NHS
Blood and Transplant

Board Meeting in Public

Thursday, 06 June 2024

Title of Paper	IBI Update - Peoples Experiences and Treloar	**Agenda No.**	3.2
Nature of Paper (tick one)	☒ Official	☐ Official Sensitive	
Author(s)	Denise Thiruchelvam, Chief Nursing Officer		
Lead Executive	Denise Thiruchelvam, Chief Nursing Officer		
Non-Executive Director Sponsor	(Insert name, if there is a NED Sponsor)		
Presented for (tick all that applies)	☐ Approval ☒ Assurance	☒ Information* ☐ Update	** See Note i*

Executive Summary (max 300 word count)

- The Infected Blood Inquiry (IBI) was published on Monday 20th May 2024.
- Volume two is dedicated to Peoples Experience and Treloar's and this report reflects the contents of this volume
- The board will be shown videos from the affected and infected which was shown on 20th May[1] reflecting peoples experience titled '2018', 'testimonials' and '2024'
- The Board is asked to read the IBI Inquiry report and reflect on volume 2 and recommendations.

Previously Considered by

Infected Blood Inquiry discussed at Executive Team meerting, 28th May 2024

Recommendation	The Board is asked to read the IBI report in full and reflect on the experience of those affected and infected. Support the extablishment of the Infected Blood Inquiry Impleemation Group which will oversee the report reccomendations and receive updates on a regular basis

Risk(s) identified (Link to Board Assurance Framework Risks)

All of the BAF

Strategic Objective(s) this paper relates to: [Click on all that apply]

☒ Collaborate with partners ☒ Invest in people and culture ☒ Drive innovation

☒ Modernise our operations ☒ Grow and diversify our donor base

Appendices:	https://www.infectedbloodinquiry.org.uk/reports/inquiry-report

[1] https://www.infectedbloodinquiry.org.uk/publication-day

People's Experiences and Treloar

Introduction

Patients received blood or blood products from the NHS since it began in 1948. Many of those treated with them, particularly between 1970 and 1998, died or suffered miserably, and many continue to suffer. This was not as a direct result of the underlying condition or illness that took them to the NHS in the first place, but as a result of the treatment itself.

This would be catastrophic enough if they were the only victims. But the treatment has caused others to suffer too – partners, family, children, friends – some by being themselves infected, some by having to watch loved ones die, some by having to give their lives to caring; and almost every one of them, infected and affected, suffering in almost every aspect of their lives.

Sir Langstaff reported a catalogue of failures which caused this to happen. Each on its own is serious. Taken together they are a calamity. Lord Winston called these events "the worst treatment disaster in the history of the NHS".

Sir Langstaff reported that it could largely, though not entirely, have been avoided. He reported systemic, collective and individual failures to deal ethically, appropriately, and quickly, with the risk of infections being transmitted in blood, with the infections when the risk materialised, and with the consequences for thousands of families.

Epidemiology

There were around 4,000 to 6,000 people with bleeding disorders in the UK at any one time. Around 1,250 were infected with HIV. It is estimated that this included 380 children. Almost all those infected with HIV were also infected with Hepatitis C and some with Hepatitis B and Hepatitis D as well. Three quarters of these 1,250 adults and children have died.

A larger number still (between 2,400 and 5,000 people with bleeding disorders) who were not infected by HIV received blood products infected with one or more hepatitis viruses, and developed chronic Hepatitis C.

People who were infected by transfusions, rather than by blood products, were infected in even greater numbers. Between 80 and 100 were infected with HIV after a blood transfusion.

Approximately 26,800 were infected with Hepatitis C after a blood transfusion, often linked with childbirth or surgery, but also from transfusions to treat thalassemia, sickle disease, or leukaemia, or tissue transfer. It has not been possible to estimate the number of people infected with chronic Hepatitis B due to limited data.

People's Experiences and Treloar

The Inquiry team recognised, that it is not possible to capture the full scale of the profound tragedy that has been caused by this disaster. Nor is it possible to convey the resilience of each person who has been Infected and Affected by infected blood.

