

1 THE INFECTED BLOOD INQUIRY: REPORT PUBLICATION

2 20 May 2024

3 SIR BRIAN LANGSTAFF: No. No, you've got it -- if that's
4 for me, or for my remarkable team, thank you.

5 But you're actually applauding the wrong people.
6 This is your report. I may have done the words,
7 certainly the errors, the omissions they're all mine --
8 and one of them's already been pointed out to me this
9 morning by one of you.

10 But the words come from you and your stories.
11 I want you please, in a moment, to give me an applause
12 at least as long, and probably longer, standing if you
13 would, if you can, to those who are really responsible
14 for what is in this report. Look to your right. Look
15 to your left. Look in front. Those of you who can
16 turn, look behind. Those are the people who have
17 written this report all from your very different
18 perspectives.

19 That's where the material comes from: you.

20 At 7.00 am this morning, my full report was handed
21 to the Cabinet Office to be given to the minister,
22 John Glen. At 8.00 am it was made available to most of
23 you here. It is now my role to present it to you and to
24 the wider public, who have watched this from home or on
25 live stream, and the wider public who have had no

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1 grievously ill partners or other family members, often
2 at the expense of their own health and careers. Early
3 on, in particular, they had to do so whilst being
4 shunned or, worse, abused by neighbours, workmates, by
5 people they had once thought of as their friends --
6 sometimes even by health professionals.

7 The Inquiry is not just investigating something
8 which happened years ago. It is still happening.
9 People still have to care for the after-effects of what
10 their loved ones still suffer. The grief, the trauma,
11 which all of those lost loved ones experienced continues
12 to this day.

13 The early treatments for HIV and hepatitis C were
14 often worse than the illnesses themselves. The side
15 effects linger, and for a number of those infected with
16 hepatitis C the damage done over so many years to their
17 liver has left them at risk of developing cancer and
18 requiring liver transplants. Every aspect of their
19 lives has been defined by their infections: childhood,
20 education, career, leisure, relationships, marriages,
21 home ownership, travel, finances. Dreams and ambitions
22 have been lost, relationships broken. True though each
23 of these consequences is, it really takes a person who
24 has lived, and is living, with them to describe them in
25 a way which brings home the full horror of what had

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1 connection with the Inquiry before.

2 Well, here it is: seven volumes. There's quite a
3 lot of detail in it. What it comes to is this.

4 In families across the UK, people -- adults and
5 children -- were treated in hospital and at home with
6 blood and blood products and that NHS treatment resulted
7 in over 30,000 people being infected with viruses which
8 were life-shattering. Over 3,000 have already died and
9 that number is climbing week by week.

10 For everyone involved, the evidence given to this
11 Inquiry has been difficult to listen to. No, that's the
12 wrong word. It's hard for those centrally involved and
13 it must have been hard for many observing. But it has
14 been much harder still for those who were recounting
15 their own experiences, or listening to stories which
16 touched a nerve, which brought back memories they would
17 rather have forgotten but which they brought themselves
18 to tell the Inquiry because the truth was important to
19 tell.

20 The harm that was done to people cannot adequately
21 be put into words. I've tried. But patients -- parents
22 watched their children suffer and, in many cases, die.
23 Children witnessed the decline and the death of one,
24 sometimes both, parents and their lives were irrevocably
25 altered as a result. People had to care for their

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1 happened.

2 And that's why in this report I've tried to record
3 peoples experiences in some detail and, where I can,
4 using their own words. They're better than mine.

5 Those experiences have been central to this
6 Inquiry's work and must be central to the response to
7 this report. But I could not record every individual
8 story in this report. I hope, therefore, that the
9 thousands of statements which speak to people's
10 suffering and endurance, which will remain accessible on
11 the Inquiry's website, along with the transcripts and
12 recordings of the oral evidence which the Inquiry heard,
13 will ensure that their voices, and their pain, are never
14 forgotten and will move future listeners and readers as
15 they have moved so many during this Inquiry.

16 This disaster was not an accident.

17 People put their faith in doctors and in the
18 government to keep them safe and their trust was
19 betrayed.

20 There are generally two elements to any major
21 public inquiry: one backward-looking, what happened and
22 why; the other, forward-looking, what next? How do we
23 stop it happening again? But this Inquiry's different.
24 There is another third element to this Inquiry's terms
25 of references: what was the response of government and

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1 others in authority to what had happened?

