

# Government Response to the Infected Blood Inquiry



# Government Response to the Infected Blood Inquiry

Presented to Parliament

by the Minister for the Cabinet Office

by Command of His Majesty

May 2025



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# Ministerial Foreword

Since the publication of the Infected Blood Inquiry's report in May 2024, the UK and devolved governments, have been considering the recommendations made by the Inquiry, and working to understand what progress can be made to ensure that a scandal of this magnitude cannot occur again.

We would all like to reiterate our wholehearted and unequivocal apology on behalf of current and previous governments to every single person impacted by this scandal. We are clear that nothing of this nature can ever happen again, but for this to be anything more than words, tangible action must be taken. The UK Government has committed £11.8bn in the Budget, delivered on 30 October 2024, to deliver the Infected Blood Compensation Scheme. Sir Brian Langstaff's 12 recommendations offer a clear route for further action and we will set out the progress that the UK's four administrations have made in responding to these recommendations.

The UK and the devolved governments have accepted the Inquiry's recommendations in full or accept them in principle, in accordance with the latest evidence-based care and clinical guidelines. Implementation is underway in Central Government Departments, ALBs and healthcare settings. Where recommendations are accepted in principle, we have sought to explain the rationale for doing so; balancing agreement of the spirit of the recommendations with the need to avoid unintended consequences. Some will be subject to future DHSC spending decisions.

Today our blood supply is one of the safest in the world and the UK's blood services working together are self-sufficient when it comes to the supply of safe blood and blood components. The NHS is subject to greater oversight and regulation, with a modern focus on patient safety, evidenced-based medicine and use of data, and a constitution that sets out the rights of all of us to access care and treatment, free of charge.

What is indisputable however is that a lot more still needs to be done. Making the necessary changes is not an easy task, nor is it something that can be done in isolation. This is particularly important when seeking to implement a systemic and cultural change. We are clear that the implementation of the recommendations made by the Inquiry must continue to be driven forward. As progress continues to be made, the relevant government leads will report on the recommendations for which they are responsible. We are committed to transparency and accountability, and will be publishing the Government's progress via a publicly accessible dashboard in due course, which will be regularly updated as progress is made.

We are determined to learn from and avoid repeating the errors of the past, and move away from the culture of defensiveness that allowed this scandal to proliferate. We are committed to building a culture of candour and honesty, so that the people of

the UK can place their utmost confidence in the institutions and the people that serve them, delivering real and lasting change.

HM Paymaster General & Minister for the Cabinet Office, the Rt Hon. Nick Thomas-Symonds MP

Parliamentary Under-Secretary of State for Public Health and Prevention, Ashley Dalton MP

Minister for Public Health and Women's Health, Jenni Minto MSP, Scottish Government

Cabinet Secretary for Health and Social Care, Jeremy Miles MS, Welsh Government

Minister of Health, Mike Nesbitt MLA, Northern Ireland Executive

# Introduction & Background

The Infected Blood Inquiry, led by Sir Brian Langstaff, placed individuals at the heart of its work, engaging closely with those infected and affected by contaminated blood and blood products on the NHS across the UK. It sought to understand not only what was done, but also what should have been done, scrutinising the roles of all the decision makers, including within the government, the NHS and pharmaceutical companies. Over a seven-year period, the Inquiry:

- Reviewed the circumstances in which men, women and children treated by National Health Services in the United Kingdom were given infected blood and infected blood products, in particular, between 1970 and 1998;
- Ascertained (as far as practicable) the likely number of people who have been infected (directly or indirectly);
- Examined whether in addition to the viruses which it is known that people were infected, people may have been exposed to the risk of other diseases;
- Considered the impact of infection from blood or blood products on people who were infected and affected;
- Examined the response of Government and other relevant bodies;
- Examined whether and to what extent people were treated or tested or their infection status was recorded without knowledge or consent;
- Examined the nature and adequacy of information provided to people who were infected and affected;
- Considered the nature and adequacy of treatment, care and support provided to people who infected and affected;
- Examined whether there had been attempts to conceal details of what happened and whether there had been a lack of openness or candour in the response of Government and other bodies;
- Identified any individual responsibility as well as organisational and systematic failures; and
- Made interim and final recommendations to the UK Government.

The UK's four administrations have worked together across these issues on a UK-wide basis, the recommendations cannot be looked at in isolation. Together, we have worked to identify differences in current practice, and how to take forward the Inquiry's recommendations to ensure as consistent a response as possible.

The UK Healthcare family, including the Department for Health and Social Care (DHSC), NHS England, NHS Blood and Transplant (NHSBT), UK Health Security Agency, and others have worked together to review the report's clinically facing findings and recommendations. Since May 2024, these public bodies have worked to

establish which recommendations can be implemented, to what extent and how quickly.

The Scottish Government has established an Oversight and Assurance Group involving patient representatives, Health Boards and other NHS bodies to consider and agree how best to make progress on the recommendations for Scotland. This group is working with a range of organisations, both in Scotland and elsewhere in the UK, to take forward the Inquiry's recommendations.

The Welsh Government has set up a Recommendations Oversight Group, chaired by their Deputy Chief Medical Officer for Health Services, to consider how best to take forward the recommendations as they relate to Wales and the wider UK. Membership includes representatives from Welsh Health Boards, Welsh Blood Service, Public Health Wales, the Joint Commissioning Committee and Haemophilia Wales.

In Northern Ireland, the Department of Health has established an Infected Blood Inquiry (IBI) Implementation Team to support the central coordination of the implementation of the Final IBI Report recommendations, reporting to an Inquiries Implementation Programme Management Board, chaired by the Department's Permanent Secretary.

An IBI Regional Group has also been established to support this work programme, bringing together policy and clinical leaders from the Department of Health and the wider Health and Social Care sector, including HSC Trusts, the Northern Ireland Blood Transfusion Service (NIBTS) and the Northern Ireland Transfusion Committee (NITC).

## The Infected Blood Inquiry First Interim Report

The First Interim report of the Infected Blood Inquiry focused on the need for interim payments. Sir Brian Langstaff recommended that an interim payment, of no less than £100,000 should be paid to all those infected and all bereaved partners currently registered on UK infected blood support schemes, as well as those registering ahead of the inception of a future scheme.

On 17 August 2022, the previous UK Government announced that an interim compensation payment of £100,000 would be paid to alleviate the immediate suffering of infected beneficiaries and bereaved partner beneficiaries of the four UK Infected Blood Support Schemes, pending the UK Government's response to any further recommendations by the Infected Blood Inquiry in its May 2024 report. Payments began in October 2022, with approximately £440 million paid through these interim payments by the end of the financial year 2022/23.

These payments met, in full, the recommendations made in the First Interim report.

## The Infected Blood Inquiry Second Interim Report

The Second Interim report of the Infected Blood Inquiry concerned the framework for compensation. It was published on 5 April 2023 and contained 18 recommendations. The Government published a summary of the proposed Infected Blood Compensation Scheme in August 2024. For completeness, the UK Government's position on compensation is set out in this update, using the Second Interim Report as a framework for comparison.

It is important to underline that the Government's final position on compensation is informed not just by the Second Interim Report, but also the positions reached within Parliamentary debates through the passage of the Victims and Prisoners Act 2024, as well as the findings of the engagement exercise with representatives of the infected blood community led by the Interim Chair of the Infected Blood Compensation Authority, Sir Robert Francis, following announcements on compensation in May 2024. The Government's response has also been informed by the work of the Government's Expert Group made of clinicians, legal and social care experts, who have provided technical advice across the range of recommendations made by Sir Robert Francis.

As a result, there are elements of the Scheme that go beyond or deviate from Sir Brian's recommendations. Where this is the case, we have highlighted the change and set out the rationale within our response.

## The Infected Blood Inquiry May 2024 Report

On 20 May 2024, the Infected Blood Inquiry published its 'May 2024' report. The Prime Minister, the Rt Hon Keir Starmer MP, spoke in the House of Commons in response to the publication of the May 2024 report, apologising for the collective failure of the state to protect the victims of the infected blood scandal. The Prime Minister said that "we must restore the sense that this is a country that can rectify injustice", and the Government has worked to ensure that the response to the report's recommendations are made in that spirit.

The report contained 12 recommendations, the first of which repeats the recommendations made on compensation in the Second Interim Report. The 12 recommendations are detailed below with an update on the Government's response.

# Summary of the Government's response to the May 2024 Inquiry report's recommendations

Overall, we have responded to 12 recommendations made by Sir Brian Langstaff in his May 2024 report, and the 18 recommendations made by the Inquiry in the Second Interim Report, based on Sir Robert Francis' Compensation Study.

Where recommendations are **accepted in principle** the Government recognises the rationale for actions and wants to deliver change. However, further work is required to fully understand the implications of implementing complex recommendations, the long- term costs involved, and to better understand where existing programmes of work can achieve the recommended outcome, rather than the specific approach set out by the Inquiry. The recommendations that we are accepting in principle are complex and far reaching and rushing their delivery may lead to unintended adverse consequences that the Government wishes to avoid.

This response has been agreed by all of the UK's administrations and where the recommendations are not UK wide (but rather for devolved governments to address individually) we have set out the progress of each government's response.

Approach taken	Recommendation
	Recommendation 1
	Recommendation 2
	Recommendation 3
	Recommendation 4a) i)
	Recommendation 4a) ii)
	Recommendation 4a) iii)
Accepting in full	Recommendation 4c) i) (accepted in principle by Scottish Government and NI Executive)
	Recommendation 4c) ii) (accepted in principle by Scottish Government and NI Executive)
	Recommendation 4e)
	Recommendation 6a) i) (accepted in principle by NI Executive)

Approach taken	Recommendation
	Recommendation 6a) iii) (accepted in principle by NI Executive)
	Recommendation 6a) iv) (accepted in principle by NI Executive)
	Recommendation 6a) vi) (accepted in principle by NI Executive)
	Recommendation 7a) ii) (accepted in principle by NI Executive)
	Recommendation 7a) iii)
	Recommendation 8 (accepted in principle by NI Executive)
	Recommendation 9a) (accepted in principle by NI Executive)
	Recommendation 10a) ii) (accepted in principle by Welsh Government and NI Executive)
	Recommendation 10a) iii) (accepted in principle by Welsh Government, Scottish Government and NI Executive)
	Recommendation 10a) v)
	Recommendation 12a)
	Recommendation 12b)
	Recommendation 12c)
	Recommendation 4a) iv)
	Recommendation 4a) v)
	Recommendation 4b)
	Recommendation 4d) (accepted in full by Scottish Government)
	Recommendation 5
Accepting in principle	Recommendation 6a) ii)
	Recommendation 6a) v)
	Recommendation 7a) i)
	Recommendation 7b) (accepted in full by Scottish Government)
	Recommendation 7c)

Approach taken	Recommendation
	Recommendation 7d)
	Recommendation 7e)
	Recommendation 7f) i) (accepted in full by Scottish Government)
	Recommendation 7f) ii) (accepted in full by Scottish Government)
	Recommendation 7f) iii)
	Recommendation 9b) (accepted in full by Scottish Government and the Welsh Government)
	Recommendation 9c) (accepted in full by Scottish Government and the Welsh Government)
	Recommendation 9d) (accepted in full by Scottish Government)
	Recommendation 9e) (accepted in full by Scottish Government)
	Recommendation 9f) (accepted in full by Scottish Government)
	Recommendation 10a) i) (accepted in full by Welsh Government and Scottish Government)
	Recommendation 10a) iv)
	Recommendation 11
	Recommendation 12d)
	Recommendation 12e)
Not accepting	None

# Update on the Government's responses to the 12 recommendations

# 1) Compensation Scheme

1. The compensation scheme should be set up now

This recommendation is accepted in full.

The Inquiry was unequivocal that those who have suffered as a result of this scandal must be compensated for the harm that has been inflicted upon them. The UK Government accepts this recommendation in full. We are grateful for the extensive work of both the Inquiry and Sir Robert Francis in publishing his Infected Blood Compensation Framework Study. The recommendations made in the Inquiry's Second Interim Report have been integral in designing the Infected Blood Compensation Scheme.

The Victims and Prisoners Act, which became law in May 2024, provided the legal basis for the establishment of the Infected Blood Compensation Authority (IBCA). The IBCA is an arms-length body, operationally independent from government, which has been set up to deliver compensation. The Act also obliged the Government to establish a compensation scheme within three months of the passing of the Act.

The previous Government announced its proposals for the Infected Blood Compensation Scheme ('the Scheme') on 21 May 2024. In June 2024, Sir Robert Francis - Interim Chair of the IBCA - undertook an engagement exercise with the infected blood community to seek their views on the Government proposal. On 16 August, the Government announced improvements to the Scheme, published alongside Sir Robert Francis' report and a final report from the Infected Blood Inquiry Response Expert Group. On 23 August, the Government published an explainer document setting out the detail of the scheme.

The Scheme has been established in regulations made in two parts - the first part (to establish the Scheme for people who are infected and claiming compensation under the core route) came into force on 24 August 2024. These regulations were debated and approved in both Houses of Parliament in October 2024. Further regulations to extend the Scheme for the affected cohort and to establish supplementary compensation routes beyond the core route came into force on 31 March 2025.

IBCA have begun making payments under the Infected Blood Compensation Scheme and are developing their service to provide compensation to everyone who is eligible as soon as possible.

Since the publication of the Government Response in December 2024, Parliament has approved the Infected Blood Compensation Scheme Regulations 2025. These ensure that IBCA establishes the Scheme in full and gives all the legal powers it needs to pay compensation to everyone who is eligible under the Scheme. The UK Government committed to the first payments being made to eligible infected persons by the end of 2024, and IBCA met this commitment by making the first payments in December 2024. As of 6 May 2025, 677 people have been invited to begin the claims process, with 432 of those starting their claim. 160 offers of compensation have been made, totalling over £150m, and 106 payments have been made, totalling £96,608,906.

## Eligibility

In accordance with **recommendations 1 and 2** of the Second Interim Report, the Government is clear that both those who have been infected and affected by this scandal are eligible for compensation and is compensating those who have been directly or indirectly infected through NHS blood, blood products or tissue. This includes anyone, living or deceased, who has been infected with HIV, Hepatitis C and chronic Hepatitis B, including those who were indirectly infected through their partners or loved ones. Those with acute Hepatitis B infections and have died from their infection during the acute period, are also eligible under the Scheme. Regarding the affected; partners, parents, children, siblings and carers will all be eligible for compensation (subject to certain criteria).