Volume 2[2] of the inquiry titled 'People's Experiences and Treloar's' highlights only some of the pieces of a complex jigsaw puzzle, every individual story has made a valuable contribution to the

[2] https://www.infectedbloodinquiry.org.uk/sites/default/files/Volume_2.pdf

findings, conclusions and recommendations of this Report[3]. The following is an extract from the report:

> *"Hopefully, the public will get a glimpse of what we have had to suffer for decades. For that's all it will be, a glimpse. The public will never see the true pain and anguish that we and our loved ones have had to suffer." Pete Burney[4].*

Some disasters are seared into the national memory, when they happen on one day or in one place. But there has been no particular day, no one-off event, that our nation will for decades associate with the deaths of men, women and children as a result of infected blood and blood products. It is too rarely acknowledged that suffering continues to this day. This disaster happened – and continues to happen – in every part of England, Northern Ireland, Wales and Scotland, and often has had to happen largely behind closed doors as people and their families lived and live with the consequences of the treatment they received, not able to realise the lives they hoped to live. The weight of unfulfilled hopes and imagined lives, or opportunities in life made unattainable, is almost unbearable.

For so many people, the blood – or the blood products they received – that was meant to help them, or their loved ones destroyed much of what life should be. What followed was life-changing, in many cases soul-destroying. It had all-encompassing effects on their day to day life: on marriages, family life, work, finances and homes. It has damaged relationships. Many have died and continue to die[5]. Children faced the loss of parents and parents faced the loss of children. The failure of government to take responsibility for what has happened has compounded the psychological burden.

The Inquiry received over four thousand statements from people infected and affected. Each of them has been read carefully. Some who gave those statements are known to the Inquiry, but have decided to remain anonymous to the public.

Many felt a need to protect their identity and way of life since their experience is that stigma remains all too real. There are those who want their voices to be heard, but after decades of being unable to speak out, do not wish even to make a statement protected by anonymity.
To help them give their accounts, the Inquiry appointed three experienced social workers as "intermediaries" to meet them for a confidential conversation, and report on their collective experiences. These accounts have echoed the evidence given anonymously, which itself has echoed the named witness statements received.

The stories shared so powerfully in each statement and in the two intermediaries' reports were amplified, illustrated and confirmed by the oral evidence, often assisted by the presence of partners, family members, or friends sitting alongside; or as part of a panel of people with certain experiences in common.

For a large number it was the first time they had spoken in public about their ordeal. It takes real courage to break silence after so many years, and Sir Langston paid a personal tribute to all those who were prepared to do so – in a written statement; in private to an intermediary; in the hearing room; or by video link. From so many different perspectives and backgrounds they have painted such a compelling overall picture that, taken together, some conclusions have become overwhelmingly obvious.

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[3] https://www.infectedbloodinquiry.org.uk/reports/inquiry-report

[4] Pete Burney Transcript 26 September 2018 p53 INQY0000000_004. Pete died in December 2019.

[5] The Inquiry has endeavoured to recognise where people infected have died after giving a written statement quoted in this Report.

The Board will be shown video clips from videos from the Affected and Infected which was shown on 20th May[6] reflecting peoples experience titled '2018', 'testimonials' and '2024'

Conclusions

As part of NHS Blood and Transplant evidence to the Inquiry, we apologised unreservedly for any respect in which the blood services of the past, or the blood they supplied, was the cause of suffering to any person.

We are sorry for the delay in introducing hepatitis C screening and the delay to beginning the hepatitis C virus look back to find people who had been infected. We are sorry for not introducing better donor screening for HIV and that blood services continued to collect blood from prisoners until 1984.

Things are very different today, NHS Blood and Transplant put patient and donor safety at the heart of everything we do. Across all our services, modern safety standards are rigorous and have improved enormously - the UK now has one of the safest blood services in the world.

Sir Langstaff reported significant improvements have been made in hemovigilance and blood safety.

We are all here to save and improve lives and proud of the organisation we are today. But we are not complacent and there are many things we will learn from this report.

We will never stop learning and improving.

Recommendations

The Inquiry has been incredibly important to help us all learn from the past and continue learning.

The blood service has changed enormously since then and we will carefully consider the recommendations in this report.

We have set up an implementation group to consider the recommendations and deliver any changes we need to make. This will be led by Chief Nursing Officer, Dee Thiruchelvam, and bring together people from across our organisation to ensure we learn from this report and these events.

Dee Thiruchelvam
Chief Nursing Officer

6th June 2024

[6] https://www.infectedbloodinquiry.org.uk/publication-day