2 Here, the NHS and successive governments
3 compounded the agony by refusing to accept that wrong
4 had been done. More than that, the government
5 repeatedly maintained that people received the best
6 available treatment and that testing of blood donations
7 began as soon as the technology was available, and both
8 claims were untrue.

9 That means that part of the "what next? How do we
10 stop it happening again?" is not only taking steps to
11 meet any threat of future infection carried by blood,
12 blood products or tissue, but how to ensure, as far as
13 we can, that the government responds to the citizens it
14 serves -- how shall I put this? -- more appropriately in
15 a way which reflects the true facts.

16 To turn back to what the report says then about
17 why infections happened on such a scale over such a time
18 to so many people, the picture is a complex one and the
19 failings were multiple.

20 First, governments, blood services, doctors knew
21 at least 80 years ago (since the mid-1940s) that blood
22 could transmit hepatitis and that this was a significant
23 disease which could lead to cirrhosis, liver failure,
24 liver cancer, and death. This was not something kept to
25 the dusty libraries of academic knowledge. The

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1 unnecessarily, and failed to reach clear and decisive
2 conclusions. And patients were simply not given the
3 information they needed to make fully informed decisions
4 about their own treatments.

5 As long ago as 1952, the World Health Organization
6 identified how to reduce the risks of transmitting
7 hepatitis through blood and blood products. UK medical
8 and government advisers took a central part in this.
9 There were four key measures highlighted by the World
10 Health Organization on which, despite its involvement in
11 identifying them, the United Kingdom fell short: the
12 first was the selection of donors; the second was
13 restricting the size of the pools used to make plasmas
14 products; the third was treating these products (for
15 example, with heat) to reduce infection; and the fourth,
16 maintaining good records and reporting infections. Each
17 of these is addressed in detail in the report, and
18 I shall say a little more about some aspects of each of
19 them now.

20 But the key point is that if we had followed the
21 World Health Organization's advice, there would have
22 been fewer infections from blood and from blood products
23 and fewer deaths.

24 As to the selection of donors, everyone who
25 received blood, or products made from blood plasma,

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1 consultant adviser on blood transfusion to the Chief
2 Medical Officer wrote in 1946 that users of plasma "must
3 be told that it is a potentially lethal fluid which
4 should be used with discretion." A 1964 circular from
5 the Scottish Home and Health Department said:

6 "No transfusion should be undertaken unless the
7 benefits outweigh the risks of hepatitis."

8 One of the leading transfusion directors used to
9 write on the boards for students "Blood can kill". The
10 risk was not limited to hepatitis but it included the
11 risks of future unknown viruses.

12 In the light of that knowledge, you might expect
13 action to be taken to reduce the risks which were known
14 of and a keen eye to be kept open in case new risks
15 started to emerge.

16 What happened was not that. Tragically, the
17 infections happened because those in authority --
18 doctors, the blood services and successive governments
19 -- did not put patient safety first. They lost sight of
20 what was known about the risks of viral infections from
21 blood. "Doctor knows best" was such a strong belief
22 that health departments did not issue guidance to curb
23 the unsafe use of blood and blood products.
24 Decision-making on measures that could make blood and
25 blood products safer was put off, then dragged out

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1 depended on the quality of the donations which ended up
2 in their veins. Now, that depended on donors. Knowing
3 your donor and the risks that might come with their
4 blood is fundamental to any system of collecting blood.
5 The blood used for transfusions and to make blood
6 products in the UK was from British donors who could,
7 and should have been, better selected.

8 For instance, in 1975 the Chief Medical Officer
9 for England said the practice of collecting blood in
10 prisons could continue, even though prisoners were known
11 to have higher numbers of hepatitis infections. This
12 practice was not ended in the UK until 1984: for
13 instance, no real efforts were made to prevent those who
14 had used intravenous drugs (and who were therefore a
15 higher risk of hepatitis) from donating blood; and, for
16 instance, the steps taken to keep donors who were more
17 likely to be incubating AIDS out of the donation chain
18 were late in starting and, when they finally began, were
19 inadequate.

20 As for pool sizes, the dangers of pooling plasma
21 from many donors were established by the Medical
22 Research Council in 1944: the greater the number of
23 donors to a pool, the greater the risk from it, because
24 one infected donation could contaminate the whole pool.