The Government acknowledges the further distress and trauma that can be caused to those applying for compensation, and so the Scheme has been designed to minimise the burden on applicants whilst protecting against fraud. People registered on a current UK infected blood support scheme or predecessor Alliance House organisation scheme will automatically be eligible for compensation. However, they may need to provide further evidence to enable assessment of the compensation award amount. People not registered with a current or former support scheme who acquired infections within the time period where evidence from the IBI suggests contamination to be likely, will be asked to provide evidence to establish infection cause (i.e. evidence of infection and relevant causative treatment). This follows **recommendation 3** of the Second Interim Report, which aims to avoid adversarial concepts of the burden of proof on applicants.

The Scheme does not include hard cut-off dates or determining whether a person is eligible for compensation based on when their infection was acquired. However, the evidence requirements will be higher where a person was infected after the introduction of screening of blood, blood products and tissue. The dates the Scheme will acknowledge for the introduction of screening are:

- HIV infection November 1985
- Hepatitis C infection September 1991
- Hepatitis B infection December 1972

With respect to **recommendation 4** of the Second Interim Report, for those who have been affected by this scandal, affected persons will be eligible where their case is linked to that of an eligible infected person. This includes affected partners, children, parents, and siblings, and carers (e.g. friends and family members) who cared for loved ones with an infection without reward or remuneration.

The Government recognises the different levels of suffering from different infections and degrees of severity. Therefore, compensation will be available for all of the

categories of loss recommended by the Inquiry - these are referred to as 'categories of award' within the Scheme, and further detail is available below.

As per the Second Interim Report's **recommendation 5**, different amounts of compensation will be paid to those who are infected and affected, depending on the severity of the infection suffered or familial relationship.

The range of awards have been developed by the Government's Expert Group under Chair, Professor Sir Jonathan Montgomery, bringing together legal and clinical expertise, and assisted by social care specialists.

## Categories of Award

With respect to **recommendation 6** of the Second Interim Report, the Government has accepted the Inquiry's recommended categories of award, and has therefore designed the Scheme to award compensation to include the following:

- Injury Impact Award;
- Social Impact Award;
- Autonomy Award;
- Care Award; and
- Financial Loss Award.

The Government has deviated slightly from the exact recommendation, as in the interest of speed and simplicity, the Care Award is routed through the person with an infection or their estate to distribute.

There is no award for exemplary damages, as recommended by the Second Interim Report in **recommendation 7.** 

In line with **recommendation 8** of the Second Interim Report, the Scheme will use a tariff-based framework to calculate the amount of compensation payable to those eligible. In practice, this means that compensation will be calculated based on set criteria and rates. Using a tariff approach will minimise the amount of information that people applying to the Scheme are required to provide. It will also help to ensure that compensation can be awarded more quickly than would otherwise be possible if all applications for compensation had to be individually assessed.

The Scheme also offers a Core Route and a Supplementary Route for awarding compensation.

The Core Route will make a tariff-based assessment of someone's compensation, under the five categories of award. The assessment will be based on a number of criteria depending on whether someone is infected or affected, including the severity of their infection or their relationship to the infected person. Once accepted onto the IBCS, all eligible applicants will initially be offered a compensation package through the Core Route. The design of the tariffs means that the Core Route is expected to be suitable for the majority of applicants, with no further assessment of personal circumstances required.

The Core Route offers two assessment paths to compensation: The first path is for those who are currently in receipt of monthly Infected Blood Support Scheme payments and wish to continue to receive these. The second path is for those who are either not in receipt of these payments, or do not wish to continue to receive them. Applicants also have a choice as to whether they wish to receive their compensation as a lump sum or periodic payments. Determining which path is most

suitable for the person who is claiming will vary depending on the circumstances of the individual, and IBCA will provide advice and support to all applicants. The decision of which path to take will ultimately be for the applicant. Regardless of which path of the Core Route an applicant opts for, nobody will be worse off under the Infected Blood Compensation Scheme than they were under the Infected Blood Support Schemes.

Supplementary Routes will provide additional awards in exceptional cases where the level of compensation offered through the Core Route does not sufficiently address a person's individual circumstances. An applicant will need to go through their Core Route assessment before they can apply to the Supplementary Route, but any assessment under the Supplementary Route will not delay payment of the compensation offer made through the Core Route.

There are three supplementary awards which infected people may be eligible for and one supplementary award which affected people may be eligible for. Should a person be eligible, multiple awards can be claimed under the Supplementary Route in addition to the Core Route Award. The Supplementary awards are set out below.

Some victims of the infected blood scandal were subjected to unethical research practices. To reflect the specific harms caused by this, an additional Autonomy Award is available via the Supplementary Route for those who were subject to unethical research practices. The eligibility criteria set out in the Regulations are based on the Inquiry's findings and follow a period of community engagement on the design of the award.

The Severe Health Condition award will be available to eligible infected people who have suffered from a specified rare severe health condition as a result of their infection that has not already been taken into account in the core awards (for example, severe visual impairment and severe psychiatric disorders). Applicants will need to provide evidence of their specific health impacts or conditions, and may need to provide evidence of their inability to return to work after developing a severe health condition, and/or assessment of their care needs to be eligible for supplementary care and financial loss awards.

The Infected Blood Compensation Scheme offers people registered with an Infected Blood Support Scheme choice between two compensation offers, either an award under the 'core route', which can be taken as a lump sum or periodic payment for 5, 10 or 25 years, or an award under the 'IBSS-route', which provides the claimant with the option to continue to receive support scheme for life, in addition to their core award, which can be taken as a lump sum or periodic payment. Under the IBSS-route, a person's future care and financial loss awards are not provided as part of the lump sum or periodic payment, as this harm is compensated for by the continuation of the support scheme payments for life.

The Exceptional Loss Award will also be available to eligible infected people without one of the specified health conditions if they can provide evidence of their financial loss and/or care costs due to their infection. To access this award, an applicant will need to show that they incurred at least one of the following:

- i) financial loss due to reduced earning capacity where the financial loss exceeded the assumptions in the core route;
- ii) where past care was paid for but was assumed, under the core route, to be unpaid; or
- iii) where past care was assumed to be paid for but the cost of that care exceeded that provided for under the core route.

This is intended to allow applicants to provide evidence of their losses beyond the set tariffs of the Core Route. An example of this would be where a person had particularly high earnings prior to their infection and therefore suffered greater financial loss from needing to give up their job due to the impact of their infection.

The tariffs have been informed, but not limited by, current practice in UK courts and tribunals. The Expert Group has advised the Government on the tariff rates in the course of their work, which Ministers decided on and set in accordance with the principles on managing public money. This deviates slightly from the Report's recommendation, which advised that tariffs should be set by the Scheme.

In line with **recommendations 9 and 10** of the Second Interim Report, acceptance of an award does not require applicants to waive their right to pursue litigation. In defined circumstances, if an infected person's condition deteriorates after their compensation award has been assessed, they will be able to return to IBCA for reassessment to determine whether they are eligible for an additional compensation payment. A reassessment following a health deterioration will be possible at any time, regardless of the time that has passed since a person's initial assessment.

With respect to **recommendation 11** of the Second Interim Report, the compensation scheme aligns with the spirit of the recommendation regarding interest payable on past financial loss. The Scheme uses the rate of current median +5% annual salary netted for tax and NI, which is then applied to all years for the working period (age of infection to retirement age) and 50% of this rate from retirement age to life expectancy age. As the Scheme uses the current median salary, as opposed to rates from previous years, interest is not payable.

## Interim payments

The Government recognises that people have been waiting for too long to receive compensation and for justice to be delivered on this scandal. In order to provide financial support prior to the rollout of the Scheme, the Government has made interim payments to infected beneficiaries, bereaved partners, and the estates of deceased infected people.

From October 2022, interim payments of £100,000 were made available to infected beneficiaries and bereaved partners. In October 2024, following a commitment made in the Victims and Prisoners Act 2024, the Government opened applications for interim payments of £100,000 to the estates of the deceased infected people whose deaths had not been recognised to date. This complies with the spirit of **recommendation 12** of the Second Interim Report, to recognise the deaths of infected people to date unrecognised, and to alleviate immediate suffering. This approach allows for payment of substantial compensation into the hands of families of victims of infected blood, while recognising that it would not be appropriate for the Government to intervene in the wishes of a deceased person, as set out in their will. In addition to those recommendations, further interim payments of £210,000 were made to living infected beneficiaries in June 2024. So far, over £1.2 billion has been paid in interim compensation payments to victims of the Infected Blood scandal and their families.

As per **recommendation 13** of the Second Interim Report, any payments made to those eligible under the Scheme will be exempt from income tax, capital gains tax, and inheritance tax. Any payments will also be disregarded from means tested benefit assessments (which includes council tax and nursing home fees). This includes payments made to recipients of compensation via the estate of an infected person

With the exception of the above mentioned interim compensation payments, any payments received through the support schemes, up until 31 March 2025, will not be deducted from compensation payments. Support scheme payments will not be taken into account when assessing an applicant's 'injury', 'social impact', or 'autonomy' awards, or in relation to past financial loss or care awards. Applicants will be able to access these parts of their compensation either as a lump sum or periodical payment. Support scheme payments received after 31st March 2025, will be taken into account when the IBCA assesses an applicant's future financial loss and care awards. This assessment will not reduce the value of support payments which will continue to be paid for life where this option is chosen by the applicant.

# Infected Blood Compensation Authority and existing support schemes

In line with **recommendations 14 and 16** of the Second Interim Report, IBCA has been established to deliver the Infected Blood Compensation Scheme and financial compensation to victims of infected blood on a UK-wide basis. All those registered with an infected blood support scheme before 1st April 2025 - both living infected persons and bereaved partners - can choose to receive regular support scheme payments for life. This goes beyond the recommendations made in the Second Interim report and reflects the recommendations made by Sir Robert Francis following his engagement exercise with the community in June 2024. In his report to the Government in August 2024, Sir Robert was clear that support scheme payments should continue for those who meet the eligibility criteria of the existing support scheme before 1 April 2025. The Government has accepted that recommendation and the regulations reflect this position.

The existing Infected Blood Support Schemes (England Infected Blood Support Scheme, Infected Blood Payment Scheme for Northern Ireland, Scottish Infected Blood Support Scheme, and Wales Infected Blood Support Scheme) will transfer responsibility for making support payments to the IBCA as part of a phased transition from January - March 2026. Applications to the Infected Blood Support Schemes closed on 31 March 2025.

Responsibility for making support scheme payments will transfer to IBCA on the following dates:

- Wales Infected Blood Support Scheme on the 15 January 2026;
- Scotland Infected Blood Support Scheme on the 1 February 2026;
- Infected Blood Payment Scheme for Northern Ireland on the 1 February 2026;
- England Infected Blood Support Scheme on the 23rd March 2026.

Cabinet Office and IBCA are working closely with devolved governments, the Department of Health and Social Care and the Infected Blood Support Scheme administrators to ensure that the payment of compensation, including continuation of support scheme payments for life, if requested, as part of the compensation package is as smooth as possible, placing a minimum burden on individuals and ensuring that no-one will experience a gap in payments.

## Non-financial support

With respect to **recommendations 15 and 17** of the Second Interim Report, the Government acknowledges the immense psychological harm that has been caused as a result of this scandal, and is committed to offering psychological support to those impacted by this scandal. Bespoke psychological support for the infected and affected people is already offered in Scotland, Wales and Northern Ireland. In England, the Infected Blood Psychological Service began supporting its first patients in some parts of the country in late August 2024, with providers building up capacity over the following six months until they are up and running in all areas of England in Spring 2025.

The Government also recognises the need to support applicants through the process of claiming compensation, and as such, the IBCA aims to ensure that appropriate advice and support is available to assist people awarded compensation to manage their compensation awards, access financial services, and access benefits advice where relevant.

# Setting up the Scheme

**Recommendation 18** of the Second Interim Report recommended that the Government set up the compensation scheme upon publication of the Second Interim Report in April 2023, and that it should begin work as soon as possible in that year. The then Government was clear that it would respond to the Second Interim Report following the publication of the Inquiry's May 2024 report, and has done so in the establishment of the compensation scheme.

# 2) Recognising and remembering what happened to people

2a. A permanent memorial be established in the UK and consideration be given to memorials in each of Northern Ireland, Wales and Scotland. The nature of the memorial(s), their design and location should be determined by a memorial committee consisting of people infected and affected and representatives of the governments. It should be funded by the UK Government.

2b. A memorial be established at public expense, dedicated specifically to the children infected at Treloar's School. The memorial should be such as is agreed with those who were pupils at Treloar's.

2c. There should be at least three events, approximately six months apart, drawing together those infected and affected, the nature and timing of which should be determined by a working party as described above, facilitated by some central funding.

This recommendation is accepted in full by the UK Government, the Scottish Government, the Welsh Government and the Northern Ireland Executive. This recommendation is being taken forward on a UK wide basis.

The Inquiry's report emphasised the need for public recognition and a formal apology for all of those impacted. The previous and current UK governments have issued unequivocal apologies for what happened on behalf of the State and this apology is reiterated in the Ministerial foreword.

It is absolutely right that both a national memorial and memorial dedicated specifically to the Children at Treloar's are created to recognise and remember what has happened.

The Government is following the Inquiry's recommendation that a steering committee be formed to decide what memorials should be provided and where, including consideration given to memorials in Northern Ireland, Wales and Scotland. The membership of the steering committee will reflect the experiences of all routes of transmission, those infected and affected and will contain representatives of all of the UK's administrations. There will also be two sub-committees to:

- a. consider a memorial dedicated specifically to the children infected at Treloar's school (recommendation 2b); and
- b. organise a biannual networking/support event for those infected and affected (recommendation 2c).

Memorials will be provided primarily at public expense. We are aware that some money has already been raised across the UK and that individuals have already begun to feed in their views to best recognise and remember what happened to people.

#### Scottish Government

In Scotland, infected blood campaigners have already raised significant money to fund a memorial to help remember victims of this tragedy and agreed an initial design for the memorial.

The Scottish Government is continuing to work with City of Edinburgh Council and Scottish campaigners to find a preferred location, and will seek any additional funds needed in discussion with the new memorial steering committee. The aim is to have the memorial in place as soon as is feasible, subject to appropriate planning permission and other approvals being granted by the Council.

#### Welsh Government

The Welsh Government is in discussion with Haemophilia Wales on their wishes for a memorial. This work will feed into the wider considerations being led by the memorial committee being set up by the UK Government.

