INFECTED BLOOD INQUIRY
INTERIM SUBMISSIONS ON RECOMMENDATIONS
ON BEHALF OF WATKINS & GUNN CORE PARTICIPANTS

Healthcare

1. **The UK and Devolved Governments must establish multi-disciplinary centres of excellence for the treatment of persons infected by blood and blood products.** Such centres should provide access to all medical advice (including consultant hepatology, consultant genitourinary and consultant neurology), treatment, dentistry and specialist social work support that is commonly required by those who have been infected with HIV or Hepatitis, with routine consideration being given to whether any referral should be prioritised. Further, the Department of Work and Pensions should undertake assessments for the purpose of applications for Personal Independence Payments at such centres and provide bespoke training to the assessors who will be carrying out such assessments, drawing upon advice from the practitioners who operate from the specialist centres.

2. **The UK and Devolved Governments should make available specialist mental health services to persons infected by blood and blood products and those affected by such infections, at a Trust or Health Board independent of the Trust or Health Board who treated the infected person when they became infected.**

3. **The UK and Devolved Governments should design and implement a Health Passport for persons infected by blood and blood products** – so that upon presentation a health care employee can see: (i) a statement of that fact that the person was infected by blood or blood products; (ii) the current status of the persons infection (presently infected, cleared, suppressed etc); (iii) the person's illnesses, symptoms and treatment side-effects; (iv) the person's treatment regime; (v) medicines that should not be prescribed; (vi) if applicable, the

severity of the person's haemophilia (or Von Willebrand's Disease) and its complications; and (vii) the necessary destination for ambulatory services (paramedics should be provided with information and training in relation to the health passport). The Health Passport would require regular updating by the treating clinicians and should appear in a prominent way when the person's records are accessed digitally, and should be provided in hard copy to the infected person. The digital passport should work across all of the UK Health Departments (so that a person usually resident in one part of the UK is not disadvantaged if they need to access healthcare provision in another part of the UK) and should appear to emergency call operatives.

4. **The UK Health Departments should adapt the criteria for organ transplants so that: (i) persons infected by blood or blood products are able to receive a liver transplant after the age of 70; (ii) prioritisation criteria which disproportionately affect persons infected by blood and blood products should be identified and disapplied in their cases; and (iii) the fact that a person was infected by blood or blood products should be a criterion which is adopted so that it leads to greater prioritisation** (bearing in mind that liver failure develops more quickly in persons infected with Hepatitis C than other causes and they have been infected for decades).

5. **The Medical Research Council should establish and fund research into the association between Hepatitis C and brain disease, including but not limited to cognitive impairment, trans-ischaemic attacks, strokes and dementia.** As an adjunct to this recommendation, clear guidance should be published by the Royal College of Pathologists on the decision to perform, and the conduct of, an autopsy of the brain for the purposes of such research (with the consent of the next of kin) where a deceased person was informed that they were at risk of vCJD infection, and the necessity to ascertain whether they in fact present a risk, so as to eradicate blanket refusals to carry out post-mortem examinations.

6. **The UK Health Departments should ensure that treatment for HIV is available at a place other than at a GUM clinic for those who were infected through blood and blood products.**

7. **The National Institute for Clinical Excellence should recommend that the children of haemophiliacs who were infected by blood and blood products should be permitted more than one round of IVF and egg selection to remove haemophilia carriers, to relieve anxiety relating to lifelong treatment for their children.**

8. **The UK Health Departments should ensure that persons infected with Hepatitis C through blood or blood products is offered an appointment with a hepatologist and routine fibro scans (every 6-12 months as appropriate).**

9. **The UK Health Departments should conduct a review of the umbrella approach to vCJD at-risk notifications** and consider whether persons infected by blood and blood products should continue to be considered at-risk for public health reasons, especially where it can be proven by taking all reasonable steps that they did not receive an implicated product or transfusion.

<u>Blood Transfusion Practice</u>

10. **The Royal Colleges should introduce a requirement that any healthcare practitioner administering a blood transfusion must check that it is recorded on the patient's record that: (i) they consent to the transfusion; (ii) that the transfusion is compatible with the patient; (iii) that the justification for a transfusion is recorded.**

11. **The UK Health Departments should ensure that Hospital Transfusion Committees: (i) complete annual audits to determine which blood products are being used, in what quantity, and by which departments; (ii) record the number of transfusion reactions, transfusion incompatibility incidents,**

bacterial infections, viral infections, and any other adverse reactions as a result of the provision of blood or blood products (however long after the transfusion they present); (iii) develop a system which encourages the recipients of blood or blood products to report any adverse health effects; and (iv) report to the UK Health Departments at regular intervals.

