Cabinet Office

Government Response to the Infected Blood Inquiry

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Government Response to the Infected Blood Inquiry

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by the Minister for the Cabinet Office

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Ministerial Foreword

The findings of the Infected Blood Inquiry are horrifying. A catalogue of failures at systematic, collective and individual level, contributing to more than 3,000 deaths that are attributable to infected blood, blood products and tissue. The report finds that these were largely avoidable.

We would all like to, once again, make a 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. 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 accept the vast majority of the recommendations in full or accept them in principle. Where recommendations are accepted in principle, we have sought to explain the rationale for doing so. This reflects

agreement with the spirit of the recommendation, but that further work needs to be undertaken on the deliverability and long term costs associated with implementing the recommendation. Many of the recommendations are wide-reaching and proper and effective implementation cannot and should not be done overnight. The UK Government will provide a further final update on the progress made on the Inquiry's recommendations by May 2025.

The final report includes sub recommendations of varying complexity. Overlaying the most complicated recommendations against one of the largest and most multi-faceted organisations in the world is a work in progress and one that must be progressed carefully. Interdependencies have been carefully mapped, between sub recommendations and existing improvement plans. This will help avoid unintended consequences and ensure health services are better placed to carry out more than 1.5 million daily patient interactions.

Sir Brian's report cannot be ignored. All those who serve public institutions must accept the collective

responsibility for ensuring that these failings are not repeated.

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.

We are absolutely committed to learning from and avoiding repeating the errors of the past to deliver lasting and real change so that the people of the UK can place their utmost confidence in the institutions and the people that serve them.

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, Andrew Gwynne 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 and the Northern Ireland Transfusion Committee.

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 final report. Payments began in October 2022.

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 Final Report

On 20 May 2024, the Infected Blood Inquiry published its final report. The Prime Minister, the Rt Hon Keir Starmer MP, spoke in the House of Commons in response to the publication of the final 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 final report's recommendations

Overall, we have responded to 12 recommendations made by Sir Brian Langstaff in his final 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. The UK Government will provide a further

final update on the progress made on these recommendations by May 2025.

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
Accepting in full	Recommendation 1
	Recommendation 2
	Recommendation 3
	Recommendation 4a) i)
	Recommendation 4a) ii)
	Recommendation 4a) iii)
	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)

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

Approach taken	Recommendation
	Recommendation 7d)
	Recommendation 7e)
	Recommendation 7f)
	Recommendation 9) (accepted in full by Scottish Government)
	Recommendation 10a) i) (accepted in full by Welsh Government)
	Recommendation 10a) ii)
	Recommendation 10a) iii)
	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 will be 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 will follow to extend the Scheme for the affected

cohort and to establish supplementary compensation routes beyond the core route. The Government intends for these regulations to be in force by 31 March 2025.

Work is continuing to ensure that IBCA is fully operational and ready to make payments as soon as possible. The first payments were made in December 2024.

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, will also be 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 experts, 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 will offer a Core Route and a Supplementary Route for awarding compensation.

Where compensation is calculated using tariffs alone, this is known as the Core Route. Once accepted onto the Scheme, 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.

In some exceptional cases, the level of compensation awarded through the Core Route may not be sufficiently reflective of the financial loss and care costs that a person has experienced as a result of infected blood. Where an applicant can demonstrate that their defined circumstances

necessitate a higher compensation payment for care and financial loss, they will have the opportunity to apply for additional compensation awards through the Supplementary Route.

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 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 £1billion has been paid in interim compensation payments to victims of the Infected Blood scandal.

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, the IBCA has been established to deliver the Infected Blood Compensation Scheme, which will provide 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.

The existing infected blood support schemes (England Infected Blood Support Scheme, Northern Ireland Blood Support Scheme, Scottish Infected Blood Support Scheme, and Wales Infected Blood Support Scheme) will transfer responsibility for making support payments to IBCA. Cabinet Office and the IBCA are working closely with devolved governments in Scotland, Wales and Northern Ireland, 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 by 31 March 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 Government was clear that it would respond to the Second Interim Report following the publication of the Inquiry's final 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.

The 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 now discussing a preferred location with some local authorities and will seek any additional funds needed in discussion with the new memorial steering committee, with the aim of having a memorial in place as soon as is feasible, subject to appropriate planning permission and other approvals being granted.