25 In 1951 the textbook that was then the bible of

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1 blood transfusion said "the use of large pool plasma
2 has, *of course*, been abandoned".
3 The use of only small pools lasted until after
4 1970. Then, however, something extraordinary happened.
5 Just as the long-term seriousness of hepatitis became
6 more and more apparent, the size of pools used to make
7 UK blood products grew ever larger and larger and, with
8 that, so too did the risk. Instead of reducing the
9 risk, the UK was steadily increasing it.

10 Blood donors in the UK gave blood freely, purely
11 for the good of other people unknown to them and they
12 deserve praise for that. By contrast, the blood
13 supplied in the United States was largely sold by people
14 who needed the money. The hepatitis that gave rise to,
15 and the number of deaths that followed, resulted in the
16 UK authorities banning sales of whole blood for
17 transfusion in 1973. But US authorities did not stop
18 people selling their plasma to pharmaceutical companies
19 to be made into blood products.

20 In 1973, the UK licensing authority gave the green
21 light to the importation and distribution of an American
22 blood product and an Austrian blood product, also made
23 using paid donations, despite the manufacturers making
24 no secrets of the risks of hepatitis they posed. The
25 licensing authority knew of the risks from the sales of

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1 three times to arrange for the Chief Medical Officer to
2 ask doctors to find out if AIDS patients had previously
3 donated blood.

4 As well as the more rigorous selection of donors,
5 and until such time as direct tests specific to
6 hepatitis C and HIV were available, a further way of
7 reducing the chances that hepatitis C or HIV would get
8 into the blood supply and be transfused was to test for
9 certain markers in the blood which could help identify
10 the donations that might be infected. This was known as
11 surrogate testing.

12 The opportunity of this surrogate testing in the
13 case of HIV was lost. In respect of hepatitis C, taking
14 a decision about it was put off, put off, and then
15 delayed until it was simply too late. One doctor
16 involved, rightly, described the process as "going round
17 in very small circles some distance away from the
18 target". Nearly four years were lost during which the
19 risks could have been very significantly reduced.

20 The government was to claim in the 1990s that the
21 direct tests for these viruses were introduced as soon
22 as the technology was available. That was wrong in the
23 cases of each of the viruses. In the case of HIV, a
24 test had been developed by August 1984. But it was not
25 introduced for the screening of blood donations until

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1 blood plasma from people who, and I quote, "did not
2 inspire confidence" and were motivated by money. The
3 licensing authority knew too that these products were
4 made from very large pools. The risks of hepatitis were
5 freely admitted by the makers.

6 I have concluded that the UK was wrong to decide
7 to license these products in 1973 and later decisions in
8 the 1970s to grant further licences for similar US
9 products were also wrong. Those products should simply
10 not have been permitted to be distributed generally in
11 this country.

12 Despite the World Health Organization's reminder
13 in 1952 of the importance of record-keeping, poor
14 record-keeping has been a problem across many of the
15 issues examined by the Inquiry. This had an impact on
16 safety. If you can't trace the source of the
17 transfusion back to the donor who was infected, you
18 cannot then tell and treat the donor and avoid any
19 further donations from that source, nor can you trace
20 previous donations to check if other people who have had
21 transfusions from the same source have then become ill.
22 And reporting of infections did not have the priority it
23 should have done. For instance, at the height of the
24 AIDS crisis, the North London Blood Transfusion Centre
25 had to ask the government committee responsible for AIDS

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1 October 1985. It takes time to produce such a test in
2 sufficient quantity to screen all blood donations and to
3 check its reliability, but I have concluded that we lost
4 months for no clear reason by delays and indecision with
5 setting up a process to evaluate each available make of
6 test. Yet a number were commercially available and
7 being used elsewhere in the world.

8 Patients receiving transfusions in the UK were
9 needlessly exposed to the risk of HIV as a result. In
10 the case of hepatitis C, the delays were even worse.
11 Screening of blood donations was not introduced until
12 September 1991. Even when a screening test was
13 available and approved, its use had to wait until all
14 regions could introduce it on the same date; in other
15 words, going at the pace of the slowest. When the
16 government claimed that screening for hepatitis C had
17 been introduced as soon as the technology became
18 available, they ignored the long list of countries that
19 introduced screening before the UK: Japan, Australia,
20 France, Luxembourg, Finland, the US, Austria, the
21 Netherlands, Canada, Germany, Belgium, Switzerland,
22 Italy ... shall I go on? Spain, Norway, Sweden,
23 Portugal, Cyprus, Greece, Hungary, Iceland, Malta and
24 Denmark. 23.

