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INFECTED BLOOD INQUIRY

INTERMEDIARIES' REPORT 2019

We are providing this report in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 January 2019.

Section 1. Introduction

We were appointed to act as intermediaries because some people told the Inquiry that the stigma attached to their experiences means they would have difficulty in providing witness statements or oral testimony in the traditional way associated with public inquiries.

We visited people who requested our support and this report covers a number of people's experiences, without identifying them individually to protect their anonymity.

Our professional backgrounds are as follows:

Pam Allen: a qualified social worker with 40 years of experience in local authorities, the courts and the independent sector. I have worked directly with adults and children who have suffered trauma, including bereaved parents.

Kay Durrant: a qualified senior investigating officer with 25 years experience in the police service. I have extensive experience dealing with people who are vulnerable and have provided training nationally with the College of Policing on vulnerability and investigation. I am also a qualified and practising counsellor.

Jackie Wilson: a qualified social worker with 38 years experience in local authorities, hospitals, family courts and the independent sector. I have worked extensively with families who have experienced trauma.

We interviewed 85 people over 12 weeks across the UK in 2019. On many occasions a spouse/partner or family member was present and contributed to the conversation.

Most of the people interviewed chose to do this at home but a small number preferred a more neutral venue, or a different town, to protect their family from potential gossip. During the interviews the intermediary took notes, and then provided a draft note for the individual to review. This was to ensure the accuracy of the information gathered. This review often triggered other thoughts and feelings. Many people commented that seeing their experience finally written down was both a shock and a relief.

Where this report includes italicised quotes, these are in the words used by the people interviewed and are included with their permission. This report is structured in line with the Rule 9 letter and the themes which emerged from the interviews: there may be more than one reference to a particular individual or family.

We were humbled by the dignity and bravery of the people interviewed. The conversations were often difficult for them, bringing back painful memories and causing them to relive the trauma of so many tragic experiences. Nevertheless, people were stoic and dignified, describing how they "*just got on with it*". Many expressed the view that they were "*the lucky ones*" despite their own traumatic experiences. Many were keen to talk about positive contacts with health professionals and some commented that relationships and practice had been more sensitive in recent years. There were, however, still some exceptions to this.

Everyone expressed concern for other people who had been affected, and an often-repeated reason for participating in the Inquiry was that this should never happen again. There was hope that the Inquiry would help them to understand where, why and by whom particular decisions were made. Some expressed reservations about the outcome as they had been disappointed by previous inquiries and a small number felt that there might still be a "*cover up*".

Section 2. How Infected

The infections had largely taken place between 1970 and 1991 though some people reported that they had been infected slightly outside this timeframe. We met people with underlying conditions such as thalassaemia, haemophilia, and Hodgkin's lymphoma. We interviewed people who had received blood products or blood transfusions during planned treatment, routine surgery, childbirth or emergency treatment, and talked to family members who had been bereaved as a result of their relative receiving infected blood or blood products. Prior to the diagnosis of an infection some of the people infected had been blood donors to express their gratitude for having received life-saving transfusions.

The following points give some sense of the range of experience across the interviews:

- 6 had been infected with HIV
- 50 had been infected with hepatitis C
- 11 had haemophilia
- 3 had thalassaemia
- 9 were infected through routine surgery
- 12 were infected through emergency surgery
- 8 were infected in connection with childbirth
- 1 person had been infected by their partner.

Infection and diagnosis with HIV

One man with haemophilia was at college when he was called to go and see his consultant, which he assumed was for a regular appointment. He went alone and despite being legally still a child, was told he had HIV and probably had done so for three years. The consultant went on to tell him that there was an incubation time of five years, which could mean he had another two years to live. He was told not to have sexual relations or to share any bodily fluids, and remembers being told in relation to bodily fluids that *"tears don't count"*. He returned to college and did not tell anyone initially, not even his parents, although some time later he did talk to them. To this day, aged 55, he has not shared with anyone outside his family his HIV and hepatitis C status.