#### Northern Ireland Executive

In Northern Ireland, the Department of Health continues to engage with local partners and stakeholders to ensure that the views of the infected and affected families and communities are considered in how best to approach the implementation of recommendations 2(a) and 2(c). This engagement, as well as the steer provided by the Memorial Committee, will feed into the work of the Regional Group and the department in considering the best approach to remembering the infected and affected communities in Northern Ireland.

The Cabinet Office is working closely with officials from devolved governments to ensure that the Steering Committee is given an accurate and up to date picture of all the ongoing efforts on memorialisation when it is formed.

We recognise the importance of continuing to bring the infected blood community together and the value that events of this kind can bring. We will work with the Committee to plan at least three events as per the report's recommendations.

#### **Next Steps**

The UK Government, and the devolved governments in Scotland, Wales and Northern Ireland, are committed to ensuring that memorials are established that sufficiently honour the victims of this scandal. The input of the community is integral to the successful delivery of this recommendation, and the UK Government has engaged with the Infected Blood community, the APPG on Haemophilia and Contaminated Blood, and relevant stakeholders across government to identify suitable candidates for the role of Chair of the Infected Blood Memorial Committee. The process for appointing members to the steering committee and its sub-committees will begin, in consultation with the Chair and the Infected Blood community, following the Chair's appointment. Once members have been appointed, the Terms of Reference will be finalised and shared publicly, alongside proposed timelines for the first 12 months of the committee and sub-committee work.

# 3) Learning from the Inquiry

3a. The General Medical Council, and NHS Education for Scotland, Health Education and Improvement Wales, Northern Ireland Medical and Dental Training Agency and NHS England, should take steps to ensure that those "lessons to be learned" which relate to clinical practice should be incorporated in every doctor's training.

3b. They should look favourably upon putting together a package of training materials, with excerpts from oral and written testimony, to underpin what can happen in healthcare, and must be avoided in future.

The UK Government, Welsh Government, the Scottish Government and the Northern Ireland Executive accept these recommendations in full. These recommendations are being addressed on a UK wide basis.

Medicine is constantly evolving and it is crucial that doctor's training is kept up to date. The Inquiry's May 2024 report is a valuable resource in learning the lessons of the past, recognising that those responsible for medical education have an important role in ensuring that this happens in practice, and a reminder that patient safety should be the central focus for everything. Patients, the public and those impacted by the tragic events described in the Inquiry should expect no less.

The General Medical Council (GMC)'s regulatory requirements for medical education and training in the UK feature learning in blood transfusion. These have been embodied in the GMC's practical procedures for undergraduate education since 2009, the content map requirements that are part of the new Medical Licensing Assessment and in the postgraduate curricula that GMC approve. These checks and balances are underpinned by GMC standards for UK medical education and training, and in the generic professional skills frameworks that have safety and quality improvement at their core.

In terms of action taken, the GMC has continued to use its convening powers to ensure that all relevant stakeholders are working together to identify and share how the Inquiry is influencing reflection and action that will strengthen learning. The results of GMC's survey of medical schools, medical royal colleges and faculties were reflected in the December 2024 update to Parliament and showed a range of activity designed to strengthen learning on the safe delivery of transfusions. The aim is to gather any further reflections on the Inquiry's findings, details of current arrangements for training in blood transfusion and details of action that is being taken. To this end the GMC has requested updates from medical schools, medical royal colleges and faculties with the aim of feeding back to DHSC findings by the end

of June 2025.

Stakeholder collaboration is being supported by the work NHS England's Workforce Training and Education Directorate and NHS Blood and Transplant (NHSBT) are coordinating. NHS England have kept GMC updated on developments. This is taking place with professional education leaders across the four nations and professions to jointly consider recommendations 3 and 7d. This broad-based group is completing work on deep dives into the professions to determine where the gaps are in undergraduate education, postgraduate training and across the established workforce. The work is underpinned by a number of sub-groups, either up and running or planned over this year, that are focussing on healthcare scientists, doctors and medical students, nursing, allied health and other professions. The discovery for healthcare science and medics is further ahead due to the surveys that have already been completed as part of Transfusion 2024, but others are not too far behind.

Overall, the four-nation group is making good progress and looking to implement accessible and impactful educational resources/learning for the gaps identified. Any recommendations arising from that may have regulatory implications, for example where changes are being proposed to postgraduate curricula. These can be escalated to the GMC through the established processes.

3c. The Inquiry website is maintained online.

This recommendation is accepted in full by the UK Government, the Welsh Government, the Scottish Government and the Northern Ireland Executive.

This recommendation is being addressed on a UK wide basis.

The report sets out that often the findings, conclusions and recommendations made by an Inquiry are needed to refer back to once the Inquiry has been disbanded. It is usual, at the conclusion of a public inquiry, for its website to be transferred to The National Archives (TNA) for preservation of the public record.

The transfer of the 'live' website to TNA does result in some loss of functionality, as TNA does not currently have the capacity to maintain a website's search engine. The Government is taking forward work to ensure that the Inquiry's website is maintained with full functionality after the closure of the Inquiry, so that all the information uncovered by the Inquiry, that might be useful in the future, is easily publicly available.

# 4) Preventing future harm to patients: achieving a safety culture

#### 4a) i-iii) Duty of Candour

4a) i. A statutory duty of candour in healthcare should be introduced in Northern Ireland.

#### This recommendation is accepted in full by the Northern Ireland Executive

4a) ii. The operation of the duties of candour in healthcare in Scotland and in Wales should be reviewed, as it is being in England, to assess how effective its operation has been in practice. Since the duty was introduced in 2023 in Wales, the review there need not be immediate, but should be no later than the end of 2026.

This recommendation is accepted in full by the Scottish Government and the Welsh Government.

4a) iii. The review of the duty of candour currently under way in England should be completed as soon as practicable.

This recommendation is accepted in full by the UK Government

The behaviour of those who allowed this scandal to be perpetuated fell unacceptably short of the standards which the public rightly expects, particularly of those working in healthcare settings. The report finds a failure to focus on risk, a failure to put safety first, a failure to listen to voices advising a different course alongside a history of systematic failures. The report's observation that leadership often sets the tone for an organisation is absolutely right. We agree that the importance of leadership and its capacity to enact change in an organisation should not be ignored and that it is crucial for bringing about increased openness and honesty.

#### Northern Ireland Executive

As part of the Health and Social Care Three Year plan, Minister Mike Nesbitt committed to advance proposals for an organisational duty of candour, in the first instance, as well as considering proposals for an individual duty of candour in the coming months, that takes account of a related consultation which closed in March 2025, the UK-wide work on a Hillsborough Law, and the work arising from the Infected Blood Inquiry.

The findings of this consultation, as well as the outworkings of a Hillsborough Law currently being taken forward by the UK Government and the findings of the Duty of Candour review in England will undoubtedly shape the introduction of a statutory Duty of Candour in Northern Ireland.

#### Scottish Government

The organisational duty of candour provisions of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016 and the Duty of Candour Procedure (Scotland) Regulations 2018 set out the procedure that organisations providing health services, care services and social work services in Scotland are required by law to follow when there has been an unintended or unexpected incident that results in, or could result in, death or harm (or additional treatment is required to prevent injury that would result in death or harm).

The Scottish Government published non-statutory guidance to support the introduction of the Regulations in 2018. This guidance has recently been reviewed in conjunction with stakeholders across health care and social work sectors to take account of recent learning including learning identified from the Covid-19 pandemic. The revised non-statutory guidance was published in April and distributed to health, care and social work services.

The Scottish Government will begin engagement with stakeholders on its review of the operation of the organisational duty of candour in June 2025.

#### Welsh Government

The impact of the Health and Social Care (Quality and Engagement) (Wales) Act 2020 which introduced the duty of candour in Wales in 2023, will be evaluated. The recommendation as laid out in the IBI inquiry report will be integrated into the specification out to tender for the evaluation research programme.

The Welsh Government welcomes any learning from the English review to add to intelligence informing any review of the Welsh NHS duty of candour.

#### **UK Government**

The Government is clear that the statutory (organisational) duty needs to act as a catalyst for health and social care providers to improve openness and commit to a learning culture.

The Government is supportive of the review we inherited into the effectiveness and implementation of the duty. On 26th November 2024, we published a report on the findings of the call for evidence issued by the Department of Health and Social Care in April 2024.

The findings suggest that the duty is functioning effectively in some places but is underwhelming in totality. For example, a majority of respondents thought the duty's purpose was not clear or well understood, that staff across health and social care do not understand the duty's requirements and therefore application of the duty is inconsistent and open to misinterpretation, and that providers do not engage patients and service users in a meaningful or compassionate way.

This cannot be justified and our aim is to examine how all providers and their leaders can act upon the statutory duty of candour consistently and effectively.

We are using the findings of our consultation on manager regulation, which closed on 18 February 2025, to help inform the final response to the review on the statutory duty of candour. The Government is preparing its consultation response and we plan to publish the final duty of candour review report once the consultation response has been published.

#### 4a) iv-v) statutory duty of candour

4a) iv. The statutory duties of candour in England, Scotland, Wales (and Northern Ireland, when introduced) should be extended to cover those individuals in leadership positions in the National Health Service, in particular in executive positions and board members.

4a) v. Individuals in leadership positions should be required by the terms of their appointment and by secondary legislation to record, consider and respond to any concern about the healthcare being provided, or the way it is being provided, where there reasonably appears to be a risk that a patient might suffer harm, or has done so. Any person in authority to whom such a report is made should be personally accountable for a failure to consider it adequately.

These recommendations are accepted in principle by the UK Government, the Scottish Government and the Welsh Government. This recommendation may be taken forward on a UK wide basis.

#### **UK Government**

4a) iv. The Government recognises the importance of strong and accountable leadership in fostering an open and compassionate culture in the NHS. That is why we have committed to implementing professional standards for and regulating NHS managers.

The Government ran a consultation from 26 November 2024 to 18 February 2025 on options for regulating NHS managers, with the aim of improving leadership quality and accountability. The consultation sought views on whether a professional duty of candour is a standard that should be introduced for NHS leaders, and whether leaders should also be accountable for ensuring that the statutory (organisational) duty of candour is correctly followed in their organisation. The Government is currently preparing its consultation response.

4a) v. Advancing patient safety and reducing harm in the NHS is a priority for this Government. We acknowledge the importance of recording and responding to patient safety incidents and the underpinning principle of this recommendation in increasing openness and transparency within the NHS.

While senior leaders' accountability is an important driver to delivering increased openness, this recommendation is complex to implement and enforce. It may have significant resourcing and employment law implications and actually be counter-productive in terms of advancing candour and safety culture.

It may be possible to hold NHS leaders accountable for the mechanisms in their organisations associated with recording and responding to patient safety incidents

through professional standards and regulating managers - and we are preparing our response to the consultation on bringing managers into regulation.

Linked with recommendation 4a)iv, the Department of Health and Social Care is also consulting on the following pledge for inclusion in the NHS Constitution: "To provide a culture of accountability where NHS leaders ensure that the statutory duty of candour is correctly followed in their organisation, and that they ensure systems and processes exist for responding to patient safety concerns."

Although the UK Government's consultation on manager regulation applies to England only, professional healthcare regulation is one element of a much broader system of ensuring patient and service user care that is typically addressed on a UK-wide basis. As such, devolved governments may take into consideration the approaches of the UK Government in relation to these recommendations.

#### Scottish Government

In Scotland, the Scottish Government recognises the benefits of a four-nations approach to the issues covered by recommendations 4a) iv. and v. It is considering its position on recommendation 4a) iv. and wants to ensure appropriate alignment across the UK when taking any proposal forward. On recommendation 4a) v., the Scottish Government will consider its approach further once the outcomes of the UK consultation are known.

#### Welsh Government

In Wales, the Welsh Government welcomes any learning from the English review to add to intelligence informing any review of the Welsh NHS duty of candour. The Welsh Government would welcome the opportunity of a four nations approach to this work.

#### Northern Ireland Executive

In Northern Ireland, the Department of Health is currently considering its position on recommendation 4a) iv. in the context of their existing engagement and work programme on Duty of Candour, as well as the wider implications arising from the ongoing developments on a Hillsborough Law.

#### 4b) Cultural Change and 4c) i-ii) Regulation

4b. That a culture of defensiveness, lack of openness, failure to be forthcoming, and being dismissive of concerns about patient safety be addressed both by taking the steps set out in (a) above, and also by making leaders accountable for how the culture operates in their part of the system, and for the way in which it involves patients.

This recommendation is accepted in principle by the UK Government, the Welsh Government, the Scottish Government and the Northern Ireland Executive.

- 4c) i. That external regulation of safety in healthcare be simplified. As a first step towards this, there should be a UK wide review by the four health departments of the systems of external regulation, with the aim of addressing all the points made earlier in this Report and in other reports since 2000.
- 4c) ii. That the national healthcare administrations in England, Northern Ireland, Scotland and Wales explore, and if appropriate, support the development and implementation of safety management systems ("SMS"s) through SMS coordination groups (as recommended by the HSSIB), and do so as a matter of priority.

Recommendations 4c) i-ii) are accepted in full by the UK Government and the Welsh Government. They are accepted in principle by the Scottish Government and Northern Ireland Executive.

The progress in implementing recommendations 4(a-b), evidence the important steps that are already being taken to address the report's findings in relation to candour within healthcare. We agree that the culture of an organisation also plays a central role in how the organisation operates.

#### **UK Government**

In relation to recommendation 4c) i. the Secretary of State for Health and Social Care asked Dr Penny Dash to conduct a review of patient safety in the health and care landscape. The focus of the review by Dr Dash is on six core bodies: Care and Quality Commission (CQC), The National Guardian's Office, Healthwatch England (HWE) and the Local Healthwatch network, Health Services Safety Investigation Body, Patient Safety Commissioner and NHS Resolution, and how they work with the wider landscape. The Secretary of State asked Dr Dash to make recommendations on whether greater value could be achieved through a different approach or delivery model. The review will be published shortly. All findings will inform the UK Government's 10-year health plan, as well as work to develop an NHS Quality Strategy, to transform the NHS and social care system and make it fit for the future.

In relation to Recommendation 4c) ii., DHSC agrees that it is important to explore approaches for enhancing the safety of services. In 2023, NHS England established an SMS coordination group with partners from across the healthcare system including providers, patients, regulators, the Health Services Safety Investigations Body (HSSIB), academia and other safety critical industries to explore the potential for SMS principles and processes to be adopted further in the NHS to improve patient safety. The group's work is ongoing and has not yet reached specific conclusions about the applicability of SMS principles to healthcare but it is likely to report later in 2025.