Welsh Government

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

Northern Ireland Executive

In Northern Ireland, the Department of Health has commenced initial engagement with key 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 will feed into the work of the Regional Group as well as the wider consideration being led by the UK Government.

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

When a Chair is appointed, the process for appointing members to the steering committee will begin, in consultation with the Chair. 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.

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 this recommendation in full. This recommendation is 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 final 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.

To this end, a combined working group to support delivery of Recommendations 3 and 7d has been established by NHS England, comprised of the 4-nation Blood and Transplant services and 4-nation Statutory Education Bodies (HEIW, NES, NHSE WT&E and NIMDTA). This group has representation from all four nations, including individuals with blood transfusion and educational expertise and will be able to support implementation of IBI education and training recommendations effectively across the UK. NHS Blood and Transplant (NHSBT) are working closely with the General Medical Council (GMC) and the Medical Schools Council to review medical curricula considering the Inquiry's findings. NHSBT has also initiated a survey targeting undergraduate and postgraduate medical training to define what learning should occur at each educational stage, identify relevant curricula and determine assessment methods.

In light of the Inquiry, and working with stakeholders, the GMC has used its convening powers to identify how learning from the Inquiry is influencing reflection and action that will strengthen learning. The GMC is working with the UK Governments, the UK Statutory Education Bodies (SEBs) and NHS Blood and Transplant to see this through. In addition, the GMC has written to all medical schools and medical royal colleges and faculties seeking their reflections on the Inquiry's findings, details of current arrangements for training in blood transfusion and details of action that is being taken. The responses received to date show a widespread focus on safe transfusions and use of the IBI report in core content and tutorial discussions.

The GMC have also confirmed that its 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 are part of the new Medical Licensing Assessment and are in the postgraduate curricula that GMC approve. These checks and balances are underpinned by GMC standards for UK medical education and

training and generic professional skills frameworks that have safety and quality improvement at their core.

In response to 3b, NHS England, the nations' blood services and UK SEBs are working together to map educational resources, including Technology Enhanced Learning and e-learning that deliver blood transfusion and patient safety training. In England, patient safety training is accessible by all NHS professions via the Patient Safety Syllabus. The Patient Safety Syllabus will be reviewed by the combined NHS England working group described above, to determine how best excerpts from the Inquiry's oral and written testimony can be incorporated, for example through case studies and face-to-face workshops. This learning is available to all nations. The four-nation SEB representatives will similarly be reviewing existing patient safety and blood transfusion training to determine how these may be adapted to incorporate voices of those affected from the Inquiry. This will ensure learning from the Inquiry is effectively disseminated across the NHS workforce in the UK.

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 currently considering options to ensure that all the information uncovered by the Inquiry, that might be useful in the future, is maintained.

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

On 11 November 2024, Minister Mike Nesbitt announced his intention to implement an organisational Duty of Candour following the closure of a related consultation in March 2025.

The findings of this consultation, as well as the outworkings of the 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 set out the procedure that organisations providing health services, care services and social 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 and social care to take account of recent learning including learning identified from the Covid-19 pandemic. The revised non-statutory guidance is due to be published shortly.

The Scottish Government proposes to allow health services, care services and social services time to embed the updated guidance within local processes before commencing its review of the operation of the organisational duty of candour in

the first half of 2025, with a view to reporting on that by mid-2026.

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, is to be evaluated and the recommendation as laid out in the IBI inquiry report has been 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

Under the previous UK Government, the Department of Health and Social Care announced in December 2023 a review of the statutory (organisational) duty of candour that applies to health and social care providers in England. The announcement formed part of the Government's response to the Hillsborough families' report by Bishop James Jones. A call for evidence for the review began in April 2024.

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. On 26 November, the UK Government published a report on the findings of the call for evidence on the statutory duty of candour on health and social care providers. The findings from the call for evidence suggest that the impact of the statutory duty of candour over the last decade has been broadly underwhelming. 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. Publication is an important step towards completing the review on the duty, which the UK Government is working to conclude, with the aim of ensuring that the health and care system can better meet the objectives of the duty. This would meet recommendation 4a) iii.

On 26 November 2024, the UK Government also published a 12-week consultation on proposals to regulate NHS managers in England. The consultation is seeking stakeholder views on the

most effective way to strengthen oversight and accountability of NHS managers. This includes seeking views on (i) the introduction of a new professional duty of candour for NHS managers, and (ii) a duty on NHS managers to ensure compliance with the existing statutory duty of candour.

