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Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board



Meeting Date	4th October 2018		Agenda Item	6b
Report Title	Infected Blood Inquiry			
Report Author & Sponsor	Christine Morrell, Director of Therapies and Health Sciences			
Presented by	Christine Morrell, Director of Therapies and Health Science			
Freedom of Information	Open			
Purpose of the Report	<p>The purpose of this report is to update the Quality and Safety Committee in regard to the UK Infected Blood Inquiry and to highlight:</p> <ul style="list-style-type: none"> • A number of immediate actions that have been undertaken • Potential risks. 			
Key Issues	<p>An UK wide Independent Public Statutory Inquiry into the use of Infected Blood has been established. This has implications for all NHS organisations. The Health Board has received two letters in relation to this inquiry and has put a number of actions in place to respond to this.</p>			
Specific Action Required <i>(please ✓ one only)</i>	Information	Discussion	Assurance	Approval
			✓	
Recommendations	<p>Members are asked to:</p> <p>Endorse approach</p>			

INFECTED BLOOD INQUIRY

1. INTRODUCTION

The purpose of this report is to update the Quality and Safety Committee in regard to the UK Infected Blood Inquiry and to highlight:

- A number of immediate actions that have been undertaken
- Potential risks.

2. BACKGROUND

2.1. Background

An Independent Public Statutory Inquiry into the use of Infected Blood has been established. The Inquiry is UK wide and will examine the circumstances in which men, women and children treated by the NHS were given blood infected with Hepatitis C and/or infected blood products, in particular since 1970. The Inquiry will look at how the authorities (including government) responded; the nature of any support provided following infection; the process of obtaining informed consent; and whether there was a 'cover up'.

The Inquiry is now formally established and investigative work has begun. The Terms of Reference are available on the Inquiry website:

<https://www.infectedbloodinquiry.org.uk/>

Welsh Government have recently issued correspondence to organisations in NHS Wales from the Inquiry team stating their expectation that we should all engage and co-operate with the inquiry and have requested formal confirmation that organisations would retain and not destroy any records considered pertinent to the inquiry (**Appendix 1**).

The Inquiry has additionally now written directly to Chief Executives specifically in regard to patients (men, women and children) with haemophilia or other bleeding disorders who have been treated through Haemophilia Centres, including Swansea Haemophilia Centre, as these are likely to be participants as witnesses to the inquiry (**Appendix 2**).

The terms of reference of the inquiry are broad and cover a long period of time. It is expected that the inquiry will last for many years. The type of documents that are required include, but are not limited to the following:

Correspondence, notes, instructions, advice, reports, briefings, policies, guidance, reviews, minutes of meetings however held (paper, electronic, microfiche, audio, video, and any other means) particularly from the 1970s and 1980s but not limited to these periods, either before or after regarding the following:

- a. The treatment of men, women or children with haemophilia or other bleeding disorders who were given infected blood products;
- b. The risks of infection associated with blood products;
- c. The extent to which people given infected blood products were warned (or not warned) beforehand of the risk that they may be exposed to infection;
- d. The systems adopted for the screening of donors and the collection, testing and licensing and supply of blood products;
- e. The testing of those who were infected with infected blood products and how their infection status was recorded;
- f. How the results of tests or information about their infection was communicated to those infected or affected;
- g. The level of information that should be provided to those infected, when this should be provided and how;
- h. The extent to which financial considerations affected decision making when treating people with haemophilia and bleeding disorders;
- i. The treatment, care and support provided to those infected and their families and
- j. The destruction of documents related to any of the above.

Health organisations have been reminded that they must take steps to not destroy any documents which may be relevant to the inquiry whilst it is ongoing, and there is an expectation that additional information will be requested in a phased approach.