It is right to ask what more the NHS could learn from other industries and to understand how SMS principles might be appropriately translated into healthcare settings, although we would caution against an approach that seeks to simply adopt a new phrase or framework such as an SMS as the solution to complex patient safety challenges.

In support of the SMS Coordination Group in August 2023, NHS England, in collaboration with the Department of Health and Social Care and the National Institute for Health and Care Research, commissioned the Exeter Health and Social Care Delivery Research Evidence Synthesis Centre to conduct research examining the application of safety management systems to patient safety in terms of effectiveness, implementation and experience. The research included publications from five countries (Australia, Canada, Ireland, New Zealand and the Netherlands). The findings highlight that:

- only the Netherlands had introduced a national patient safety programme explicitly based on a high-risk industry SMS approach,
- the main components of an SMS were identified, to varying extents, in the
  patient safety policies and initiatives of other countries included in the review,
  and
- other concepts from wider safety science had influenced patient safety approaches in all countries.

These findings suggest there is no single most effective approach to patient safety, and emphasise the need for any approach to safety to be operationalised and adapted to fit the healthcare context. These findings will inform ongoing discussions undertaken by NHS England's SMS co-ordination group.

#### Scottish Government

For recommendation 4b), over the past few years, the Scottish Government has responded to a number of recommendations arising from reviews about raising concerns in the workplace (Francis Review) and concerns around workplace culture (Sturrock Review). The overall aim is to ensure that mechanisms are in place in all NHS Boards in Scotland which promote and encourage staff to raise concerns, engendering a workplace where the culture is supportive, open and transparent.

To date, the Scottish Government has developed and introduced the role of Independent National Whistleblowing Office (INWO) for the NHS in Scotland, whose role is underpinned by legislation and supported by the National Whistleblowing Standards which forms the Once for Scotland Whistleblowing Policy. The National Whistleblowing Standards are applicable to all staff delivering services on behalf of the NHS in Scotland. Non-Executive Whistleblowing Champions have also been introduced in all Health Boards, providing an independent assurance and oversight role which ensures managers are responding to whistleblowing concerns appropriately and in accordance with the National Whistleblowing Standards.

Whilst the Scottish Government recognises that robust mechanisms have been introduced to encourage and enable staff to raise concerns, we remain conscious of the scale of the challenge and that in many cases staff remain reticent about raising concerns. This appears to be for a number of reasons, including: that they may suffer detriment for doing so; that they will not be listened to; and that the concern that they raise will not be followed up. Cultural change within the NHS in Scotland, where staff recognise the importance and benefits of raising concerns, particularly where this relates to patient safety, is key, and whilst positive cultural change will take time, Boards must maintain a continued focus on the desired outcome.

The Scottish Government continues to monitor staff experience of confidence in raising concerns and that these will be acted upon via the annual iMatter Health and Social Care Staff Experience Survey, and has a formal Whistleblowing policy as described above. The policy includes Stage 1 early resolution, which is for simple and straightforward concerns that can be responded to within five working days or less. This is intended to create a less formal process which supports staff to raise concerns in a business as usual manner, and lowers barriers for staff to raise concerns. Issues that are more complex and will clearly take more than five working days to address, or, where the staff member is dissatisfied with the actions taken, should move straight to Stage 2, the formal investigation stage. To further support staff, organisations must make sure they have access to an impartial, confidential contact who they can contact by email or phone, or talk to in person.

In July 2024, the Scottish Government published <u>Improving Wellbeing and Working Cultures (IWWC)</u>, setting out the ambition to enhance working cultures through programmes of work at a national level that focus on the pillars of wellbeing, leadership and equality.

The delivery of national interventions under IWWC supports the delivery of the Scottish Government's wider ambitions within health and social care, including staff retention, improving wellbeing, creating psychological safety in the workplace – where everyone feels heard, respected and valued.

The Scottish Government recognises the importance of ensuring that all of the actions identified in response to the Inquiry's recommendations encourage the meaningful involvement of all those affected in ways that support healing and reflect

restorative practices in identifying and responding appropriately where harm (including compounded harm) is identified.

In relation to recommendation 4b), the Patient Safety Commissioner for Scotland Act 2023 requires the Commissioner to create a Patient Safety Charter, which makes clear that it is healthcare providers (not patients and families) who are required to act where there has been harm. The Charter will help to ensure that organisations recognise their respective accountabilities and obligations towards patients and families when harm has occurred.

For recommendation 4c) ii., the Scottish Government and Healthcare Improvement Scotland (HIS) are building knowledge and understanding of what is required to extend and further embed a quality and safety management system across all health and care services. The existing Essentials of Safe Care framework is a Scotland-wide practical package of evidence-based guidance and support that enables the whole health and social care system to deliver safe care. The package includes tools for assessing organisational readiness, prioritising areas for improvement and a measurement framework covering the essential drivers of safe care: person-centred systems and behaviours, safe communication within and between teams, and safe and consistent clinical and care processes, along with leadership to promote a culture of safety at all levels.

The Scottish Government and HIS have mapped the Inquiry's recommendations against each of the essential drivers of safe care, in order that further actions required are identified in support of the delivery of cross-cutting themes reflected in the Inquiry's findings.

The Scottish Government will work with their counterparts in the Department of Health and Social Care and other devolved governments to ensure that HIS and the Health Services Safety Investigations Body (HSSIB) are supported to work together effectively to share learning and good practice, and to promote patient safety (including considering the ways in which HSSIB's work on safety management systems might inform HIS' work on essentials of safe care and implementation of quality and safety management systems).

For recommendation 4c) i., the Scottish Government is engaging on work being taken forward by the UK-wide Inter-Ministerial Group, particularly on proposals for a UK Patient Safety Group.

Scottish Government officials will continue to support this work, providing insight into the current landscape in Scotland and how this aligns with work across the other nations, facilitating effective working, and looking for opportunities for improvement and alignment.

#### Welsh Government

In Wales, the Health and Social Care (Quality and Engagement) (Wales) Act 2020 introduced the duties of candour and quality and established a new citizen voice body, Llais (voice). It came into force in April 2023. The duty of quality describes how continuous learning is at the centre of a quality management system. Reporting, investigating and learning from patient safety incidents is an important element. The duty of candour places a statutory organisational duty on all NHS bodies to inform and support when things go wrong. It builds on the 'Being Open' principles of 'Putting Things Right', further embedding openness and transparency.

#### Northern Ireland Executive

In addition to the introduction of a statutory organisational Duty of Candour in Northern Ireland, as detailed under the response to Recommendation 4(a)i, the Department of Health is also implementing a new Being Open Framework. This Framework will be a fundamental part of efforts to support an open, just and learning culture throughout the Health and Social Care Service.

Further consideration and wider engagement will be required to fully assess the local regulatory picture and how best to give effect to Recommendation 4(c).

#### **Next Steps**

DHSC are considering how to incorporate these proposals as part of the NHS manager regulation, whilst also considering how the duty of candour proposals under recommendation 4 interact with the forthcoming Hillsborough Law.

#### 4d) Patient Records

4d. Before the end of 2027 there should be a formal audit, publicly reported, of the extent of success of digitisation of patient records in each of the four health jurisdictions of the UK, measuring at least the levels of patient access to their personal records, their ability to identify and correct apparent errors in them, their interoperability, and the confidence of health professionals in the detail, accuracy and timeliness of any record they enter, and that little material which should be recorded has been omitted. Next steps should be identified.

This recommendation is accepted in principle by the UK Government, the Welsh Government and the Northern Ireland Executive. It is accepted in full by the Scottish Government.

The historic findings of the Inquiry regarding the failings of NHS record keeping are unacceptable. As the report sets out, work is already well underway to give patients greater access to their own records. We are determined to ensure that the digitisation of patient's records is as successful as possible and agree with the Inquiry's recommendation of a formal audit.

#### **UK Government**

NHS England is supporting the NHS frontline to digitise its data. Linked to this, the Frontline Digitisation programme aims for all secondary care trusts to have an electronic patient record system (EPR) that meets its standards.

This work is informed by ongoing Digital Maturity Assessments, which capture most of the content called for within the audit set out within this recommendation. NHS England is determining the best means to capture the remaining items, such as the views of care professionals.

This approach aims to collate the information called for in this recommendation as efficiently as possible, making best use of existing processes and ensuring it's joined up with wider work. NHS England is continuing work to confirm how this could be publicly reported and identify next steps as set out in the recommendation and will be able to outline a plan for this by the summer 2025.

#### Scottish Government

The Scottish Government agrees that digitisation of patient records is essential, and that patients should have full access to relevant information about them. The Scottish Government is committed to this. As well as modernising existing infrastructure, such as via new GP IT systems, plans are being developed for a new national personalised digital health & social care service which will provide the enabling capability for patients to interact with their health information. The 'digital

front door' programme will launch an initial prototype version of an online app for health & social care in Lanarkshire in December 2025. This will, for the first time, allow people to access elements of their core health information. This will be expanded over the next few years to be the primary means of people being able to access their personal records and identify and seek resolution of any apparent errors, with the range of information accessible increasing over time.

Health Boards will be required to continue with their local digitisation progress and assurance of delivery will involve adapting the Digital Maturity assessment to check on Health Board progress in digitising patient records. All Health Boards are asked to submit an update by the end of July of each year on their Digital Maturity

Assessments. This is already a publicly reported process with the work on reporting on the 2024 assessments recently concluded (see <u>Digital Maturity Assessment 2024</u> - <u>Digital Healthcare Scotland</u> for the most recent overview). The question set will be expanded in 2025 so that this assurance can be taken forward in line with the Inquiry's recommended timescales by the end of 2027. Progressing this in 2025 will provide us with baseline intelligence around spring 2026, which will then allow the Scottish Government to identify appropriate next steps in terms of how we coordinate digitisation of patient records more broadly.

#### Welsh Government

The Welsh Government agrees that digital record access empowers patients, and the NHS Wales App has been introduced as the front door to digital services. Progress has been made in primary care services. The goal is for patients and the public to:

- personalise their health journey;
- monitor health conditions more easily;
- share and receive important health information;
- take an active part in their own health and wellbeing;
- plan for and take control of their health and care journey; and
- stay healthy for longer.

The Welsh Government will be commissioning with its system partners the development of an Electronic Health Record in secondary care which is planned to improve the wider accessibility of digital records for clinicians and patients. The NHS App continues to develop in Wales and is at the heart of plans to increase access to records for patients during 2025.

#### Northern Ireland Executive

A regional Electronic Patient Record (EPR) is currently being deployed, covering Acute Care, Secondary Care, Social Care and Mental Health sectors. Deployment is scheduled to complete by May 2025, followed by a stabilisation phase of one year. Reviews will be carried out as part of an optimisation stage to ensure processes are fit-for-purpose and can be improved.

Patient access to information held is provided through multiple channels including an App and a website. The EPR solution also enables patients to share selected information with others. The easy access to information will support patients to exercise their existing rights (under UK GDPR & Data Protection legislation) to ensure their records are accurate.

Northern Ireland is currently exploring how a holistic record, to include input from independent sector providers under controlled conditions, can be created. Several governance matters have been identified and consideration is being given to addressing these.

Once the regional EPR is fully rolled-out across the five HSC Trusts, it is anticipated that planned optimisation work will include an element of review and audit. Discussions with the Departmental Chief Digital Information Officer will seek to explore how the solution in place will continue to meet the requirements of Recommendation 4d). As part of the system's implementation, timelines and performance reports have been and are still being published as part of ongoing continuous monitoring, a formal audit as such will not be required.

#### 4e) Coordination of patient records with devolved governments

4e. Consideration should be given by the national healthcare administrations in England, Scotland, Wales and Northern Ireland, to further coordination of their approaches particularly to ensure that patterns of harm, or trends, are identified and any response which for the sake of patient safety would be better coordinated than left to each individual administration can collaboratively be agreed and implemented.

This recommendation is accepted in full by the UK Government, the Welsh Government, the Scottish Government and the Northern Ireland Executive.

We acknowledge that patient safety incidents in healthcare are a source of learning and patient safety priorities. Intuitive patient safety incident reporting and learning systems, which capture and provide structured learning, are key to improving patient safety and preventing the occurrence of harm.

The NHS in England is world-leading in this regard, having operated a single national database of all recorded patient safety incidents since 2004. This database was recently overhauled and updated. Called the Learn From Patient Safety Events (LFPSE) service, it collates and supports the analysis of around 3 million patient safety incidents a year, most of which are no harm (near miss) and low harm incidents. NHS England's National Patient Safety Team reviews hundreds of these incidents each week via LFPSE looking for risks that can be acted on, including through issuing National Patient Safety Alerts and collaborating with partners to address patient safety issues identified. NHS England estimate this work saves 160 lives per year, reduces disability due to severe harm incidents by around 480 cases per year and saves £13.5m in additional treatment costs per year. This is in addition to the primary responsibility of NHS providers to respond to these patient safety incidents as they are recorded locally.

#### Scottish Government

The Scottish Government is committed to supporting the development of an open and learning culture in the NHS in Scotland, and a robust and consistent adverse event review process is a key part of that. Since January 2020, all NHS health boards have been required to notify Healthcare Improvement Scotland (HIS) when they have commissioned a significant adverse event review (SAER) for a category 1 adverse event. This is with a view to developing a more comprehensive national overview of adverse events across Scotland, including an agreed number of defined 'harms' and associated learning and improvement actions. HIS reviewed the national adverse event framework and published an updated version, 'A national framework for reviewing and learning from adverse events in the NHS in Scotland', in February 2025.

As part of a quality management system, HIS considers a range of sources of data to identify patterns of harm, or trends, including concerns brought to it through the 'Responding to Concerns' process, intelligence shared by partner organisations through the Sharing Intelligence Health and Care Network, and quantitative and qualitative data on system safety, quality and performance.

#### Welsh Government

In Wales 'putting quality and safety above all else' is the first core value in "A Healthier Wales". All patient safety incidents, including near misses, are reported through Datix Cymru. NHS bodies are able to analyse data, identify risks, themes and trends to extract learning and disseminate locally. Nationally Reportable Incidents (NRIs) are reported to NHS Wales Executive (NHSWEx) which provides an oversight and assurance function. It used data and intelligence from NRIs to inform local and national assurance activities. The NHSWEx has developed the Beacon dashboard to support the management of quality and safety intelligence across NHS Wales. It contains All-Wales, individual health board and NHS trust data, which is used in Welsh Government and NHS Wales, with work being undertaken to add further data.