The Government will use the findings of the consultation on manager regulation, and the call for evidence, to help inform the final response to the review of the statutory duty of candour.

4a) v. DHSC recognises the importance of recording and responding to patient safety incidents and the principle of this recommendation in increasing openness and transparency within the NHS. The Department also recognises senior leaders' accountability is an important driver to delivering increased openness, however this recommendation is complex in both implementation and enforcement. It may have significant resourcing and employment law implications and care needs to be taken to avoid unintended consequences such as reducing transparency by forcing safety reporting underground.

With patient safety at the forefront of our minds, we accept this recommendation in principle and have identified the opportunity to utilise work in relation to professional standards and regulating managers to hold senior leaders accountable for the mechanisms associated with recording and responding to patient safety incidents. As such, a consultation on regulating NHS managers, launched on 26th November, seeking views on making NHS managers accountable for responding to concerns about patient safety. Following the consultation, the findings will be used to determine how best to implement this recommendation across the UK in principle, with the involvement of Devolved Governments.

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.

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 the 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.

These recommendations are 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.

These recommendations 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 UK Government is taking a fresh look at how to make the current oversight system in England efficient and effective, in order to protect patient safety. The first step was a review by Dr Penny Dash into the operational effectiveness of the Care Quality Commission (CQC) which was published on 15th October 2024 and the recommendations are now being taken forward. The CQC is now working to

rebuild its approach to regulation. A newly appointed Chief Executive will now lead the organisation back to being an effective regulator.

Dr Dash is conducting a second review with a focus on patient safety and quality, to look at the suitability of the current arrangements. The focus of the second review is on six health bodies in England with responsibility for patient safety and how they interact with one another and the wider NHS England and Social Care landscape. The conclusions of this review are due to be published early in 2025. 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 acknowledges that patient safety accountability and delivery could be enhanced by taking a safety management systems (SMS) approach across the health system, and recognises that there are lessons to be learned from other industries in terms of good practice. NHS England is currently working with partners from across the healthcare system (including the Health Services Safety

Investigations Body (HSSIB)), academia and other safety critical industries to explore how the principles of SMSs may be translated within a healthcare context.

Scottish Government

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.

Scottish Government will work with their counterparts in the Department of Health and Social Care and other devolved administrations 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).

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. Officials have established an informal working group with policy leads from the four nations' governments, and this will consider whether any of the recommendations could be actioned UK-wide.

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.

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).

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, the Scottish Government and the Northern Ireland Executive.

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 seeking to achieve the vision of a digitised NHS by March 2026. 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. It is possible that this will be included in planned EPR surveys, where NHS England is reaching out to frontline users of systems to understand how usable their EPR is and whether it provides them with what they need. These surveys will help to improve on the implementation of EPRs that are already in place and bring a national perspective to discussions with system suppliers in terms of enhancements.

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 carrying out further work to confirm how this could be publicly reported and next steps identified, as set out in the recommendation.

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. Health Boards will be required to continue with their local digitisation progress and assurance of delivery will likely involve adapting the questions in the next Digital Maturity assessment to check on Health Board progress in digitising patient records, but this still needs to be confirmed. This assurance will be taken forward in line with the Inquiry's recommended timescales by the end of 2027, and

the Scottish Government will work with the UK Government to align questions.

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.

Work has commenced on secondary care electronic health record.

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, and further optimisation beyond.

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.

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.

A working group has been established to determine opportunities to improve patient safety coordination across the four nations. We are committed to taking this forward together. An options paper has been circulated at working level across the four nations to identify the best way to take forward this recommendation.

In 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 which provides an oversight and assurance function. It used data and intelligence from NRIs to inform local and national assurance activities. It supports the management of quality and safety intelligence across NHS Wales. We remain committed to working on a Four Nation basis to take this work further.

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 before the next anniversary of the Hillsborough disaster in April 2025.

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. A bill will be introduced to Parliament before the next anniversary of the Hillsborough disaster in April 2025. The UK government and devolved governments are working together to consider how a Duty of Candour can apply to civil servants and public servants across the UK.

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 will be considering several revisions to the Welsh Ministerial Code in the coming months which will include this issue.

