findings and recommendations of this report and decide how to apply them to their own work;
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> Each such organisation should announce at the earliest practicable time its decision on the extent to which it accepts the recommendations and what it intends to do to implement those accepted, and thereafter, on a regular basis but not less than once a year, publish in a report information regarding its progress in relation to its planned actions;
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> In addition to taking such steps for itself, the Department of Health should collate information about the decisions and actions generally and publish on a regular basis but not less than once a year the progress reported by other organisations;
>
> The House of Commons Select Committee on Health should be invited to consider incorporating into its reviews of the performance of organisations accountable to Parliament a

review of the decisions and actions they have taken with regard to the recommendations in this report. [7]

41. In the *Mid-Staff Inquiry Report* Sir Robert Francis observed that,

> "The experience of many previous inquiries is that, following the initial courtesy of a welcome and an indication that its recommendations will be accepted or viewed favourably, progress in implementation becomes slow or non-existent. It is respectfully suggested that the subject matter of this Inquiry is too important for it be allowed to suffer a similar fate."[8]

42. The risk of that occurring in relation to the findings and recommendations made at the conclusion of this Inquiry is equally present. The recommendations in the report must make clear and robustly that action is expected and required.

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[7] "Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, Executive Summary", recommendation 1, p.85.

[8] "The Mid Staffordshire NHS Foundation Trust Public Inquiry Chaired by Robert Francis QC: Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, Executive Summary", para 41.