25 Just because the Department of Health hoped what

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1 they said was true didn't mean to say it was. You might
2 have thought that as soon as a screening test for
3 hepatitis C was introduced across the board in
4 September 1991, donors who were infected and might not
5 have realised it could be identified and told, and then
6 anyone who had previously been given their suspect blood
7 could be traced and checked. Well, you would have been
8 wrong. It took around four years for there to be a
9 general look-back like this.

10 One transfusion director, Dr Jack Gillon,
11 Edinburgh and South East Scotland, thought this was so
12 unethical that he arranged to conduct a look-back in his
13 area. He had to call it a pilot study but he wanted to
14 do it and did it. His work deserves praise. It was
15 instrumental in a UK look-back being delayed no further
16 than it was. But the delay which had already occurred
17 made the look-back less successful than it would and
18 should have been.

19 Hepatitis C tests concerned, obviously, hepatitis.
20 Almost everyone who had a severe bleeding disorder --
21 severe bleeding disorder -- had hepatitis too as
22 a result. But 1,250 people with bleeding disorders were
23 also infected with HIV. Nearly one-third of those
24 infected with HIV were children. Three-quarters of
25 those who have HIV have died.

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1 dismissiveness, and delay. The government's response
2 was unconscionably slow. So too was the response of
3 haemophilia centre directors and of their organisation,
4 the UKHCDO.

5 Professor Arthur Bloom was Chairman of the
6 haemophilia directors and he died many years ago. He
7 must bear some of the responsibility for the UK's
8 slowness in responding to the risks of AIDS to people
9 with haemophilia. In May 1993, the Mail on Sunday put
10 "Hospitals using killer blood" on their front page. We
11 in the Inquiry now believe that one of the sources for
12 that story was Professor Bloom's respected senior
13 colleague in Cardiff, who was reluctant at the time to
14 be identified as a whistle-blower. Professor Bloom told
15 the Haemophilia Society that "in spite of inaccurate
16 statements in the press" he was unaware of any proven
17 case in the UK and there was no need to change their
18 treatment. The Haemophilia Society then relayed his
19 advice to their members.

20 Yet he, Professor Bloom, himself was treating
21 a patient he believed had AIDS. He reported as much to
22 the UK Centre for Disease Surveillance. He was a member
23 of the various committees involved in the response to
24 AIDS and, disastrously, the Department of Health and
25 Social Security was over-influenced by his advice, in

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1 Now, these are figures. They're numbers, they're
2 percentages, they're difficult to relate to. But look
3 around you. The number of you who are filling this
4 great hall today is roughly the same as the number of
5 people who had bleeding disorders who were infected with
6 HIV. Picture that. And now picture only a quarter of
7 you being here.

8 A number of failures contributed to the infection
9 of so many with bleeding disorders: failing to plan
10 sufficiently to produce enough blood products to avoid
11 the UK having to rely on imports; to a failure to
12 achieve self-sufficiency, which, though it became
13 government policy, was not delivered until the end of
14 the 1980s; failing to suspend imports in mid-1983;
15 continuing importations of products made from plasma
16 collected before safety measures were adopted in the
17 USA; and being slow to adopt and develop heat-treated
18 blood products in which HIV had been inactivated and
19 neutralised.

20 A real risk that blood products transmitted the
21 cause of AIDS was known by government in July 1982. It
22 was known by all haemophilia doctors by the end of 1982.
23 There was already a growing epidemic in the
24 United States likely to come to these shores, yet the
25 response here was one of denial, disbelief,

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1 particular his advice to continue importing commercial
2 factor concentrates when the leading epidemiologist and
3 head of the Communicable Disease Surveillance Centre,
4 Dr Spence Galbraith, had advised against it.

5 Inexplicably, no government minister was shown the
6 epidemiological advice to suspend imports until the risk
7 of AIDS was better understood. The decision taken in
8 July 1983 not to suspend them was a bad one for a number
9 of reasons.

10 One was the idea that the risk of AIDS was
11 out-balanced by the benefits of using the products
12 because, it was said, in the case of haemophilia it was
13 life-saving. Well, that ignored both the fact that most
14 treatments for people with haemophilia were not used in
15 life-threatening situations and the fact that there were
16 tried and trusted life-saving alternatives, in
17 particular much less risky cryoprecipitate, each unit of
18 which was produced from a single donation by a British
19 voluntary donor.