Scottish Government

In Scotland, the First Minister has also announced a number of changes he will be making to the Scottish Ministerial Code in order to significantly strengthen 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 designed to ensure 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 is currently considering its position in that context.

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.

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

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

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

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

These recommendations are accepted in principle by the UK Government, the Welsh Government, the Scottish Government, and 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 final report, healthcare leaders and clinicians wrote to the Inquiry, seeking clarification around this recommendation. The Inquiry replied, confirming

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. These letters are available to read in full on the Inquiry website.

The Inquiry's response in relation to NHS England's request for clarification on Recommendation 6(v) and the role of a consultant hepatologist was as follows:

'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'.

UK Government

NHS England and its clinical experts accept the principles of this recommendation, but balance it against NHS England's role to promote equitable access for all, the practicability of implementing different pathways for cohorts of patients, and the latest evidence based care and clinical guidelines. All patients will have their care overseen by a consultant hepatologist and NHS England will additionally be pro-actively identifying patients with

haemophilia 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.

DHSC and the NHS are now committed to ensuring that all hepatitis patients receive appropriate care, including those patients who contracted hepatitis via a blood transfusion or blood products. To this end, the relevant healthcare leaders, including senior clinicians have been identified and are now meeting regularly to ensure this recommendation is implemented as quickly and as appropriately as possible. This has included establishing an audit of current practices in hepatology services

Consideration is being given to any prospective data changes required to enhance ongoing cirrhosis surveillance.

Scottish Government

The Scottish Government and NHS 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 has commissioned clinical advice on some of the points raised in the recommendations to determine how they should be delivered.

Officials are working with the Scottish Health Protection Network's Viral Hepatitis Strategic Group to assess how sub-recommendations 6a(i-v) fit with current practice and where further action may be necessary. Whilst ultrasound scans are already offered every six months for most patients with cirrhosis, the OAG is seeking further advice in relation to evidence-based clinical guidelines in relation to recommendations 6a(ii) and (iii), to ensure that any changes that may be required to implement the recommendations are appropriate, equitable and prevent any potential unintended consequences or harms.

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, OAG has agreed that the Scottish Government should seek to take 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. We are working with the LDIN to

consider this recommendation, and to take forward any necessary actions.

In addition, the Welsh Deputy Chief Medical Officer for Health Services wrote to all Health Board Medical Directors in July 2024 to ask that they consider this recommendation in relation to liver disease and the actions they were taking in response.

Northern Ireland Executive

In Northern Ireland, 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 this recommendation.

Currently, any patient diagnosed with hepatitis C will have a documented baseline fibroscan to determine cirrhosis or fibrosis. Confirmed cases will then be offered six-monthly outpatient ultrasound and blood test for alpha fetoprotein.

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.

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

The working group, with engagement from four nations stakeholders, is currently considering plans for an “opt out” approach for tranexamic acid. Under these plans, when undertaking a surgical checklist, reasoning must be given for why tranexamic acid is not being used, to encourage its take up. Work is underway with the Centre for Perioperative Care, to consider provider guidance and give careful consideration to the needs of local organisations. Planning is underway for associated

comms 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 requirements, including model health dashboard and national clinical audit is also underway, which will be followed by the development of new benchmarking categories. A proposal has been submitted to the National Institute for Health and Care Excellence (NICE) with request to update guidance and the subgroup plans to work with CQC and UKAS to review inspection standards as part of the work programme for 25/26 and beyond.

Scottish Government

The Scottish Government's Oversight and Assurance Group Chair and Deputy Chair have written to Health Boards asking them to review practice within their Board and confirm by the end of January 2025 that they are offering tranexamic acid to patients wherever it is appropriate for them in advance of elective surgery as identified in the existing NICE quality standard on tranexamic acid

use. This letter also asks 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.

Welsh Government

The Welsh Government has asked our 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

Northern Ireland Executive

In Northern Ireland, the Department of Health is currently undertaking engagement with the Health Trusts, Royal College of Surgeons and Northern Ireland Blood Transfusion Service (NIBTS) to ask them to give consideration to use of tranexamic acid in advance of elective surgery and the measures required to do this.

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 Welsh Government, the Scottish Government and the Northern Ireland Executive. 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 and a full report will be finalised during the fourth quarter of 2024/25. A Transfusion Transformation Strategy (TTS) for the next 5-10 years is in development, 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.