Following an independent appraisal of quality and safety in NHS Wales, the NHS Wales Executive will be developing a 3-5 year Quality and Patient Safety Plan. This will be a key component of a broader quality management system. The plan will set the cultural shift required to establish an efficient learning healthcare system that drives improvement by listening and learning to patients and staff, and through effective quality management processes.

A working group is considering the different approaches for how patterns of harms or trends in patient harm are identified in each of the four nations and will decide what areas improved coordination should focus on and how an aligned response amongst the four nations could work in practice and opportunities for learning lessons are seized.

# 5) Ending the Defensive Culture in Civil Service and Government

5a. The Government should reconsider whether, in the light of the facts revealed by this Inquiry, it is sufficient to continue to rely on the current non-statutory duties in the Civil Service and Ministerial Codes, coupled with those legal duties which occur on the occasions when civil servants and ministers interact with courts, inquests and inquiries, as securing candour.

5b. If, on review, the Government considers that it is sufficient to rely on the current non-statutory duties in the Civil Service Code, it should nonetheless introduce a statutory duty of accountability on senior civil servants for the candour and completeness of advice given to Permanent Secretaries and Ministers, and the candour and completeness of their response to concerns raised by members of the public and staff.

5c. The Government should consider the extent to which Ministers should be subject to a duty beyond their current duty to Parliament under the Ministerial Code.

These recommendations are accepted in principle and the Prime Minister has committed to bringing forward legislation on a duty of candour for public servants.

The actions of Civil Servants and Ministers uncovered within the report are extremely concerning and do not reflect the values we expect those who serve the public to uphold. The Government accepts that in light of the facts uncovered by the IBI and other public inquiries that a statutory duty of candour should be introduced.

The Prime Minister has committed to legislation on a Duty of Candour being delivered by this Government. He confirmed that the duty will apply to public authorities and public servants and will include criminal sanctions. The Government is consulting widely on this issue, and is working to draft the best version of a Hillsborough Law ahead of its introduction to Parliament. The Bill will address the unacceptable defensive culture prevalent across too much of the public sector - highlighted by recent reports such as Bishop James Jones's report into the experiences of the Hillsborough families and that of this Inquiry. The Bill is part of our wider efforts to create a politics of public service.

The Prime Minister issued a Ministerial Code on 6 November which emphasised that ministerial office requires openness and candour, and that ministers should both demand and welcome candid advice.

#### Welsh Government

The First Minister is reviewing the Ministerial Code and will bear this recommendation in mind as part of this process.

#### Scottish Government

In Scotland, the First Minister published a revised Scottish Ministerial Code on 17 December 2024, significantly strengthening transparency, accountability and independent scrutiny. Investigations into alleged breaches of the Code will no longer happen only at the instruction of the First Minster; Independent Advisers will be able to launch their own investigations whenever they feel it is warranted. Where there has been a breach, they will be able to advise the First Minister on appropriate sanctions. These changes are the most significant made to the Code since Independent Advisers were introduced in 2008 and will ensure that the highest standards of integrity, accountability and honesty are adhered to at every level of leadership.

#### Northern Ireland Executive

The Northern Ireland Civil Service (NICS) is a devolved matter, and each civil servant is expected to undertake their duties under the core values of **the NICS Code of Ethics**. This Code is issued by the Department of Finance and is regularly reviewed.

All Northern Ireland Executive Ministers must affirm a statutory **Pledge of Office** before taking office. This includes a pledge to comply with the **Ministerial Code of Conduct**, which requires Ministers to maintain the highest standards of conduct and behave in a way that upholds the highest standards of propriety, and to uphold the seven principles of public life. The Pledge of Office and the associated Ministerial Code of Conduct are set out in Schedule 4 to the Northern Ireland Act 1998 ("the 1998 Act").

The Assembly Commissioner for Standards can examine alleged breaches of the Ministerial Code of Conduct.

In addition, the **Northern Ireland Ministerial Code** sets out the rules and procedures for the exercise of the duties and responsibilities of Ministers and junior Ministers of the Northern Ireland Assembly. By virtue of section 28A of the 1998 Act, Northern Ireland Executive Ministers are under a statutory obligation to act in accordance with the Ministerial Code, which also includes within its provisions the Pledge of Office and Ministerial Code of Conduct as referenced above.

The Northern Ireland Executive accepts Recommendation 5 in principle. Work is ongoing under the leadership of the Department of Finance to determine a position in relation to a Hillsborough Law, which will inform how best to implement Recommendation 5 in that context going forward. The NI Executive agreed that the

UK Government's Bill should extend to NI, subject to an assessment of risk prior to the legislative consent motion.

# 6) Monitoring Liver damage for people infected with Hepatitis C

All patients who have contracted hepatitis via a blood transfusion or blood products should receive the following care:

6a) i. Those who have been diagnosed with cirrhosis at any point should receive lifetime monitoring by way of six-monthly fibroscans and annual clinical review, either nurse-led, consultant-led or, where appropriate, by a GP with a specialist interest in hepatitis.

This recommendation is accepted in full by the UK Government, the Scottish Government and the Welsh Government. It is accepted in principle by the Northern Ireland Executive.

6a) ii. Those who have fibrosis should receive the same care

This recommendation is accepted in principle by the UK Government, the Welsh Government, the Scottish Government, and the Northern Ireland Executive.

- 6a) iii. Where there is any uncertainty about whether a patient has fibrosis they should receive the same care
- 6a) iv. Fibroscan [ultrasound] technology should be used for liver imaging, rather than alternatives

Recommendations 6a) iii-iv) are accepted in full by the UK Government, the Scottish Government and the Welsh Government. They are accepted in principle by the Northern Ireland Executive.

6a) v. Those who have had Hepatitis C which is attributable to infected blood or blood products should be seen by a consultant hepatologist, rather than a more junior member of staff, wherever practicable

This recommendation is accepted in principle by the UK Government, the Welsh Government, the Scottish Government, and the Northern Ireland Executive.

6a) vi. Those bodies responsible for commissioning hepatology services in each of the home nations should publish the steps they have taken to satisfy themselves that the services they are commissioning meet the particular needs of the group of people harmed by NHS treatment

This recommendation is accepted in full by the UK Government, the Scottish Government and the Welsh Government. It is accepted in principle by the Northern Ireland Executive.

The Inquiry highlighted the inexcusable failure to recognise, at the earliest opportunity the risks of transmission and the potentially serious nature of Hepatitis C. This failure meant a missed opportunity, for "...any noticeable difference of approach to treatment, or even of any consideration whether a changed approach was warranted", which was clearly disastrous.

Following the publication of the Inquiry's May 2024 report, NHS England wrote to the Inquiry (via DHSC), seeking clarification around this recommendation. Two letters were written, one on 10.06.24 (letter 1) and one on 11.09.2024 (letter 2).

Letter 1 related primarily to issues around scanning techniques used to monitor liver disease. Responses were received (21.06.24) from DHSC and Cabinet Office confirming NHS England's clinical interpretation. This pertains especially to the use of fibroscan and ultrasound in monitoring liver disease progression. NHS England, through discussions with expert clinicians has attended to this issue through ensuring adherence to recognised international, evidence based guidance for the management of liver disease.

Letter 2 (11.09.24) related to the nature of hepatology service provision and care. This letter is available on the Inquiry website. A response was received on 16.10.24 which is also available on the Inquiry website. The Inquiry response, confirmed the objective for recommendation 6 is that there should be both surveillance for hepatocellular cancer and monitoring for the progression of fibrosis and cirrhosis in the groups identified.

In relation to the role of a consultant hepatologist (Recommendation 6(v)), the Inquiry provided the following clarification:

'It follows that the Inquiry's recommendation is for every patient infected with Hepatitis C through infected blood or blood products to be offered at least one consultation with a consultant hepatologist wherever practicable'.

On 16 October 2024, the Chair of the Inquiry wrote to the National Medical Director/Chief Medical Officers of England, Scotland, Wales and Northern Ireland on related issues. This letter provided further clarity on the references to fibroscan and ultrasound technology in relation to Recommendation 6 as follows:

'For people reading this correspondence, based on all the material before the Inquiry at the time of the Report and since, monitoring for the presence of fibrosis, and of cirrhosis, and their progression, is best performed by a Fibroscan or a similar elastographic test. However, monitoring for the development of liver cancer is best performed by the use of ultrasound, with (or, as appropriate, without) the use of an AFP test.

#### **UK Government**

We accept this recommendation but will balance its implementation against NHS England's role to promote equitable access for all, the principle that patients should receive the same treatment irrespective of how the disease was acquired, the practicability of implementing different pathways for cohorts of patients, and the latest evidence-based care and clinical guidelines.

The Government's acceptance in full or in principle of 6a) i-v. is contingent on the clarifications received from the Inquiry via correspondence referenced above.

DHSC and the NHS are committed to ensuring that all hepatitis patients receive appropriate care, including those patients who contracted hepatitis via a blood transfusion or blood products. All patients will have their care overseen by a consultant hepatologist and NHS England has undertaken an audit of current pathways to satisfy itself that patients with a Hepatitis C diagnosis receive appropriate follow-up and monitoring in line with the relevant National Institute for Health and Care Excellence (NICE) and professional guidance.

NHS England will additionally be pro-actively identifying patients with bleeding disorders:

- who may have been infected with Hepatitis C but never received a fibrosis test, so not had fibrosis staged, and may have been lost to hepatology services. A framework is being developed to define these individuals and enable haemophilia centres to refer forward to local ODN for fibroscan, and assessment for onward monitoring if appropriate; and
- 2. who are known to have been exposed to 'factor' blood products. but not known to have been tested or treated for hepatitis. These patients will be contacted and offered testing and signposted to onward care as appropriate.

A new NHS cirrhosis surveillance registry will be introduced to ensure there is a single data source to support the long-term surveillance of patients with cirrhosis.

While the numbers of patients who may require testing and follow-up are expected to be small, NHS England is committed to making every effort to ensure all patients with bleeding disorders who may have historically been exposed, have received appropriate testing, treatment and ongoing monitoring.

#### Scottish Government

The Scottish Government and the NHS in Scotland are committed to ensuring that all patients infected with Hepatitis C (HCV) through blood transfusions or blood products receive the highest quality care and therefore should be offered appropriate surveillance and monitoring, and that we should ensure these services are being provided consistently. The Infected Blood Inquiry Oversight and Assurance Group (OAG) for Scotland commissioned clinical advice on some of the points raised in the recommendations to determine how they should be delivered.

Ongoing monitoring (including six-monthly ultrasound scans) is already offered for most patients with cirrhosis so the Scottish Government is content that recommendation 6a) i. is in line with current practice. Also in line with current international clinical guidelines, the Scottish Government accepts 6a) ii. in principle for those with advanced fibrosis.

In line with the subsequent clarification issued by the Infected Blood Inquiry, which confirmed that fibroscans were recommended to assess fibrosis (liver scarring), while ultrasound scans should be used to monitor patients for hepatocellular carcinoma (liver cancer), the Scottish Government fully accepts recommendation 6a) iv. and is content that this aligns with current clinical guidance.

The Scottish Government is also committed to ensuring the consistent delivery of appropriate care to meet the needs of the group of people harmed by NHS treatment. Therefore, although hepatology services are not commissioned in Scotland, the Scottish Government is taking forward recommendation 6a) vi. to ensure that appropriate services and support are available in all Scottish Health Boards.

Separately the OAG asked for clinical advice on ongoing monitoring for infected blood victims with chronic Hepatitis B (HBV) and has agreed that the actions the Scottish Government will undertake in relation to recommendation 6a(vi) should also ensure appropriate monitoring is in place for those with chronic HBV.

#### Welsh Government

The Welsh Government published the Liver Disease Quality Statement in November 2022, which sets out our vision for good quality liver disease services for the next ten years. We are working closely with the Liver Disease Implementation Network (LDIN) to implement the quality statement. Priority areas include improving early detection of liver disease and Hepatitis B and C elimination.

Wales is able to meet recommendation 6 in general and the Welsh Government is currently working at UK level to seek a common position. The Welsh Deputy Chief Medical Officer for Health Services wrote to all Health Board Medical Directors in July 2024 to ask that they consider recommendation 6 in relation to liver disease.

#### Northern Ireland Executive

Currently in Northern Ireland, as is the case in Scotland, most patients with cirrhosis are already offered ultrasound scans every six months as part of their long-term clinical monitoring. This applies to all patients with cirrhosis, and as such, satisfies the requirements of Recommendation 6a) i.

Complexity arises for those who have been treated in the past and are not being actively clinically reviewed due to their diagnosis predating the availability of fibroscans.

On recommendation 6a) v., the current practice in Northern Ireland is for patients diagnosed with Hepatitis C, where it is attributable to infected blood, to be offered a consultant-led appointment.

The Office of the Chief Medical Officer Northern Ireland and expert clinical colleagues are being consulted to gain further insight and a deeper understanding in respect of the implications of these recommendations.

#### **Next Steps**

#### **UK Government**

NHS England will design a 'Look back' exercise to identify a list of people to be contacted and will publish complete guidelines for identification and management of historic HCV treatment population patients, who may not have had fibrosis/cirrhosis assessment, ensuring a linkage to care.

#### Scottish Government

In relation to 6a) ii. and iii., the Scottish Government continues to work with clinical experts and stakeholder representatives to ensure that appropriate, equitable and high quality care is provided for all cohorts of patients in line with evidence-based clinical guidelines and the principles of Realistic Medicine. Patient care is currently delivered through multi-disciplinary teams overseen by a consultant hepatologist or other appropriately experienced consultant (e.g. a gastroenterologist). However, the OAG is considering whether any further review is required to ensure that those treated in the past had appropriate consultation and assessment. The Scottish Government is also considering a number of options to take forward recommendation 6a) vi. to ensure that appropriate services and support are available to patients in all Scottish Health Boards. The Scottish Government is keen to explore an aligned response with other UK nations in the absence of any divergence in terms of clinical advice.

#### Northern Ireland Executive

Work will continue with clinical experts, partners and stakeholders to ensure equitable care is provided to all patients in line with current clinical guidelines, and maintain engagement with four nations counterparts, in particular in relation to Recommendations 6a) ii. and iii.

## 7) Patient Safety: Blood Transfusions

#### 7a) Tranexamic Acid

7a) i. In England, Hospital Transfusion Committees and transfusion practitioners take steps to ensure that consideration of tranexamic acid be on every hospital surgical checklist; that hospital medical directors be required to report to their boards and the chief executive of their Trust as to the extent of its use; and that the board report annually to NHS England as to the percentage of eligible operations which have involved its use. If the percentage is below 80% or has dropped since the previous year, this report should be accompanied with an explanation for the failure to use more tranexamic acid and thereby reduce the risk to patient safety that comes with using a transfusion of blood or red blood cells.