20 Another reason it was a bad decision was the
21 conclusion it was not feasible to replace concentrates
22 with cryoprecipitate "on grounds of supply". Yet
23 transfusion directors told the Inquiry that, if asked,
24 they could have made more of the safer cryoprecipitate
25 treatment for people with bleeding disorders. They

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1 weren't asked.

2 Some clinicians explained how they would have
3 adapted their treatment practices if fewer American
4 products had been available, and this is not the benefit
5 of the hindsight. On either side of the Peninnes,
6 Alder Hey and Sheffield children's hospitals treated
7 children with bleeding disorders at the height of the
8 AIDS crisis.

9 Alder Hey treated its children almost exclusively
10 with large pool commercial concentrates. Utterly
11 inappropriate. Almost all the children were infected
12 with AIDS.

13 By contrast, at Sheffield Professor John Lilleyman
14 sought to minimise exposure to multiple donors by using
15 cryoprecipitate. There was one infection with HIV at
16 Sheffield Children's Hospital. It's still one too many
17 but it's illustrative of the fact that the adoption of
18 different treatment practices by haemophilia clinicians
19 could have substantially reduced the number of
20 infections. Treatment choices mattered.

21 Take the case of a haemophilia centre at Treloar's
22 School. Of the 122 pupils with haemophilia who attended
23 the school between 1970 and 1987, only 30 survive. The
24 pupils were often regarded as objects for research,
25 rather than first and foremost as children whose

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1 to make an informed decision about their treatment with
2 blood or blood products so they knew what to be alert
3 for if they were infected. Very early on in the
4 Inquiry, it became clear that most people were not told
5 enough about the risks of treatment with blood or blood
6 products to give informed consent, if indeed they were
7 told anything, nor were they given information about
8 alternative treatments. And yet respecting people's
9 right to control what happens to their own body has
10 always been an ethical cornerstone of medicine. Always.

11 A booklet produced by the Medical Defence Union in
12 around 1953 explained that consent had to be "genuine
13 consent ... a real expressed willingness by the patient
14 to undergo the treatment after ... its nature, its risks
15 and its objective" had been clearly explained.

16 In 1980, the British Medical Association's
17 handbook on medical ethics said:

18 "Consent is freely given if the patient
19 understands the nature and consequences of what is
20 proposed."

21 The next year they added:

22 "Doctors offer advice but it is the patient who
23 decides whether or not to accept the advice."

24 The failure of clinicians to tell people of the
25 risks of infection from blood or blood products, the

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1 treatment should be firmly focused on their individual
2 best interests alone. There was a particularly heavy
3 use of factor concentrates. Different concentrates were
4 indiscriminately used, increasing risk. Pupils were
5 given extra to see how prophylaxis might work. Research
6 prejudiced the quality of treatment, and convenience of
7 administration trumped safety.

8 Children were treated in this way without their
9 parents having been provided with any, or anywhere near
10 enough, information about the risks of treatment. It
11 was unconscionable to treat children with concentrates
12 capable of transmitting serious viruses without
13 explaining those risks clearly to their parents. There
14 were multiple research projects where informed consent
15 for participation was neither sought nor given. That
16 was unethical. It was wrong.

17 There are some echoes of what happened in
18 Treloar's in the evidence relating to the haemophilia
19 centres across the UK which is extensively examined in
20 this report. All the evidence points to a single,
21 inescapable conclusion: that children and adults were
22 not treated in a way which prioritised their safety
23 above other considerations.

24 Just as treatment choices by doctors mattered, so
25 too did giving patients or their parents the information

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1 failure to tell people of the availability of
2 alternative treatments, the failure to tell them they
3 were being tested for HIV or hepatitis C, and sometimes
4 the failure even to tell them, or to tell them promptly,
5 that they had been infected with HIV or hepatitis by
6 their treatment, the failure to explain these
7 devastating diagnoses privately in person and with
8 sensitivity, these failures were widespread. They were
9 wrong. They were unethical.

10 The failures in decision-making that led to the
11 original infections were then compounded by
12 institutional defensiveness and that's a pattern of
13 institutional defensiveness that must stop.