Work is ongoing to determine the current status of transfusion staffing, reviewing best practice from other areas including nursing, and developing a set of minimum staffing level standards. The data for staffing is complex and will require careful cross-checking and analysis to determine the best way forward.

The stakeholder group, including a range of staff and statutory education 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.

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. Consideration of accreditation

for SHOT as an organisation for the use of the Central Alerting System (web-based cascading system for issuing patient safety alerts), in order to streamline recommendation cascade and maximise the visibility of recommendations in Trusts.

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 Scotland Planning and Delivery Board is including blood banks as part of a remote and rural workstream to review the sustainability of hospital services in rural 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.

The Scottish Government has established a short-life working group involving NHS staff, SNBTS and SHOT to consider how best to support Health Boards to implement recommendation 7e).

Welsh Government

In relation to 7b), Wales has a Blood Health Plan 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.

On recommendation 7c), Wales are updating national laboratory information systems to improve the efficiency of transfusion laboratory practice and will further review staffing requirements once the system has been rolled out in 2025, taking into account the findings and recommendations of the UK Transfusion Laboratory Collaborative.

On 7d), Health Education and Improvement Wales (HEIW) in conjunction with the Welsh Blood Service and other NHS organisations in Wales are in the process of formally updating training procedures and records for medical staff, independent authorisers of blood transfusion and other staff involved in the process.

On 7e), The BHNOG has a SHOT subgroup and oversees the implementation of SHOT recommendations.

Northern Ireland Executive

Transfusion 2024 was an NHS England document and was not adopted in Northern Ireland. Consideration may however be given to the adoption of an updated iteration of Transfusion 2024, which would need to be reviewed for current circumstances.

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.

Northern Ireland is part of an established National Working group (represented by NIMDTA and NIBTS), which is taking forward the requirements around Recommendation 7d).

The Department of Health is currently undertaking engagement with Health and Social Care Trusts to assess the level to which Recommendation 7e) is already being carried out.

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.

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.

These recommendations are accepted in principle by the UK Government, the Welsh Government, the Scottish Government, and

the Northern Ireland Executive.

UK Government

These sub recommendations are particularly challenging, involving 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. Once scoping is complete, there will be requirements for significant investment for digital, capital and capability.

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 to scope and develop detailed proposals

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 to help identify the gaps in current digital systems provision in the transfusion process within the Health Boards. This can then be developed into an options appraisal to help inform a business case for changes which will be discussed in detail with all the Health Boards and will take into account the capabilities offered by Scotland's new Seer 2.0 data platform and the work on a national Laboratory Information Management System (LIMS). As noted by the UK Government, recommendation 7f) iii. is likely to require significant investment to ensure successful implementation of the preferred option across all Scottish Health Boards.

Welsh Government

Welsh Government officials are working with the Welsh Blood Service and Digital Health & Care Wales (DHCW) to agree next steps on the introduction of LIMS 2 across the health boards. Assistance is needed with the data systems to help with the tracking and monitoring of blood – when and why blood is given to help better predict

demand and monitor use. A tracking system would not only help address this recommendation but as recognised by Health Technology Wales would also prove to be cost effective as there would be less reliance on manual tracking.

Northern Ireland Executive

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.

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.

Work in this area is already advanced with changes to the online GP registration service being scoped, which could introduce a question aimed at locating people who received a blood transfusion prior to 1996. 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.

Consideration will also be given to the feasibility of offering those people identified with a triple test for Hep C, Hep B and HIV, rather than testing for Hep C only as recommended by the inquiry, where this is clinically appropriate. If introduced, guidance will be developed to support GPs in preparedness for the introduction of the question into the online GP registration service and expected follow up for new patients.

The online GP registration service is being rolled out to all GP practices in England with currently 96% of GP practices already enrolled by December 2024.

Scottish Government

In Scotland, there has already been awareness raising in this area in 2015 and 2016 following the

Penrose Inquiry's recommendation, so 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 is due to write to all Health Boards asking them to implement the test where appropriate.

Northern Ireland Executive

In Northern Ireland, further engagement will be necessary to determine which processes are in place within Primary Care at the point of registration, and ascertain further what protocols are in other parts of HSC when it is disclosed that

a patient has had a blood transfusion in the past but has not seemingly undergone a test for Hepatitis C.

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

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.

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.