Another man with haemophilia was told at 19 that he was HIV positive and had been so for three years. He thought he would die in two years' time. He described being in a state of denial, not complying with health appointments or health advice, and taking a number of years to accept the diagnosis and start treatment.

One family had to cope with their child being diagnosed with HIV when only eleven. The devastating news was not delivered in person but in a letter from their consultant. Desperate for more information, the parents contacted the hospital and were informed that the consultant was on holiday and they would need to wait for his return. The nurse later told them that their son had been infected some years earlier, and this was subsequently backed up by the medical notes.

Another couple's son was wrongly diagnosed with haemophilia when he was three. When he was around four or five he had his tonsils removed, and a clotting agent was used in the operation. Following blood tests two years later it was discovered that this boy (now seven) was HIV positive. It took his parents two months to get the results of the blood test. They saw the local GP who said to them *"You do know he is going to die?"* When their son was 14

his parents told him about his HIV status, and had to answer the question “*Am I going to die?*”. Although he survived, the stress for this family has affected many aspects of their life, with the sound of a telephone ringing prompting apprehension of bad news, stress and panic.

Infection and diagnosis with hepatitis C

Although some people had a face-to-face discussion of their diagnosis, most people had a very different experience. Some were informed by letter after they had attempted to give blood, and others were told on the phone by their GP after routine blood tests or tests following the reporting of symptoms.

Some people who were receiving treatment for ongoing conditions, particularly haemophilia, described their doctors and nurses as being devastated, and very angry, at the news of the infections.

Few people were given detailed information about hepatitis C, and many described having to research and find out things for themselves which was difficult in the days before the internet. Some described their GPs as acknowledging that their patient knew more about the condition than they did. Several described themselves or their loved ones being asked about their lifestyle, including whether they had used drugs or had contact with sex workers. One woman was told she “*must have caught it abroad*”.

One young man with mild haemophilia was being treated with DDAVP. This suited him well but during a routine operation he was, in his view unnecessarily, given Factor VIII. This one instance of receiving Factor VIII caused the infection.

Another man, who had haemophilia, attended his regular clinic with his wife and two small children, to be told without any warning that he had hepatitis C and had three years to live.

One 23 year old man with thalassaemia was told by his consultant that he had tested positive for hepatitis C. This conversation took place in a hospital corridor. He had not been asked whether he consented to the testing being carried out and no treatment was discussed. The consultant told him that he would not be able to have unprotected sex, and again, this was discussed in the corridor. Other than this, he was told nothing about the implications of the hepatitis C infection.

Some negative experiences were caused by insensitive language. One woman who asked questions about her diagnosis was told “*You could be dead by the time your child is 12 or need a liver transplant*”. She felt unable to ask any further questions following that experience.

One man with haemophilia was told by his consultant that he was imagining his hepatitis C symptoms and when his wife saw the medical notes after her

husband's death she saw that the consultant described him as "...a miserable man...who was always complaining."

The blood transfusion infected with hepatitis C which one woman received is inextricably linked with the death of her child. Her husband had agreed to a caesarean at 25 weeks as the placenta was ruptured, his wife was haemorrhaging, and he was told that she might die. His wife however feels she was not consulted about this decision and its grave consequences for the baby.

Late diagnosis of hepatitis C

For many people, the diagnosis came several years - or even decades - after the initial infection. Some did not develop active symptoms for years, whereas others started to experience symptoms soon after being infected. In many cases, the symptoms of fatigue, mental confusion and severe aches were assumed by themselves or their GP to be caused by busy lives, stressful jobs, underlying health conditions, being new parents or having caring responsibilities.

Many went back and forth to their GP without tests for hepatitis C being carried out. One woman had a private appointment with a physician who – without examining her or undertaking any tests – told her she had ME (myalgic encephalomyelitis). Women who had contracted the infection following transfusions at childbirth seemed particularly susceptible to their symptoms being explained away. Many endured years of chronic fatigue and poor mental health as well as liver damage. One woman infected her husband during this period, and he subsequently died.