14 When citizens have concerns that something has
15 gone seriously wrong, fairness should be that they get
16 answers. People infected with blood and blood products
17 did not. Instead, their trauma has been compounded by
18 the lack of recognition of what happened to them and by
19 a lack of accountability. The report details how three
20 lines were repeatedly deployed by successive
21 governments: that people had the best available
22 treatment, that the infections were inadvertent, and
23 that screening for hepatitis C could not have been
24 introduced earlier than September 1991. All of those
25 claims were untrue.

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1 That list I gave you earlier of the 23 countries
2 that introduced screening before the UK did was compiled
3 by a High Court judge in a landmark case in 2001. He
4 found the screening should have been introduced earlier.
5 Yet the government continued to assert that screening
6 began as soon as the technology was available, even
7 after campaigners pointed out that that was wrong and
8 contrary to what the judge had found.

9 Much of the responsibility for this institutional
10 defensiveness lies with the Civil Service. It was not
11 until 2003 that a limited financial support was
12 announced for people infected with hepatitis C through
13 NHS treatment with blood and blood products. Prior to
14 then, the line taken by successive governments was that
15 no financial support whatsoever should be provided. On
16 each occasion in the 1990s when a minister, having heard
17 the pleas for help from people infected and affected,
18 expressed an interest in changing that line, they were
19 persuaded against it by civil servants.

20 One minute could have come from Yes, Minister:

21 "It is quite clear that he [that is the minister]
22 is trying to change the line, little by little. He has
23 had plenty of briefing (written and oral) on the subject
24 but his sympathy for those concerned is clearly
25 uppermost in his mind."

21

1 decided that the government's position was an error.
2 The Irish government did not set up a compensation
3 scheme because it accepted there had been fault. Yet
4 Civil Service briefings to ministers simply ignored this
5 and repeated the original approach, and documents which
6 might have been thought to assist those seeking
7 compensation went missing.

8 Now, I've devoted a whole chapter in the report to
9 that. In the case of some documents, it's simply not
10 possible now to know how and why they went missing. For
11 others, I have concluded that they were deliberately and
12 wrongly destroyed in an attempt to make the truth more
13 difficult to reveal.

14 Well, let me turn from what happened and how
15 successive governments responded to the third element of
16 the Inquiry's report: the future. At the start of the
17 Inquiry, people told me they wanted to ensure that a
18 disaster like this never happened again. The report
19 begins to address that by setting out a number of
20 lessons to be learned.

21 The first and most important lesson to be learned
22 is that patient safety must be the guiding principle.
23 Many, indeed most, infections would have been prevented
24 if patient safety had been paramount throughout.

25 The second lesson to be learned concerns risk.

23

1 When, later in the early 2000s, a minister did
2 seek an investigation to see if the advice given to her
3 predecessors about the failure to achieve
4 self-sufficiency was correct, because she doubted what
5 was being told to her by her civil servants, the
6 resulting report was not published for nearly four
7 years. By then, it had been substantially changed from
8 the initial draft which had, as the minister had asked,
9 set out a factual account of what available documents
10 had said. It had now become one which, without any
11 input from the original author, expressed opinions
12 favouring the lines the government had been taking and
13 providing an incomplete and thus misleading picture.

14 The report as then published, the so-called
15 Self-Sufficiency chronology, was an insult to
16 campaigners who had, despite the challenges of
17 ill-health and grief, determinedly pieced together a
18 much fuller understanding of what had happened than the
19 Department of Health. To cap it all, it was repeatedly
20 asserted (as a reason for not paying affected people
21 similar sums to those paid in Ireland) that in Ireland
22 the sums paid were because the government there accepted
23 there had been a fault, whereas in the UK the government
24 had not. Yet again, it fell to a campaigner to
25 challenge this and he succeeded. A High Court judge

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1 Risk was poorly understood and poorly communicated and
2 the wrong questions were asked and answered. The line
3 that there was no conclusive proof that AIDS had been
4 transmitted by blood and blood products may have been
5 strictly true at the time, but it was misleading and it
6 misled. It gave false comfort to patients and
7 clinicians that the risks were not as real as indeed
8 they were. The public should be trusted with the truth
9 with all its uncertainties.

10 Professor Arthur Bloom, to return to him in this
11 context, was warned in a letter from the US Centres of
12 Disease Control in March 1983 that AIDS was an epidemic
13 evolving "with a frightening pace" and that blood
14 products could transmit its cause. He failed to share
15 that letter or the information within it. Instead, some
16 clinicians advised that the small number of cases meant
17 that it was not a big risk for the UK haemophilia
18 population. Now, that confused incidence and risk. In
19 a disease with an incubation period of some two years,
20 the cases you diagnose on day 1 only tell you who was
21 infected two years ago, not who is infected today but
22 has not yet been diagnosed. The day cases showing today
23 are just the tip of the iceberg.