These recommendations 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

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. A group of clinical experts, including the national Peer Review lead is producing an overview of the current peer review process, to establish the costs and investigate any barriers to implementing peer review recommendations, this work will be completed by December 2024.

The existing NHS England Haemophilia service specification has been updated to ensure a contractual requirement for centres to undertake, and act upon peer review findings.

Additionally, and in line with recommendation 6, the specification has also been reviewed to consider and address any necessary interdependencies with hepatology and liver services recommendations.

NHS England is undertaking work to consider how to appropriately build regional networks and the resources needed to operate these effectively, a task and finish group has been established to support this work. NHS England will work with UKHCDO and other key stakeholders to consider any actions needed to revise the database and additional funding that may be required to support this. NHS England currently provides 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 also been established, reporting into the overarching recommendation 9 expert group.

NHS England is reviewing the clinical evidence regarding the use of recombinant coagulation factors. There is a clinical policy in place for adults. NHS England has now progressed the development of a policy to extend the use of a recombinant therapy (vonicog alpha), outside of current licensing, for the treatment of a blood clotting disease in children.

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, are being made to do Scottish-led peer reviews of these smaller centres (in Inverness, Aberdeen and Dundee). It has been agreed that the Scottish Oversight and

Assurance Group Chair will write 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 Scottish 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 working with the Chief Pharmaceutical Officer has agreed that recombinant coagulation factor products should be offered in place of plasma-derived ones where clinically appropriate. AWMSG has been asked to consider further and to provide a paper for further consideration.

Northern Ireland Executive

In Northern Ireland these recommendations are carried out as standard practice. The Belfast Health and Social Care Trust is the regional lead on haemophilia and is commissioned by the Department (through the Strategic Planning and Performance Group) to carry out this work.

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

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.

These recommendations are accepted in principle by the UK Government, the Welsh Government, the Scottish 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, 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 being taken forward by NHS England such as, National Clinical Audits and Patient Outcomes Programme, which will require careful handling.

In relation to 10a) ii-iii, work is underway in DHSC to review the support being offered to relevant charities to the infected and affected community in

England. Similar work has been scoped by the Devolved Governments (Scotland and Wales), whilst stakeholder engagement has been initiated in Northern Ireland and will seek to draw a clearer local picture. By Spring 2025, we will have a clearer picture of activity in this space across the UK and options to provide further support.

Scottish Government

The Scottish Government is including recommendation 10a) i. in the scoping exercise being taken forward under recommendation 4 on patient safety. 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 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). The newly established Patient Safety Commissioner for Scotland will focus on raising the profile of the patient voice.

Welsh Government

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.

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 following their review for the sickle cell pathways. Work is underway to incorporate the needs of patients with Thalassemia

into this programme. Additional funding will be required to holistically address the needs of these patients.

The UK Thalassaemia Society and Sickle Cell Society are engaged in this ongoing work programme. NHS England already 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

Whilst there are no regional groups of people suffering from these conditions in Northern Ireland, local clinical specialists are involved at UK level and fully engaged with organisations such as the UK Thalassaemia Society and the Sickle Cell Society.

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) and SHOT have held initial planning meetings and agreed on a high-level curriculum to deliver training workshops.

Next Steps

MHRA is planning to raise awareness through a series of UK wide workshops starting from October 2024, in collaboration with SHOT. With further

promotional activities planned via updates to the online Yellow Card platform, bulletins and the upcoming 60th Anniversary of the platform.

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 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*".

If Parliament is minded to accept these recommendations, it might be appropriate for the new Public Inquiries Committee to fulfil the functions of recommendation 11, rather than PACAC.

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.

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.

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) a-c) are accepted in full by the UK Government.
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 final 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.

This update on the progress of considering and implementing the recommendations by all of the

UK’s administrations fulfils the obligations set out in recommendation 12b. A commitment has already been made for the Government to provide a further and final update on the implementation of recommendations to Parliament before the end of May 2025. We can confirm once again that this recommendation will be met.

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/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 give a further update to Parliament on this work before the end of March 2025.

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 Final Report
- Further detail on the Infected Blood Compensation Scheme is available at https://www.gov.uk/government/publications/infected-blood-compensation-scheme-summary-august-2024/infected-blood-compensation-scheme-summary-august-2024
- Further detail on the work of the IBCA can be found at https://www.gov.uk/government/organisations/infected-blood-compensation-authority
- 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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