#### This recommendation is accepted in principle by the UK Government.

7a) ii. In Scotland, Wales and Northern Ireland offering the use of tranexamic acid should be considered a treatment of preference in respect of all eligible surgery.

The Scottish Government and the Welsh Government accept this recommendation in full, and the Northern Ireland Executive accepts this recommendation in principle.

7a) iii. Consideration be given to standardising and benchmarking transfusion performance between hospitals in order to deliver better patient blood management.

This recommendation is accepted in full by the UK Government, the Welsh Government, the Scottish Government and the Northern Ireland Executive. Parts of the recommendation are being taken forward on a UK wide basis.

The Inquiry highlights that many lessons have been learnt since the peak of this scandal. Whilst no medical treatment can be completely risk free, current safety standards for blood donation and transfusion are rigorous. Throughout the blood donation journey, there are processes in place to ensure the safety of blood and blood products. Thankfully, the risk of serious harm because of blood transfusion in the UK is low, at approximately one/1 in 11,000 blood components issued, however more must be done to ensure best practice is consistently implemented.

#### UK's governments

Recommendation 7 includes an especially complex set of sub recommendations. To ensure a joined up approach across the four nations, experts from across the four nations NHS bodies, blood services and external bodies such as the National Blood Transfusion Committee and Serious Hazards of Transfusion (SHOT) have formed a working group to take this forward carefully. Given this complexity, it is likely to take

several years to fully work through these sub recommendations. Funding will also be required to implement these clinical policies, and this has not yet been identified.

Whilst we agree with the Inquiry's recommendation for the increased use of tranexamic acid, further work is needed to ensure its safe and smooth implementation into patient care. The working group, with engagement from four nations stakeholders, is currently considering plans to increase use of tranexamic acid. Work is underway with professional bodies and specialists to consider provider guidance and give careful consideration to the needs of local organisations. Planning is underway for associated communications activities to support implementation with minimal disruption to patients.

#### **UK Government**

In relation to the recommendation on standardising and benchmarking, a review of current benchmarking practices and associated data collection and ongoing intelligence and analysis requirements, including model health dashboard and national clinical audit, has been initiated. This will be followed by the development of new benchmarking categories and funding will be required to expand the model health dashboard.

A proposal has been submitted to the National Institute for Health and Care Excellence (NICE) in December 2024 with a request to update guidance. Work is underway with CQC to incorporate standards within the relevant framework.

#### Scottish Government

The Scottish Government's Oversight and Assurance Group (OAG) Chair and Deputy Chair wrote to Health Boards in November 2024 asking them to review practice within their Board and confirm that they are offering tranexamic acid to patients wherever it is appropriate for them in advance of elective surgery. This letter also asked Health Boards to use the Scottish National Blood Transfusion Service's (SNBTS) Clinical Transfusion Dashboard to consider areas for improvement to ensure they are only providing transfusions where this is necessary in line with recommendation 7a) iii. Health Boards were supportive in their responses, although some raised questions about the full and updated evidence base for use of tranexamic acid in some cases/particular surgeries so it is clear some additional guidance is needed on what should be considered 'eligible surgery' (as this was not specified by the Inquiry). There is general consensus that tranexamic acid should be used in advance of operations where blood loss of over 500ml is likely to occur. However, given ongoing discussions at UK level and an anticipated request to NICE to update its guidance, the Scottish Government will provide a further update to Health Boards on these matters once updated clinical guidance is available. All Health Boards have confirmed that the SNBTS Clinical Transfusion dashboard is being utilised to benchmark and improve transfusion practice.

#### Welsh Government

The Welsh Government has asked the Blood Health National Oversight Group (BHNOG) to work with our Health Boards and Trusts to confirm adherence to the current NICE guidance. The BHNOG will then review the findings and propose improvements as necessary. A WHC has been issued to support this recommendation including support from the Chief Pharmaceutical Officer on dosing guidance ahead of the anniversary of the publication of the IBI report. Longer term projects on data through eMPA (e-Prescribing and Medicines Administration System) and development of an All Wales Surgical Checklist to include Patient Blood management – such a use of TXA. As these are national programmes of work expected implementation will need to be phased therefore rolling completion is expected by 2026.

#### Northern Ireland Executive

In Northern Ireland, the Department of Health is currently liaising with Health Trusts, Royal College of Surgeons, Northern Ireland Blood Transfusion Service (NIBTS) and Northern Ireland Transfusion Committee (NITC) to understand the extent to which the use of tranexamic acid is used or offered across the system. The NITC, in particular, has asked all Trusts to ensure tranexamic acid is being offered to patients receiving relevant surgery and have engaged with each Trust's Transfusion Committee to reconcile the necessary assurance that current practices do indeed meet the requirements of this recommendation.

- 7b) Review of progress towards the Transfusion 2024 recommendations,
- 7c) Transfusion laboratories, 7d) Training in Transfusion Medicine, and
- 7e) Implementing SHOT reports
- 7b. Progress in implementation of the Transfusion 2024 recommendations be reviewed, and next steps be determined and promulgated; and that in Scotland the 5 year plan is reviewed in or before 2027 with a view to determining next steps.
- 7c. Transfusion laboratories should be staffed (and resourced) adequately to meet the requirements of their functions.
- 7d. That those bodies concerned with undergraduate and postgraduate training across the UK of those people who are, or intend to be, working in the NHS ensure that they are adequately trained in transfusion, that the standards by which sufficiency of training is measured are defined, and accountability for training in transfusion be defined.
- 7e. That all NHS organisations across the UK have a mechanism in place for implementing recommendations of Serious Hazard of Transfusion (SHOT) reports, which should be professionally mandated, and for monitoring such implementation.

These recommendations are accepted in principle by the UK Government, the Scottish Government, the Welsh Government, and the Northern Ireland Executive. Recommendation 7b) is accepted in full by the Scottish Government. Parts of these recommendations are being taken forward on a UK wide basis.

Progress against Transfusion 2024 recommendations has been initially reviewed jointly by NHS England and NHSBT and a wider four nations stakeholder review is being scheduled. The draft report was discussed with key stakeholders at the end of November 2024 with further input underway in April/May 2025, and finalisation of the full report during the first quarter of 2025/26. Key aspects have been incorporated into the Transfusion Transformation Strategy (TTS).

The TTS is focusing on the next 5-10 years, amalgamating progress, learnings and future ambition in this area. Sub-recommendations from the working group on recommendation 7 are expected to be incorporated into the TTS, to provide a coherent future forward implementation plan for blood transfusion practices. This includes the potential creation of a National Blood Transfusion Board to improve national governance and delivery oversight across the complex system. Substantial funding will be required to design and deliver a transfusion transformation programme.

Work is ongoing to determine the current status of transfusion staffing, reviewing best practice from other areas including nursing, and developing an evidence base

to inform minimum staffing level standards. The data for staffing is complex and will require careful cross-checking and analysis to determine the best way forward. Funding will be required to undertake full workforce modelling and develop minimum staffing level standards.

The stakeholder group, including a range of professional and statutory bodies, have been working together to review and propose educational and training requirements. The group is currently collating patient safety e-learning material to provide a four nation mapping document for patient safety e-learning material. Curricula for medical, scientific, and nursing / allied health professional staff are undergoing review to determine future provision and recommended practices. Funding will be required to address training gaps and to establish practice educators to ensure future sustainability.

Work is underway to develop governance practices for the implementation of SHOT recommendations, with careful consideration given to the needs for standardisations and the needs of local organisations. Accreditation for SHOT as an organisation for the use of the Central Alerting System is under consideration, which will allow the use of the web-based cascading system to issue patient safety alerts. This will streamline SHOT recommendation cascade and maximise the visibility of recommendations in Trusts, which is funding dependent. Furthermore, SHOT is developing safety standards to provide guidance for NHS provider organisations.

#### Scottish Government

In relation to 7b), the Scottish National Blood Transfusion Service (SNBTS) will update its five-year transfusion team plan by 2027 in line with recommendation 7b). On recommendation 7c), the Scottish Government-NHS in Scotland Planning and Delivery Board is considering blood banks as part of both rural and island and diagnostics workstreams to review the sustainability of hospital services in these areas. This will include looking at staffing, as well as other options to help improve resilience and therefore ensure these services can continue to operate safely 24 hours a day, 7 days per week. In addition, the Health and Care (Staffing) (Scotland) Act 2019 provides a statutory basis for the provision of appropriate staffing in health and care services, enabling safe care and improved outcomes for patients. The Act came into force in April 2024 and covers a wide range of NHS staff, including those working in transfusion laboratories.

In relation to recommendation 7d) (along with recommendation 3), a separate Scottish working group is now in place to take forward the work. This will complement the work being done by the UK-wide stakeholder group, but focus on particular actions needed to be delivered in Scotland.

The Scottish Government established a short-life working group involving NHS staff, SNBTS and SHOT to consider how best to support Health Boards to implement recommendation 7e). This OAG agreed with recommendations made by the group and will write to Health Boards following the publication of the next SHOT report in

July 2025 asking them to ensure they are meeting this IBI recommendation on an ongoing basis. While it is primarily for Health Boards to monitor progress and assure themselves that the actions being taken are sufficient, the Scottish Government will carry out an initial period of external assurance and monitoring in order to ensure fulfilment of this recommendation and sufficient focus on the new standards.

#### Welsh Government

In relation to 7b), Wales has a Blood Health Plan (BHP) which is regularly reviewed and updated. The Blood Health Plan is overseen by the Blood Health National Oversight Group (BHNOG). While separate from "Transfusion 2024" which applies to England, the BHNOG considers this and other initiatives in the UK when considering plans in Wales. The current BHP acknowledges the need to support the IBI recommendations and the BHNOG has performed a full workplan review, and produced recommendations to support implementation of the IBI recommendations within its remit (primarily recommendation 7). The recommendations have been accepted by the Welsh Government and the All Wales Medical Directors Group. The BHNOG has reviewed its ToR to improve clinical governance and ensure engagement with relevant clinical stakeholders to raise the profile of transfusion safety issues at a health board level and support local implementation.

On recommendation 7c), (transfusion laboratories) Wales are updating national laboratory information systems to improve the efficiency of transfusion laboratory practice. Work is ongoing to determine the current status of transfusion staffing and developing a minimum staffing level standards which consider the impact of staffing requirements once digitisation programmes have been rolled out in 2025. WBS are currently costing the staffing gap within the transfusion laboratories across NHS Wales to address these issues.

On 7d), The BHNOG Education Strategy Group has been established to provide governance and oversight of transfusion education across Wales. Through this group and in conjunction with key stakeholders such as Health Education and Improvement Wales (HEIW), Welsh Blood Service and other NHS organisations in Wales, the process of formally reviewing training procedures and agreeing the strategy for transfusion education for all staff involved with the transfusion process in a standardised, equitable manner across Wales and will build upon already embedded programmes of education. A pilot programme for Foundation Doctors has been developed with planned implementation from Autumn cohort 2025. Exploratory work in progress to support mandatory transfusion e-learning for all staff involved in the transfusion process. Work is ongoing in liaison with HEIW and Cwm Taf University Health Board to secure an additional postgraduate training post in Haematology that would rotate into WBS to enhance transfusion knowledge in Wales.

On 7e), The BHNOG has a Serious Hazards of Transfusion (SHOT) subgroup and oversees the implementation of SHOT recommendations. The BHNOG is supported by the SHOT subgroup by outlining more robust transfusion safety governance

within Health Boards linking with established patient safety mechanisms. The SHOT subgroup works closely with the National SHOT team to support development of governance practices to support local implementation of SHOT recommendations.

## WBS on behalf of NHS Wales are currently drafting a business case for resources required to meet the IBI recommendations in full.

#### Northern Ireland Executive

Transfusion 2024 is an NHS England document and was not adopted in Northern Ireland. The most recent transfusion strategy remains the 2011 Better Blood Transfusion 3 Northern Ireland (BBT 3 (NI)), but work is ongoing to update this strategy and produce a new NI Transfusion Strategy under the collaborative leadership of the NI Transfusion Committee (NITC) and NI Blood and Transfusion Service (NIBTS).

This strategy will provide a framework for optimising transfusion practice in Northern Ireland, and will cover all aspects of blood transfusion from donation, through laboratories, to clinical teams, and ultimately, patient safety. The overarching objectives are to ensure the safety, efficiency, and sustainability of blood and blood products, emphasising Patient Blood Management to reduce blood component use and ensuring safe and secure supply and education for clinicians. It will align with national and international best practices, and provide recommendations to benefit patients and the broader healthcare system.

Work has been done by the Department to scope the requirements across the region in order for transfusion laboratories to meet the requirements of their functions.

NIBTS, NITCE and the NI Medical & Dental Training Agency (NIMDTA) represent Northern Ireland at an established National Working group, which is taking forward the requirements around Recommendation 7a), b) and d). The NITC has also been a member of the UK & Ireland Better Transfusion Network for many years, and all national training for safer blood transfusion comes through this group.

Available HSC training modules are currently being updated, but there has been significant compliance with national training among postgraduate nursing and medical staff (including bank and locums), and NITC provides training for medical students at Queen's University Belfast and the University of Ulster.

On 7e), the Department of Health is currently undertaking engagement with Health and Social Care Trusts to assess the level to which the recommendation is already being carried out. NIBTS is contributing to the national SHOT working group to support the implementation of 7e) and SHOT recommendations.

#### 7f) Establishing the outcome of every transfusion

7f) i. That a framework be established for recording outcomes for recipients of blood components. That those records be used by NHS bodies to improve transfusion practice (including by providing such information to haemovigilance bodies). Success in achieving this will be measured by the extent to which the SHOT reports for the previous three years show a progressive reduction in incidents of incorrect blood component transfusions measured as a proportion of the number of transfusions given.

7f) ii. To the extent that the funding for digital transformation does not already cover the setting up and operation of this framework, bespoke funding should be provided.

Recommendations 7f) i-ii) are accepted in principle by the UK Government, the Welsh Government, and the Northern Ireland Executive. They are accepted in full by the Scottish Government.

7f) iii. That funding for the provision of enhanced electronic clinical systems in relation to blood transfusion be regarded as a priority across the UK.

This recommendation is accepted in principle by the UK Government, the Welsh Government, the Scottish Government, and the Northern Ireland Executive.

#### **UK Government**

Implementing these sub recommendations is particularly challenging and requires substantial investment, as it involves working across the four nations and with multiple system partners.