2.2 Actions on behalf of NHS Wales

The Welsh Blood Service applied for 'Core Participant' status and this has been granted on the basis that it is considered that the organisation has a significant interest in the areas outlined in the Terms of Reference. Welsh Blood has undertaken to:

- Update NHS Wales on the role of the Welsh Blood Service in the inquiry and have held discussions with Blood Transfusion organisations across the UK who will also be called to the Inquiry.
- Explore how NHS Wales can work collaboratively in response to the inquiry with a view to ensuring we are able to fully contribute and reducing the burden on individual organisations.
- Worked with NHS Shared Services to obtain legal representation and to appoint a Queens Counsel (Q.C.) to represent NHS Wales organisations and to consider management of a central coordinating function. There will be associated legal and travel costs.
- It is planned that there will be coordination and advice in regard to Freedom of Information requests, communications etc via a single office,

potentially within NHS Shared Services to enable a single point of contact with Health Boards.

There will be due regard given to ensure that advice given is clear and doesn't undermine current confidence in blood supply.

There have been claims and Freedom of Information requests by patients within the last 12-15 months, as the archives are not easily searchable, or have been destroyed due to legitimate destruction policies it has been impossible to provide information in most cases. In addition some patients across NHS Wales may be holding their own notes as some have previously requested them.

As staff who are retired may be called to inquiry there may be a requirement to support them.

2.3 Implications for the Health Board

2.3.1 Swansea Haemophilia Centre

Patients with haemophilia and other coagulopathies will have received blood components and fractionated products which would have come from multiple donors and thus there was an increased risk of becoming infected for this group of patients. There is a patient database identifying these patients.

Dr Saad Al-Ismael Consultant Haematologist was the haemophilia lead in Swansea for the past 30 years, until his retirement in February this year. He has agreed to return under an honorary contract to support this work and commenced on 10th September 2018.

Advice has been sought from the Cardiff Haemophilia Centre of the list of evidence and searches they have carried out. Cardiff is the lead centre in Wales and patients may move across these services. Abertawe Bro Morgannwg University Health Board (ABMU HB) will now begin assessing and collating available evidence in a consistent way, from the Swansea Haemophilia centre from 1970 onwards (services are not doing this for blood products at this time). This includes

- Developing a timeline of governance and accountability of the service
- Reports detailing how haemophilia and hepatitis services have been delivered since the 1970s
- Any records in relation to research and development
- History and logs of activity including research and development
- Any correspondence produced by the department
- Folders of legal claims and settlement managed by the department
- Search for any policy and procedures in place at the time and now
- Board meetings and medical director reports

- Archive search for any information including corporate information.
- Management reports, correspondence (particularly around blood transfusions hepatitis and HIV)
- Searched emails of all current staff for the terms, haemophilia, hepatitis, blood products and HIV
- Inpatient records but these have been set aside as the inquiry do not want patient records at the time (but records must not be destroyed)
- Information in relation to testing of bloods and the procedures in place
- Any testing of families
- Identification of current and former staff
- Linked with community paediatric service and Gastro if they hold relevant information
- Any patient information procedure by the haemophilia service
- Any policy and procedures
- Any recording of risk

This information should be supplied to the inquiry by 12th September and it is unlikely we will have all of this information within that timescale, although we will have an assessment of the service and a response with a timeline for us to obtain the documents. Dr Ishmael has advised that no patients were recruited to trials in Swansea in the 70's and 80's. They were all recruited by Cardiff.

2.3.2 Acute Health Records

As a consequence of the Inquiry, Health Boards received notification from Welsh Government to suspend immediately the destruction of all corporate and patient records. This places the Acute Health Records service in a very difficult logistical position, as currently around 6000 records per month are validated or destroyed. This process is essential for the smooth running of the department and ensuring that the libraries can remain open. Without this process the libraries become overcrowded, unsafe and can no longer function.