24 In their slow and protracted decision-making,
25 civil servants and ministers lost sight of the value of

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1 taking steps to reduce risk even if full elimination was
 2 not yet possible. The infections could have been
 3 prevented and lives could have been saved even if just
 4 some of the measures examined in the report had been
 5 implemented. And if patient safety were the guiding
 6 principle, there should have been curiosity before 2017
 7 about what led over 3,000 people to die and thousands
 8 more to live with infections.

9 Apart from lessons which should be learned, what
 10 else should happen next? Well, I fully expect the
 11 government to make an apology.

12 To be meaningful, though, that apology must
 13 explain what the apology is for.

14 It should recognise and acknowledge not just the
 15 suffering but the fact that the suffering was the result
 16 of errors, wrongs done, and delays incurred. It should
 17 provide vindication to those who have waited for that
 18 for so long.

19 And it should be accompanied by action.

20 Action, obviously, to recognise and remember what
 21 happened to so many people and to learn from the
 22 Inquiry, action to implement recommendations I made over
 23 a year ago to set up a proper compensation scheme.

24 A major task is the further work to be done in
 25 each of the four health services to put patient safety

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1 Health Services Safety Investigations Body. All of this
 2 should be informed by developments in the digitisation
 3 of patient records.

4 I've also recommended measures to end a defensive
 5 culture in the Civil Service and government. To do
 6 this, I have encouraged the government to reconsider
 7 whether, in the light of the facts revealed by this
 8 Inquiry, it is sufficient to continue to rely on the
 9 current non-statutory duties in the Civil Service Code
 10 and the Ministerial Codes to end the defensive culture
 11 in the Civil Service and government.

12 In particular, I recommend that there should be a
 13 statutory duty of accountability on senior civil
 14 servants for the candour and completeness of advice
 15 given to permanent secretaries and ministers and for the
 16 candour and completeness of their responses to concerns
 17 raised by members of the public and by their own staff.

18 I've recommended measures to ensure that people
 19 who have been infected with hepatitis C from blood
 20 transfusion or blood products have the monitoring for
 21 further liver damage which they need, and I have
 22 recommended that GPs should ask newly registered
 23 patients on registration if they have ever had a blood
 24 transfusion to try to find more of the people as yet
 25 undiagnosed.

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1 at their heart. Now, ensuring a patient safety culture
 2 is not an easy task. Inquiry after inquiry has
 3 recommended it and it has not been achieved as yet.
 4 What I recommend is that where an individual is
 5 responsible for something going wrong that was or might
 6 have been harmful, they should not usually be blamed for
 7 owning up (owning up enables patient safety to be better
 8 achieved after all), but they should certainly be blamed
 9 if they keep silent.

10 They should be obliged to report near-misses as
 11 well as actual wrongs. Leaders in healthcare should be
 12 made subject to a statutory duty of candour where they
 13 are not already.

14 And to be made accountable both for ensuring that
 15 that duty is observed by those they lead and for
 16 recording and properly considering reports of concerns
 17 made to them. The regulatory landscape for patient
 18 safety should be decluttered so that patients, and for
 19 that matter healthcare professionals, know where to take
 20 any concern they may have and leaders know exactly what
 21 is expected of them.

22 Learning from other safety-critical enterprises
 23 and industries, the NHS should establish a safety
 24 management system and I highlight in my recommendations
 25 the work on patient safety being led in England by the

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1 That is, of course, in addition to the free postal
 2 testing now available in England and Wales. And if
 3 there is anyone who is listening online to this who
 4 feels that they need that test, that is where they can
 5 currently get it.

6 Amongst measures I recommend to improve the safety
 7 of transfusions is action to establish the outcome of
 8 every transfusion and to increase the use of
 9 alternatives to blood or blood products where possible,
 10 and there are measures I recommend to protect the safety
 11 of haemophilia care.