12. The UK Health Departments should adopt into guidance the findings and recommendations of the Better Blood Transfusion initiative.

Education

13. The Royal Colleges should work collaboratively to design and implement an education programme for all established practitioners to be undertaken as part of continuing professional development and for students of medicine or dentistry to raise awareness of Hepatitis C in relation to: (i) the symptoms of present infection; (ii) the consequences of past infection; (iii) infection through blood and blood products; and (iv) the long incubation period.

14. The Chief Medical Officers of the UK and Devolved Governments should send a letter to all doctors to raise awareness of Hepatitis C in relation to: (i) the symptoms of present infection; (ii) the consequences of past infection; (iii) infection through blood and blood products; and (iv) the long incubation period.

15. The UK and Devolved Governments should design and implement a public health campaign to raise awareness of Hepatitis C in relation to: (i) the symptoms of present infection; (ii) the consequences of past infection; (iii) infection through blood and blood products; and (iv) the long incubation period.

16. The UK and Devolved Government should make available routine screening via general practitioners and pharmacies for those who reasonably believe

they may have been infected with Hepatitis C through blood and blood products, followed by a mandatory referral into the centres of excellence following a positive rest result.

17. **The Royal Colleges should recommend a question relating to the receipt of blood and blood products prior to 1991 on routine health screening by general practitioners.**

Social security

18. **The Secretary of State for Work and Pensions in conjunction with the Secretary of State for Health, the Welsh Ministers, the Scottish Ministers and the Northern Ireland Executive should consult upon, design and implement a decision making tool for disability assessments which involve those infected by blood and blood products and that tool should be made publicly available to infected persons and used by assessors** so that there is a common understanding of the symptoms of infections, the effects of treatment and the criteria applied by assessors. Any targets that are set by the Department of Work and Pensions for private contractors in the procurement of assessments should be disapplied to those infected by blood and blood products.

Duty of Candour

19. **The UK Government should introduce legislation to Parliament to strengthen the duty of candour imposed on NHS bodies[1] and all healthcare practitioners who provide care and treatment to a patient to inform them of significant risks of treatment and positive test results as soon as is reasonably practicable, and creating new statutory offences for breach of the duty –** the duty should apply where a health professional becomes aware or has reason to

[1] Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 20

suspect that a patient has not been informed of significant information about their health.

20. **The UK Government should introduce legislation to Parliament to impose a duty on Government and its advisors not to make misleading statements (unjustified assurances) in press releases or Parliamentary statements in relation to the knowledge of emerging health risks, the severity of risk and the level of risk posed to the population.**

21. **The UK and Devolved Governments should design and implement a comprehensive lookback exercise to identify, so far as is possible, all patients who may have received blood or blood products derived from donations which subsequently tested positive or whose donor subsequently tested positive, and compile a comprehensive database of interrogable data by reference to a patient's NHS number.**

22. **The UK Government should introduce legislation to Parliament, with the consent of the Devolved Legislatures, to: (i) make the destruction of patients' medical records an offence; (ii) to make it a legislative requirement that all notes are recorded on the patient's records; (iii) to allow access to medical records free of charge; (iv) to require each hospital to appoint a medical records manager whose duties involve ensuring the secure and effective storage, retention and retrieval of medical records.**

<u>Conflicts of Interest</u>

23. **The UK Government should introduce legislation to Parliament imposing a requirement on doctors to disclose any potential conflicts of interest (including any transfers of value made by pharmaceutical companies) to a publicly available register of potential conflicts of interest (such as the General Medical Council register).**

24. **The UK Government should introduce legislation to Parliament imposing a requirement on pharmaceutical companies to report payments made to teaching hospitals, research institutions and individual clinicians.**

25. **The UK Government should introduce legislation to Parliament requiring all bodies discharging or assisting in the discharge of the functions of the UK Health Departments to adopt a code of conduct requiring the declaration of potential conflicts of interests by all persons involved in the decision making processes of such bodies or who provide advice to those who are, and requiring such bodies to proactively consider whether any conflicts of interest exist by reference to the register of interests or otherwise.**

26. **The UK and Devolved Governments should jointly establish a register of organisations and advisory committees which include doctors as members or advisors and publish in the register the names of the members, advisors and observers** (which would include bodies such as the UK Haemophilia Centre Directors' Organisation and the Haemophilia Reference Centre Directors' Meetings).