At the beginning of September an exercise commenced to try and identify patients in order to prioritise records that may be required by the inquiry, as no definitive list of patients was available at that time. The Health Records Service worked with Informatics colleagues to produce a list of 19,000 ABMU patients who have been identified as receiving a blood transfusion, based on coded procedures information on the Patient Administration System and data warehouse. This list will also need to be shared with Departments/Services that manage records that create and hold information/records separately from the acute record.

It is important to note that as the inquiry relates to activities in the 1970s and 80s many records have already legally been destroyed. Currently from the checks already completed on the 19,000 records, the records of 4000 patients of the list have already been legally destroyed, these may or may not form part of the inquiry. Earlier this year the Health Board received two subject access requests for information from family member involved in the infected blood cases, and on both

occasion the main Health Record had been legally destroyed and only very limited information from the Pathology system could be provided.

In order to further identify the patient a more detailed investigation is ongoing that will access the Haemophilia database to develop a more specific list of patient and these records will be set aside as a priority.

The current process that is being adhered to is that all records will be retained indefinitely. In addition to this all destruction has ceased with no known end date. All areas that manage their own records should also immediately cease destruction.

The impact of retaining these records and any other records identified through this process on an indefinite basis will have a significant impact on the ongoing storage requirements for the records that are identified. This will also have a significant impact on the delivery of the RFID Project due to the fact that the Service cannot destroy the number of records previously identified and this will have a detrimental impact on the space required to implement the RFID project.

It is imperative that additional storage space is identified to support the department to ensure the service can still operate day to day as once the libraries reach full capacity then they will need to close, this means that the service will not be able to provide records for patient care, resulting in cancellations. There would also be a detrimental impact on the implementation of RFID. Options for additional storage are currently being explored, with a possible immediate solution available in Unit 32 at Baglan Industrial estate.

3 GOVERNANCE AND RISK ISSUES

It is possible that we will not be able to provide all the information required by the inquiry on the date requested due to the time scale and the reorganisations of the Health Board.

There are reputational risks for UK NHS organisations

4 FINANCIAL IMPLICATIONS

There will be financial implications both for NHS Wales and ABMUHB as there:

- Will need to be a central coordinating function for NHS Wales and legal and risk input in excess of the standard provision. Based on previous inquiries it is expected that this input will be needed for many years. There is no indication of how this cost will be met.
- Is a resource requirement to enable the Health Board to identify documents for the inquiry

- Additional storage will be required in order to retain records which may be needed for the inquiry.

5 RECOMMENDATION

Members are asked to note this report and approve actions to ensure that the Health Board are able to properly address the requirements for this Inquiry. These include resourcing to carry out a full comprehensive research of archives to provide documents to the inquiry, and to approve additional storage for records which will need to be retained.

Governance and Assurance							
Link to corporate objectives (please ✓)	Promoting and enabling healthier communities		Delivering excellent patient outcomes, experience and access	Demonstrating value and sustainability	Securing a fully engaged skilled workforce	Embedding effective governance and partnerships	
						✓	
Link to Health and Care Standards (please ✓)	Staying Healthy	Safe Care	Effective Care	Dignified Care	Timely Care	Individual Care	Staff and Resources
		✓					
Quality, Safety and Patient Experience							
The Inquiry relates to patient care and treatment in the 1970s and 1980s.							
Financial Implications							
The inquiry will lead to some unbudgeted financial pressures related to resource to carry out the information gathering and assessment, additional storage and possible legal costs. The costs will begin from August 2018 and will be recurrent until the inquiry concludes.							
Legal Implications (including equality and diversity assessment)							
The Inquiry is being carried out							
Staffing Implications							
Long Term Implications (including the impact of the Well-being of Future Generations (Wales) Act 2015)							
Briefly identify how the paper will have an impact of the “The Well-being of Future Generations (Wales) Act 2015, 5 ways of working.							
Report History							
Appendices		Appendix 1: Letter to Andrew Goodall re Infected Blood Inquiry Appendix 2: Letter to Tracy Myhill in regard to Swansea Haemophilia Centre					