12 This Inquiry has aimed to listen and I hope it's
 13 succeeded in that. But listening is not just for
 14 inquiries or courts. I recommend measures to empower
 15 the patient voice so that it is heard and taken
 16 seriously in day-to-day healthcare. In particular, that
 17 clinical audit should, as a matter of routine, include
 18 measures of patient satisfaction or concern and that the
 19 results are reported to the board of the body concerned.
 20 I have recommended funding for patient advocacy and a
 21 particular consideration should be given to meeting the
 22 needs of people with sickle cell disorder or
 23 thalassaemia.

24 Another damaging failure to hold a public inquiry
 25 when one is clearly merited must be it avoided. Though

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1 I recognise that the power to call an inquiry remains
 2 with the minister under the Inquiries Act, I believe
 3 there is a role here for the Public and Constitutional
 4 Affairs Committee (that's a Select Committee of the
 5 House of Commons) to consider whether to recommend to a
 6 minister that they should exercise their power and that
 7 if the minister disagrees with the committee, they must
 8 set out in detail and publish reasons for this
 9 disagreement sufficient to satisfy the committee that
 10 the matter has been carefully and properly considered.

11 My final recommendation considers the question of
 12 implementing the recommendations I have set out. I've
 13 written to the minister to tell him that I cannot as yet
 14 notify him that the Inquiry has fulfilled its terms of
 15 reference. Those terms include the nature, adequacy and
 16 timeliness of the response of government. As I've said
 17 repeatedly in public, delay not only causes frustration
 18 but it compounds the harm and suffering many of those
 19 infected and affected have endured. In the context of
 20 this Inquiry, perhaps beyond all other, it is
 21 unconscionable to allow a state of affairs to exist in
 22 which people's fears that the lessons and
 23 recommendations of this Inquiry will collect dust on a
 24 Cabinet Office shelf are realised.

25 I'm satisfied that I must do what I properly can
 29

1 But I would like to thank too those who have
 2 contributed who would be here but can no longer be. Too
 3 many are too seriously ill as a result of their
 4 infections. Too many have died.

5 I will mention one person, but everyone here knows
 6 of others who have not survived to hear the outcome of
 7 this Inquiry. Perry Evans gave evidence on the very
 8 first day of the Inquiry's hearings in 2019. He had
 9 mild haemophilia and led an active life treated only
 10 with cryoprecipitate before factor products were
 11 introduced. He was diagnosed with HIV in 1985 and told
 12 he had two to three years to live. He survived. But he
 13 was diagnosed with an HIV-related cancer in 2002. He
 14 survived. He was in a coma for ten days in 2008 and
 15 wasn't expected to live. He survived, although with a
 16 range of health problems associated with HIV and
 17 hepatitis C and the treatments he had received.

18 But very sadly Perry died exactly five weeks ago.
 19 His wife Heather is here today.

20 You don't need me to tell you more people die each
 21 week. Imagine the difference it would have made if this
 22 Inquiry had been held 30 years ago.

23 **FROM THE FLOOR:** Justice now. Justice now!

24 **SIR BRIAN LANGSTAFF:** If people were given answers then and
 25 had recognition of their losses, they could have lived

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1 within my powers to try to ensure that that does not
 2 happen. Now, it's for the government to respond as it
 3 will but I intend to use my position, as far as
 4 I properly can, to prevent any unreasonable delay in its
 5 doing so.

6 I hope to be able to say soon that the Inquiry's
 7 work is completed.

8 **FROM THE FLOOR:** We'll see.

9 **SIR BRIAN LANGSTAFF:** After that, I recommend that the
 10 Public and Constitutional Affairs Committee should
 11 review both the progress the government has made towards
 12 responding to the recommendations of the Inquiry and, if
 13 those recommendations are accepted, towards implementing
 14 them.

15 Finally, I'd like to thank again all of you here
 16 and all of those of you who are watching remotely for
 17 your contribution to this Inquiry. Whatever your
 18 perspective has been, the sheer numbers here pay
 19 testament to the importance of the issues this Inquiry
 20 has been considering and it pays tribute to the interest
 21 and engagement which you have shown, which has never
 22 flagged, since the days when so many of you came to the
 23 preliminary hearing. An inquiry serves its purpose best
 24 when everyone involved from whatever perspective
 25 participates as you have done.

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1 the rest of their lives free from financial hardship and
 2 without having to fight for justice and recognition. It
 3 may be late but it's not too late. Now is the time,
 4 finally, for national recognition of this disaster, for
 5 proper compensation, and for vindication for all those
 6 who have been so terribly wronged.

7 That-- that -- is what my report amounts to.

8 Thank you.

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