To support an effective long term implementation plan that minimises complexity, a design team is currently undertaking mapping of clinical pathways, the requirements of digitisation along the pathway, interoperability and the employment of standards. Careful consideration needs to be given to the digital maturity of local organisations. Interdependencies will need to be mapped against other large digital initiatives and systems to be implemented.

#### Scottish Government

The existing 'Account for Blood' system already helps Scottish Health Boards to monitor outcomes for transfusion patients. SNBTS is working with its digital colleagues in NHS National Services Scotland (NSS), with help from the Haematology and Transfusion clinical network, to amend this system to ensure it can deliver the key elements envisaged by recommendation 7f) i. Separately the Scottish Government is working with SNBTS and NSS, with help from the Haematology and

Transfusion clinical network, to help identify the gaps in current digital systems provision in the transfusion process within the Health Boards. This will then be developed into an outline business case to consider the most appropriate options for digitisation, which will be discussed in detail with all the Health Boards.

#### Welsh Government

A Digital working group consisting of Welsh Government officials, Welsh Blood Service, BHNOG and Digital Health & Care Wales (DHCW) has been established and has developed a roadmap outlining the interdependencies of current national IT programmes to meet this recommendation in full including timelines and costing required. Data accessibility to allow monitoring and benchmarking via the National Data Resource (NDR) is also underway, this work is supported through a proof of concept for clinical benchmarking within a data dashboard for Preoperative anaemia management for major surgery that will include red cell transfusions.

#### Northern Ireland Executive

As part of an extensive programme of transformation and modernisation of the Health and Social Care System (HSC) in Northern Ireland, the Pathology Blueprint Programme, a new regional pathology management structure, will provide a digital roadmap and the introduction of digital interoperability across the whole local system and digitalisation of pathology services through three electronic systems for blood transfusions: on the clinical side, a regional Electronic Patient Record (EPR) will create a single digital care record for every citizen in Northern Ireland who receives health and social care; for laboratories and blood banks, the WinPath Core Laboratory Information Management System (LIMS) will significantly improve the delivery of key clinical diagnostic services; and the new Blood Production and Tracking (BPaT) solution will integrate blood production and tracking information to provide a fully functioning regional electronic vein-to-vein donor management, blood production and tracking system.

Once fully developed and integrated, these solutions will lead to an improved ability to ascertain patient outcomes for those receiving a transfusion, and will be paramount in providing one safe effective interface for clinical staff to ensure the right blood goes to the right patient. Moreover, service users will have access to all the relevant pathology data, including blood transfusion outcomes.

The Department of Health is currently engaging with Data Management colleagues within the Department and HSC Trusts to assess the extent to which this recommendation is already being carried out amid these ongoing developments.

## 8) Finding the undiagnosed

8a. When doctors become aware that a patient has had a blood transfusion prior to 1996, that patient should be offered a blood test for Hepatitis C.

8b. As a matter of routine, new patients registering at a practice should be asked if they have had such a transfusion.

These recommendations are accepted in full by the UK Government, the Welsh Government and the Scottish Government. These recommendations are accepted in principle by the Northern Ireland Executive.

#### **UK Government**

NHS England is committed to identifying all those infected with a bloodborne disease, however it is transmitted.

We would like to reassure the public that evidence shows the likelihood of contracting Hepatitis C via a blood transfusion after 1992 is extremely low following the introduction of universal blood screening to detect Hep C infection in September 1991. However, to address the Inquiry's conclusion that it is 'reasonably possible' that some infections may have occurred from blood transfusions after universal screening was introduced, the UK Government accepts this recommendation.

Delivery is progressing and the recommendation is ready to be implemented. Changes to the GP Online Registration service, which will help deliver this recommendation, have been agreed and the national "go-live" date is the end of May. NHS England is publishing supporting implementation guidance for GP practices in advance of this go live.

#### Scottish Government

In Scotland, there has already been awareness raising in this area in 2015 and 2016 following the Penrose Inquiry's recommendation, therefore many transfusion patients were tested for Hepatitis C at that time. An updated Chief Medical Officer (CMO) letter was issued in June 2024 to ask all GP practices and staff in secondary care in Scotland to offer Hepatitis C testing to anyone transfused prior to 1996 who has not already been tested. The letter also asks GP practices to ensure they ask new patients about any previous blood transfusions when they have their initial appointment with a new GP practice. Information for patients on the NHS Inform website has been updated to align with the CMO letter. These recommendations have therefore now been implemented.

#### Welsh Government

In Wales, the Deputy Chief Medical Officer along with the Senior Medical Officer for Primary Care, have issued a Welsh Health Circular (WHC (2024)50) to all Health

Boards asking them to advise those in Primary Care to test patients when the circumstances meet the criteria and for them to update their new patient screening to include a question on previous blood transfusions. These recommendations have been implemented.

#### Northern Ireland Executive

In Northern Ireland, the Chief Medical Officer issued a Circular on Hepatitis C Testing Guidance (HSS(MD)16/2024) to advise that Hepatitis C testing was currently carried out via routine clinical care for people who think they might have been infected through a blood transfusion or in another way.

Further engagement is currently ongoing with the Department's Strategic Planning and Performance Group and primary care policy leads to ascertain the best approach to adopt in relation to General Practice registration.

### 9) Protecting the Safety of Haemophilia Care

9a-c) Peer review of haemophilia centres, 9d) Networks for haemophilia care, 9e) Recombinant Products, and 9f) National haemophilia database

9a. That peer review of haemophilia care should continue to occur as presently practised, with any necessary support being provided by NHS Trusts and Health Boards; and

This recommendation is accepted in full by the UK Government, the Scottish Government and the Welsh Government. The Northern Ireland Executive accepts this recommendation in principle.

9b. That NHS Trusts and Health Boards should be required to deliberate on peer review findings and give favourable consideration to implementing the changes identified with a view to ensuring comprehensive, safe, care.

This recommendation is accepted in principle by the UK Government, the Welsh Government and the Northern Ireland Executive. The Scottish Government accepts this recommendation in full.

- 9c. A peer review of each centre should take place not less than once every five years.
- 9d. The necessary administrative and clinical resources should be provided by hospital trusts and boards, integrated care boards, and service commissioners to facilitate multi-disciplinary regional networks to discuss policy and practice in haemophilia and other inherited bleeding disorders care, provided they involve patients in their discussions.
- 9e. Recombinant coagulation factor products should be offered in place of plasma-derived ones where clinically appropriate. Service commissioners should ensure that such treatment decisions are funded accordingly.
- 9f. That the National Haemophilia Database, run by the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO), merits the support of additional central funding.

Recommendations 9) c-f) are accepted in principle by the UK Government, the Welsh Government and the Northern Ireland Executive. The Scottish Government accepts this recommendation in full.

The practice of peer reviews of haemophilia centres, highlighted by the Inquiry, is valuable and should be supported.

#### **UK Government**

Recommendation 9a-9c: Peer review of UK comprehensive care centres has been

an essential part of haemophilia services for many years. The triennial audit was replaced in 2019 with a more formal peer review process on a five year cycle.

The existing NHS England specialist services for haemophilia and related bleeding disorders (adults and children) service specification has been updated to ensure a contractual requirement for providers to participate in, and act upon peer review findings. NHS England will also write to Integrated Care Boards and Trust Boards to emphasise the valuable role of peer review and ask for their commitment to review and implement findings. The revised service specification is intended to proceed to public consultation in summer 2025.

Recommendation 9d: The need to develop and strengthen multi-disciplinary regional networks to discuss policy and practice in haemophilia and other inherited bleeding disorders to improve patient care and support standardisation is supported by the clinical community. NHS England has drafted a proposed National Clinical Network Specification specifically for these networks, which would embed key new requirements for providers to participate in a networked model of care. This would require additional funding to implement, as is the case with other clinical network models, in recognition of the staff time required, and funding has not yet been identified.

Recommendation 9e: NHS England, working with clinical advisors, has reviewed the existing gaps in the availability of recombinant factors, and other blood product alternatives, and is currently developing clinical commissioning policies for these indications. As a rapid response to this recommendation, in August 2024, NHS England commenced funding recombinant Von Willebrand factor (VWF), for all patient age groups, to manage bleeding episodes and surgical pre-treatment (but not regular prophylaxis). Further clinical policy work, which includes reviewing the clinical evidence base, cost effectiveness and service implementation factors, is required relating to the use of recombinant products for prophylaxis. Work is currently underway on the following:

- Recombinant VWF: currently licensed for prophylaxis in adults (regular treatment for those with the severest bleeding) but not currently commissioned for this indication.
- Emicizumab as prophylaxis in people with moderate congenital haemophilia A without factor VIII inhibitors.

Funding will be required to implement these clinical policies, and this has not yet been identified.

Recommendation 9f: NHS England currently provides 'central' funding of approximately 40% of the total annual cost for running the National Haemophilia Database. A task and finish group relating to the database has been established, reporting into the overarching recommendation 9 expert group.

#### Scottish Government

These recommendations have largely been implemented in Scotland. Regular peer reviews are already taking place for the larger Comprehensive Care Centres (in Glasgow and Edinburgh), but, given limits in the UK Haemophilia Centre Doctors' Organisation's (UKHCDO's) capacity to schedule peer reviews for the Haemophilia Treatment Centres, arrangements are being made to do Scottish-led peer reviews of these smaller centres (in Inverness, Aberdeen and Dundee). The Scottish Oversight and Assurance Group Chair has written to the relevant Health Boards to ask them to implement any future findings and recommendations from these peer reviews.

The Scottish Inherited Bleeding Disorders Network is an established managed clinical network which includes staff and patients and helps ensure learning and promotion of good practice across Scottish haemophilia centres in line with recommendation 9d).

The great majority of bleeding disorders patients in Scotland are already provided with recombinant products rather than plasma-based ones. However, in relation to provision of the recombinant product vonicog alpha (known as Veyvondi) for children under 18 years old with von Willebrand disease, given the medicine is not currently licensed for use for under 18s, the Chief Pharmaceutical Officer for Scotland wrote to Scotlish Health Boards in October 2024 to ask them to ensure it is prescribed for children where this is appropriate for them in line with recommendation 9e).

#### Welsh Government

The Welsh Government is currently working with the Haemophilia Centres on their peer review findings to take forward any recommendations and implement changes as necessary.

The recombinant coagulation factor Vonicog alfa is routinely available in Wales for the treatment of haemorrhage and surgical bleeding, and for prevention of surgical bleeding, in people with a confirmed diagnosis of von Willebrand disease (VWD) in accordance with the NHS Wales Joint Commissioning Committee policy.

The All Wales Medicines Strategy Group (AWMSG) endorsed One Wales interim decision which extends routine use to children up to 17 years with VWD.

The IBI Oversight Group has recommended Vonicog alfa should also be made available for long term prophylaxis against bleeds in people with VWD. Officials are considering the implications of implementing this recommendation and are working with the Joint Commissioning Committee and All Wales Therapeutics and Toxicology Centre (AWTTC) to prepare advice for consideration by Ministers later this spring.

#### Northern Ireland Executive

In Northern Ireland, Recommendations 9a) to 9d) are carried out as standard practice. The Belfast Health and Social Care Trust is is commissioned by the Department (through the Strategic Planning and Performance Group) to carry out this work and houses the Haemophilia Comprehensive Care Centre (CCC), which is the only centre in Northern Ireland; there are not any Haemophilia Treatment Centres (HTCs).

There is no Regional Network in Northern Ireland, and this is taken into consideration by Peer Review Teams while Peer Review Audits are carried out within both the Haemophilia Adult and Paediatric Services within the Trust.

In relation to Recommendation 9e), the Department of health has a formal link with the National Institute for Health and Care Excellence (NICE) under which NICE Technology Appraisals are reviewed locally for their legal and policy applicability in Northern Ireland, and where applicable, they are endorsed for implementation within HSC organisations. As such, in practice, treatments that have been recommended by NICE for routine use in the NHS in England are also routinely available in Northern Ireland.

The Health and Social Care (HSC) Managed Entry of New Medicines process applies NICE recommendations as policy. In the absence of a NICE recommendation, guidance from the Scottish Medicines Consortium (SMC) or All Wales Medicines Strategy Group (AWMSG) advice can be applied on a discretionary basis.

Where such guidance is not available as described above, an Individual Funding Request (IFR) process will provide a mechanism to consider requests from clinical consultants for treatments for individual patients that are not routinely commissioned, and which are deemed as clinically exceptional. Funding will be on an individual patient basis only, but where a cohort of 3 or more patients may potentially benefit from a treatment, this then will fall out of scope of the IFR process.

In the specific case of vonicog alfa (Veyvnodi) for long-term prophylaxis of haemorrhage in adults (licensed indication) or children (unlicensed indication) with von Willebrand disease, in the absence of NICE, SMC or AWMSG guidance, there is no route in Northern Ireland under extant arrangements to make this treatment routinely available within the HSC. However, the Department of Health will remain abreast of any developments arising from England, Scotland or Wales and give their advice due consideration.

#### **Next Steps**

NHS England are reviewing the wording in the draft national service specification to consider if further edits are required to align the wording with the recommendations of the IBI report. NHS England will also formally write to the Chair of each NHS Trust with a Comprehensive Care Centre (CCC) or Haemophilia Treatment Centre (HTC) designation asking for their commitment as a board to consider and implement the findings of peer reviews. The outcomes of the peer review process will be reviewed at NHS England's Specialised Commissioning National Quality Governance Group for assurance that recommendations are being acted on.

The definitions for CCCs and HTCs will be reviewed to ensure that the criteria to be designated as a CCC or HTC remain relevant.

## 10) Giving patients a voice

## 10a) i-iii) That the patient voice be enabled and empowered by the following measures

10a) i. A clinical audit should as a matter of routine include measures of patient satisfaction or concern, and these should be reported to the board of the body concerned. Success in this will be measured by comparing the measure of satisfaction from one year to the next, such that the reports to the board concerned demonstrate a trend of improvement by comparing this year's outcomes with the similar outcomes from at least the two previous years.

This recommendation is accepted in principle by the UK Government and the Northern Ireland Executive. This recommendation is accepted in full by the Scottish Government and the Welsh Government.

10a) ii. That the following charities receive funding specifically for patient advocacy: the UK Haemophilia Society; the Hepatitis C Trust; Haemophilia Scotland; the Scottish Infected Blood Forum; Haemophilia Wales; Haemophilia Northern Ireland; and the UK Thalassaemia Society.

This recommendation is accepted in full by the UK Government and the Scottish Government. The Welsh Government and the Northern Ireland Executive accept this recommendation in principle.