27. **The General Medical Council should introduce a restriction on doctors receiving disproportionate hospitality from the pharmaceutical industry and publish guidance on what amounts to disproportionate hospitality.** Such guidance should, for example, make it clear that travel expenses and hotel accommodation for medical conferences must be paid for by the clinician or their employer and they must not be reimbursed by commercial enterprises or otherwise receive benefits in kind, save where the clinician is invited to give a presentation in which case they are allowed to recover reasonable expenses from the organiser of the event or conference.

Financial Schemes

28. **Any new financial schemes which may be established in response to the Inquiry must be administered by the UK Government**, because: (i) they are not devolved matters; and (ii) to avoid unjustifiable differences in treatment of those infected and affected by the UK and Devolved Governments.

29. **Persons infected with Hepatitis B through blood and blood products should be included in any new financial schemes** as infections continued to occur after the introduction of routine screening in 1972, particularly as HBc testing was not introduced across the UK.

<u>Regulation of medicines and medicinal products</u>

30. **The UK and Devolved Governments should establish a body with the function of monitoring the use of unlicenced medicines and medicinal products,** to whom doctors must report when they prescribe unlicensed medicines and medicinal products and inform them of any adverse health reactions that may be associated with the unlicensed medicine or medicinal product. Such a body should monitor trends in the prescription of unlicenced medicines and medicinal products and look for unjustified prescribing and trends in adverse reactions.

31. **The General Medical Council should make it a requirement that where a doctor prescribes an unlicenced medicine or medicinal product, the patient is informed of the fact that the medicine or medicinal product is unlicenced, why its use is justified in that particular case, what all of the significant potential risks are, and that the conversation is recorded and signed by the patient.**

32. **The Medicines and Healthcare products Regulatory Agency ('MHRA') should review its enforcement of licence conditions so as to ensure it has effective systems in place to monitor that warnings relating to adverse health reactions are given to patients for a licenced product.**

33. **The UK Government should introduce legislation to Parliament mandating the reporting of adverse health reactions to licenced medicines and medicinal products to the MHRA, and establishing a register of adverse reactions which can be interrogated by the MHRA and others to identify emerging trends.** The Patient Safety Commissioner should investigate any complaints of a failure by a doctor to report an adverse health event.

34. **The online portal for patients to use the yellow card system should be made more user friendly, more easily understood and used by the patient.**

Emerging health risks

35. **The UK Health Departments should establish systems for the monitoring, collecting, assimilation and distribution of worldwide published scientific papers to ensure that medical officers, health officials and (where appropriate) clinicians are made aware of developing knowledge of emerging risks.**

36. **The UK Health Departments should establish guidance for their medical officers and health officials on their roles and responsibilities in respect of the monitoring, collection, assimilation and distribution of published scientific papers on emerging health risks to ensure that information about health risks is received by the appropriate person and all necessary decisions based on the evidence are taken as soon as is reasonably practicable.**

37. **Such guidance should also set out when epidemiological advice should be sought in response to information about an emerging health risk.** *On this point, we submit that the Inquiry should call evidence about the response of the UK and Devolved Governments to the current outbreak of hepatitis in children to assess how the current systems operate.*

38. **UK and Devolved Government medical officers should normally apply the precautionary principle to emerging health risks**. This means identifying and implementing all reasonable steps to mitigate the risk of infection in at-risk groups when an association, rather than a causal link, is established by the science. The more serious the consequences of infection, the more action is likely to be reasonable.

Redress

39. **The UK Government should accept all the findings made by the Inquiry and apologise for any failures or wrongdoing.**

40. **The General Medical Council should investigate any fitness to practice concerns arising from the evidence received by the Inquiry.**

41. **The Charity Commission should investigate any failures or wrongdoing by the trustees and/or employees of the Alliance House Trusts.**

42. **The UK Government should introduce legislation to Parliament, with the consent of the Devolved Legislatures, establishing a Commissioner for Persons Infected and Affected by Blood and Blood Products, assisted by an advisory panel of infected and affected persons** (as was done in Northern Ireland with the Commissioner for Survivors of Institutional Childhood Abuse (COSICA)). The Commissioner should have the duty to encourage and monitor the provision and co-ordination of relevant services in the UK and provide information on how to access services and support, including services to improve physical or mental health and provide counselling. The Commissioner should be furnished with a number of statutory powers to:
    a. Undertake or commission research into matters concerning the interests of infected and affected persons;
    b. Compile information concerning the interests of infected and affected persons;

c. Provide advice or information on matters concerning the interests of infected and affected persons;
d. Publish anything concerning the interests of infected and affected persons;
e. Make representations or recommendations to any person concerning the interests of infected and affected persons.

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