Another family, after discovering that their mother had hepatitis C, requested her medical records and found that she had been diagnosed some 13 years previously. The GP had taken the decision not to inform her or her family based on the patient's mental health at that point. The woman was suffering with depression but not lacking mental capacity and feels that the decision should not have been withheld. She states: "*I should have been told, I could have infected my family*". Her family comment: "*It's disgusting and it makes me angry that they did not tell her. It was irresponsible and put my mum, the family and health professionals at risk*".

One man had an underlying condition resulting in a liver deficiency. In 1996, following a perforated duodenal ulcer, he received a blood transfusion. Some years later he needed a liver transplant which initially was thought to be a consequence of his underlying illness. However screening for the liver transplant showed he had hepatitis C which must have been as a consequence of the blood transfusion some 18 years previously. Despite numerous blood tests during the 18 years it appeared that he had not been tested for hepatitis C until 2004. He had the liver transplant but still needed

treatment for hepatitis C as this had remained in his blood stream. He was successfully treated in 2017.

One woman was notified in 2005 that her dentist had contracted hepatitis C and all previous patients should have a blood test. Her test was positive for hepatitis C. This was not related to the dentist's infection but a result of a blood transfusion in 1985 – twenty years previously.

The family of an infected woman described how, after her diagnosis, she attended an appointment with the consultant hepatologist. During this appointment she was given a flow diagram produced by the British Liver Trust showing the progression of hepatitis C and its implications. The diagram showed a life expectancy of 30 years from infection to cirrhosis and liver cancer as the end stage. At the point of diagnosis, it was 26 years since she had been infected and though the consultant did not comment further she made the calculation herself.

Two other women who had blood transfusions in 1973 and 1985 were referred for blood tests in connection with the menopause in 2013 and 2014. Both women had been ill for most of their adult life with chronic fatigue, general aches and pains, stomach cramps and low mood. The hepatitis C diagnosis came as a huge shock to both of them. Neither had any idea that there were other women in the same situation. At that point they struggled to find information relevant to their experience. They had little sense of whether their health symptoms were common to hepatitis C or specific to them.

In 2015 one woman went to hospital alone to receive the results of routine blood tests linked to the menopause. She became confused at the line of questioning from the consultant, who asked *“if she had ever used intravenous drugs, shared syringes, been a sex worker, or snorted drugs”*. She was also asked whether she drank excessive amounts of alcohol, and whether or not her husband had sex with sex workers. Finally, she was asked about her sexual practices. Her assumption was that they had got her name wrong, though she then realised that they thought that her lifestyle had caused her infection. In fact, this infection had been caused by a blood transfusion following an ectopic pregnancy 30 years earlier.

A woman born in the 1960s was given a blood transfusion at birth because her mother was rhesus negative. Medical records show that as a child she suffered ill health. In 1992 she was diagnosed with chronic kidney disease. In 2009 when referred for IVF treatment she was made aware of her hepatitis C status. She finds it hard to believe that this was not discovered earlier given the poor health she suffered all her life. She feels badly let down: *“I feel like I have been fobbed off and nobody knew. Why did they make me sign things? I believe it was to stop me taking things further and to protect the government.”*

One woman born in 1926 had surgery to replace a heart valve in the period from 1972 to 1974. She died in 1986 at the age of 60. The end of her life was

very distressing and her family recall vividly how upsetting this was for all of them. Her death certificate stated chronic active hepatitis and cerebral infarction. The information about hepatitis was not known by her family until her death.