10a) iii. That favourable consideration be given to other charities and organisations supporting people infected and affected that were granted core participant status (as listed on the Inquiry website) to continue to provide support for at least the next 18 months. Further support should be reviewed at that stage with a view to it continuing as appropriate.

This recommendation is accepted in full by the UK Government. It is accepted in principle by the Scottish Government, the Welsh Government and the Northern Ireland Executive.

When talking about the patient voice, the Inquiry report says "...it is currently speaking in a very quiet whisper, steps must be taken, as best can be done, to enable those who should listen to hear it far more loudly". We agree - medical authorities and the Government must become less defensive when patients report problems with their care.

#### **UK Government**

The Health Secretary, the Rt Hon Wes Streeting MP, in setting out his mission for saving the NHS earlier this year, stated his aim to return to the "highest patient satisfaction in history". Giving patients a voice, and then listening to it, will be crucial to the success of this mission.

In regard to clinical audits, the principles underpinning these recommendations are well represented within new workstreams commissioned by the UK Government and NHS England. NHS England is undertaking work to understand what already exists across clinical audits and wider, particularly those related to blood, to clarify where there might be gaps in patient involvement and satisfaction/concern reporting and what more can be done to support these recommendations. There may be other measures, alongside what already exists, like Friends and Family Test to better understand patient experience. There are interdependencies with multiple other programmes and strategies to capture patient voice being taken forward by NHS England such as the HaemTrack app and in light of 10YHP policy developments, which will require careful thought and consideration.

In relation to 10a) ii, funding totalling £500k will be provided to the charities named by the Inquiry; the Haemophilia Society, The Hepatitis C Trust and the UK Thalassaemia Society, to support their valuable patient advocacy work. Meetings are being held with these charities to go through the grants process and the next steps for agreeing awards to the individual charities. Consideration is being given as to how to best support organisations and charities listed under 10a) iii, however the Government is committed to supporting them as appropriate.

#### Scottish Government

There is currently some patient involvement in audit steering groups and Public Health Scotland has been considering the best ways to engage patients in future and planned audits. The Scottish Government MOU with Public Health Scotland, in relation to the Scottish National Audit Programme, has the requirement to ensure patient voice and experience is included in the development of new audits. The Scottish Government will also build on existing work utilising patient experience data at a Board level or across specialties gathered via Care Opinion (a patient experience platform used by all NHS Boards across Scotland). Once appointed, the newly established Patient Safety Commissioner for Scotland will focus on raising the profile of the patient voice.

In relation to recommendation 10a) ii., the Scottish Government has agreed grant funding for both Haemophilia Scotland and the Scottish Infected Blood Forum for 2025-26, which will particularly support patient advocacy work by the charities.

#### Welsh Government

On 10a) i., in Wales, the Patient Experience Programme has developed the Peoples Experience Framework and Peoples Experience Survey in partnership with Welsh Government, NHS health boards and Trusts; Llais (the citizen's voice body) and third sector organisations. It builds upon the Assuring Service User Experience Framework, and the Patient Reported Experience Measure mechanism launched in 2013.

Guidance was issued to NHS Wales and professionals in the Autumn 2024. Organisations will be fully supported with the transition and preparation for the formal Go Live of the People's Experience Framework and People's Experience Survey April 2025. The Health Boards have established governance structures to oversee, audit and report patient feedback to the quality, safety, and patient experience committees, and ultimately to the board. The revised framework empowers organisations to evaluate their current position and to develop an ambitious improvement plan.

The NHS Wales Performance Framework for 2025-2026 emphasizes the creation of a higher value health and social care system in Wales, as outlined in Quadruple Aim 4. This aim focuses on rapid improvement and innovation, enabled by data and centred on outcomes. One of the key Performance measures for 2025/26 (measure 45) under this aim is the number of people experience surveys completed and recorded on the CIVICA platform.

Since August 2023, the people experience survey initiative has been piloted in Emergency Department (ED) settings and it was rolled out in full across all NHS services in April 2025. The results of the people experience surveys are now captured via the CIVICA platform and displayed on the BEACON Dashboard. These findings are shared at monthly Integrated Quality Performance Delivery (IQPD) forums to ensure continuous improvement and informed decision-making.

On 10a) ii., the Welsh Government continues to work with Haemophilia Wales to scope the future advocacy requirements for those infected and affected.

#### Northern Ireland Executive

In Northern Ireland, an Infected Blood Stakeholder Group was set up as part of the work around the establishment of the Infected Blood Compensation Scheme, and this group has been kept updated and engaged on the local response to the IBI report.

This group includes representatives from Haemophilia NI, Families and Friends of Haemophilia NI and the UK Haemophilia Society, as well as members of the infected and affected community.

Specific discussions have also been held in relation to Recommendations 10a) ii. and iii. in order to identify the best approach and mechanism to support the advocacy and support functions of the local voluntary and community sector organisations.

#### **Next Steps**

DHSC are developing options following the initial review of clinical audits to explore how best to support patient experience measures. The response will depend on the scope and scale of the requirements, and their associated costs.

#### 10a) iv) Thalassaemia and Sickle Cell

10a) iv. Particular consideration be given, together with the UK Thalassaemia Society and the Sickle Cell Society, to how the needs of patients with thalassaemia or sickle cell disease can best holistically be addressed.

This recommendation is accepted in principle by the UK Government, the Welsh Government, the Scottish Government and the Northern Ireland Executive.

It is regrettable, but understandable, that the Inquiry heard from relatively low numbers of people with thalassaemia or sickle cell disease. It is especially important therefore, that further consideration be given to the needs of these patients, so they can be addressed.

#### **UK Government**

NHS England has successfully established a comprehensive programme of work to prioritise reduction of clinical risk, increase support and care in the community, digitise care plans and step up prevention activities following their review of both the sickle cell and thalassaemia care pathways. The programme of work has been planned to be delivered in tandem with the 10YP with initial funding provided to support focussed work on improving care during an acute crisis. Further funding will be needed to fully implement the programme and this has not yet been identified. The ultimate aim of the work programme is to improve outcomes and quality of life for persons with thalassaemia or sickle cell disease. The UK Thalassaemia Society and Sickle Cell Society are engaged in this ongoing work programme. NHS England has an SCD Patient Advisory Group and has set up a Thalassaemia Patient Advisory Group so both stakeholders can work collaboratively with NHS England to co-produce the outputs.

#### Scottish Government

The Scottish Government's Rare Disease Action Plan aims to improve the care and treatment for people living with rare conditions, including sickle cell and thalassaemia. The Scottish Government is engaging with existing networks in Scotland, including the Scottish Paediatric and Adult Haemoglobinopathy Network, to understand the needs of these patients and identify opportunities to further support them through the work of the Action Plan.

#### Welsh Government

In Wales the Hereditary Anaemia Service: The Sickle Cell & Thalassaemia Centre was set up in 1990 to provide screening, counselling and support services. The multi-disciplinary team works with health boards to ensure patients receive quality-based service appropriate for their needs. The paediatric team provides care

from birth until patients transfer to the adult team.

#### Northern Ireland Executive

The population affected by thalassaemia and sickle cell diseases resident in Northern Ireland is very small and is considered a low prevalence area. However, this population is expanding and therefore, the Public Health Agency is currently looking at the potential for screening pregnant women for sickle cell and thalassaemia. At present, there aren't any local clinical specialists in Northern Ireland, and therefore, no engagement. A Service Level Agreement is however in place with St Thomas' Hospital, London.

#### 10a) v) Patient Feedback

10a) v. Steps be taken to give greater prominence to the online Yellow Card system to those receiving drugs or biological products, or who are being transfused with blood components.

This recommendation is accepted in full by the UK Government, the Welsh Government, the Scottish Government and the Northern Ireland Executive.

The online Yellow Card system is UK wide and therefore this recommendation has been addressed on a UK wide basis. The Yellow Card system has provided vital feedback, but we agree with the inquiry that this deserves greater publicity.

The Medicines and Healthcare Regulatory Agency (MHRA) in collaboration with Serious Hazards of Transfusion (SHOT) have put plans in place and agreed a high-level curriculum to deliver blood training and awareness workshops.

The first workshops were delivered to the Welsh and South West region in January 2025, with a second workshop arranged to be delivered in Scotland in May.

User stories for the Yellow Card platform changes have been approved and are undergoing user acceptance testing for delivery by September 2025. A scoping meeting for final delivery of the changes is to be arranged.

Further promotional activities are planned via updates to the online Yellow Card platform, bulletins and the upcoming 60th Anniversary of the platform. The Yellow card 60th anniversary events publicised the MHRA yellow card function. Further opportunities will be made from MHRA events and conference invites where MHRA speak to raise awareness and further education about the Yellow Card scheme in relation to blood, working with patient organisations, other healthcare partners and Royal Colleges.

## 11) Responding to calls for a Public Inquiry

11a. That a minister should retain the power to call an inquiry as the minister sees fit, in accordance with the Inquiries Act 2005 – but where a minister does not choose to do so, then:

11b. If there is sufficient support from within Parliament for there to be an inquiry, the question whether there should be one should be referred to the Public Administration and Constitutional Affairs Committee (PACAC) for it to consider the question.

11c. If it appears to PACAC that there is sufficient concern to justify a public inquiry, either because what happened and why has caused concern (as the committee sees it) or there are likely to be lessons learned which may prevent similar concerns arising in future, the committee may recommend to an appropriate minister that there be an inquiry.

11d. If the minister disagrees with the recommendation, they must set out in detail and publish reasons for this disagreement which are sufficient to satisfy PACAC that the matter has been carefully and properly considered.

These recommendations are accepted in principle by the UK Government.

#### **UK Government**

It is clear that blood products and blood were contaminated, and despite a wealth of evidence, no action was taken to spell out the risks, and insufficient precautions were taken. It is also evident that despite these failings, no proper action was taken to investigate and understand what had happened. Understandably, a number of participants to the Inquiry have called for a recognised process in deciding whether or not there should be a public inquiry into a matter which is potentially of public concern, or from which lessons might be learned.

The Inquiry recommends that the UK Parliament should have a role in recommending the establishment of a public inquiry, and that Ministers should set out the reasons behind a decision not to hold an Inquiry. The Government welcomes these recommendations, recognising that Parliamentary Select Committees already have the power to scrutinise departments and make recommendations, and it is for Parliament to consider these recommendations.

The Government also notes that the recent report by the House of Lords Committee on Inquiries recommends that "formal implementation monitoring should be undertaken by a new, joint, select committee of Parliament: the Public Inquiries Committee". Therefore while we note the recommendations made by the Inquiry, it is for Parliament to decide whether to accept these recommendations, and decide how to fulfil recommendation 11 alongside its existing scrutiny mechanisms.

Should Parliament decide to adopt recommendation 11, the Government accepts its obligation under 11d), to set out in detail and publish reasons when it disagrees with a recommendation to establish an inquiry.

#### **Next Steps**

The Government's response to the recommendations of the House of Lords Statutory Inquiries Committee was published on 10 February. In its response, the Government committed to providing a further update to Parliament on its intentions for wider reforms of the frameworks around inquiries.

# 12) Giving effect to the recommendations of this Inquiry

12a. Within the next 12 months, the Government should consider and either commit to implementing the recommendations which I make, or give sufficient reason, in sufficient detail for others to understand, why it is not considered appropriate to implement any one or more of them.

12b. During that period, and before the end of this year – the Government should report back to Parliament as to the progress made on considering and implementing the recommendations.

12c. This timetable should not interfere with earlier consideration and response to the Recommendations of the Second Interim Report of the Inquiry.

#### Recommendations 12) a-c) are accepted in full by the UK Government.

12d. The Public Administration and Constitutional Affairs Committee ("PACAC") should review both the progress towards responding to the Inquiry's recommendations and, to the extent that they are accepted, implementing those recommendations.

12e. PACAC should accept the role in respect of any future statutory inquiry of reviewing the Government's timetable for consideration of recommendations, and of its progress towards implementation of that inquiry's recommendations.

Recommendations 12) d-e) are accepted in principle by the UK Government.

#### **UK Government**

The Government understands that the delay on the part of successive governments to take heed of the need for a public inquiry to be held into this matter has led to a fundamental loss of trust in authority for those who have been infected and affected. The recommendations made in the Inquiry's May 2024 report are being taken very seriously, with work being taken forward across Whitehall, with devolved governments, and external bodies to scrutinise and address them all in full.

The Government Update in December 2024, fulfilled the obligations set out in recommendation 12b). This document is the Government's comprehensive response on the implementation of the recommendations by all of the UK's administrations. It replaces that document and fulfils the obligations set out in recommendation 12a).

In August 2024, we published a summary of the Infected Blood Compensation Scheme. The detail set out on recommendation 1 fulfils the formal obligation to respond to the recommendations made in the Second Interim report. However, as

we have outlined, the position on Compensation was not just informed by the Second Interim report, but also parliamentary debate, engagement with the Expert Group and engagement with the community, led by Sir Robert Francis.

The Government accepts the principles behind recommendations 12d) and 12e), and notes that they are for Parliament to consider. Alongside the UK Government's response to the House of Lords Statutory Inquiries Committee report, the UK Government is actively considering where there is scope for wider reforms to the frameworks within which inquiries are set up, run and concluded. As part of this, the UK Government will also examine how best to ensure more effective transparency and accountability around the response to inquiry recommendations and the implementation of those which are accepted. The Government will update Parliament as this work progresses.

#### **Next Steps**

As progress continues to be made against the Inquiry's recommendations, the relevant government leads will report on the recommendations for which they are responsible. We are committed to transparency and accountability, and will be publishing the Government's progress via a publicly accessible dashboard in due course, which will be regularly updated as progress is made.

## **Useful Links**

- Sir Robert Francis' Compensation Study
- Infected Blood Inquiry First Interim Report
- Infected Blood Inquiry Second Interim Report
- Infected Blood Inquiry Response Expert Group Final Report
- Infected Blood Inquiry May 2024 Report
- Further detail on the Infected Blood Compensation Scheme is available at <a href="https://www.gov.uk/government/publications/infected-blood-com-pensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-s
- Further detail on the work of the IBCA can be found at <a href="https://www.gov.uk/government/organisations/infected-blood-co-mpensation-authority">https://www.gov.uk/government/organisations/infected-blood-co-mpensation-authority</a>
- IBCA website
- Infected Blood Inquiry website
- Exchange of letters on recommendation 6 (see here on the Inquiry website).
- Scottish Government's Rare Disease Action Plan

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