People were angry that there was no simple recall programme which could have identified their illness at an early stage as this would have significantly improved the chances of the infection being cleared and prevented further damage 'silently' developing. One woman, now deceased, left a written testimony of her experience of infection. In this she writes: *"I feel that my country knew where they were sourcing this blood from and when they had the opportunity to correct this terrible disaster by completing a recall programme they failed to carry it through. This was proposed in 1985. If I had been traced and tested in 1985 then the virus would have been more treatable, maybe even clearable, and today I would not be left with cirrhosis of the liver which could lead to liver cancer."*

Infection of blood donors

Several people were concerned that they had been blood donors when not aware of their own infection. In some cases they had given blood for many years. One example was where a teenager had been involved in a road traffic accident and needed a blood transfusion. Later in life he became a blood donor and continued for 15 years until he received an official letter stating that he could no longer donate blood. He had to wait a number of weeks before he could get an appointment and was then told about his hepatitis C infection. He has suffered from guilt that he may have infected other people over the years of donating blood prior to the introduction of hepatitis C screening. In another example, a woman had a blood transfusion in 1979 following a caesarean which her baby did not survive. She had a rare blood group and became a blood donor, continuing with regular donations until 1999 when she was informed about the hepatitis C infection.

Section 3. Other Infections

A number of the people we interviewed were informed that they might have been exposed to vCJD. This was seen as yet another blow in the context of existing infection with HIV and/or hepatitis C.

Section 4. Consent

Very few people could recall being asked for consent about the use of blood products or a blood transfusion and nobody recalled any of the risks of transfusion or blood products being discussed with them by doctors at the time. It was just accepted that people with haemophilia and thalassaemia would receive these products. The relatives of older patients recalled that new blood products were seen as a "wonder drug" with life-saving properties, because previously people had been treated with more invasive therapies.

Where people were given transfusions in emergencies they were rarely in a condition to consent: one person's parents were called by the hospital in the middle of the night and asked to consent on the phone – but were told that this was in the context of a life-saving procedure. Many people said that they had often reflected on the terrible irony of their life being saved on the one hand, but being given a life-threatening disease on the other.

One woman described being informed by her consultant that her treatment at a previous hospital appeared to have been without her consent and that she had been part of a trial where she was given interferon only, with a low likelihood of success because she had genotype 1 hepatitis C.

Section 5. Impact

Living with infection

The people we spoke to about infection with HIV shared brief but vivid accounts of the traumatic impact of the early treatments for HIV. Some recalled that they considered giving up the treatment as death seemed preferable.

People also described the impact of hepatitis C in vivid detail. Chronic, debilitating fatigue was an early symptom, with this often lasting for years without diagnosis. Other symptoms were severe aches, gastro-intestinal problems, skin changes and sweating. Cognitive impairment was frequently described as 'brain-fog', a debilitating level of confusion and inability to focus, often combined with anxiety and depression.

There were also mental health problems as a result of the effect of chronic illness on everyday life, relationships and life chances. People described the later stages of the disease, when the liver and other organs were affected. They lived with the worry that enlarged veins (varices) would rupture; had to have painful tests such as gastroscopies, fluid-draining procedures and biopsies; and underwent lifestyle limiting treatments such as beta-blockers and blood-thinning treatments. One witness said: *"As a result of my infection and the worry around it, I have suffered stress and mental strain to the point of thoughts of suicide out of fear of having a nasty death"*.

Another family whose son contracted hepatitis C during treatment for leukaemia said that the infection felt like the last straw at a time when they were already going through so much stress. His mother has suffered bouts of depression, and mental health breakdowns, which she believes were triggered at this time.

Impact on family and other relationships

Many people had felt responsible and guilty when the infection was confirmed and their partners and children needed to have blood tests. Where individuals had been infected as children, their parents often felt deep guilt, and in many cases, decided that the infection would not be discussed within the family.

One mother of four described how she had tried to protect her family from her own needs caused by living with hepatitis C. *"In order to protect my family I thought it was best not to disclose my illness lest they be shunned or isolated. However, by not sharing my struggles I missed out on the support of relatives and friends which made the suffering a lonely experience."*

An infection of this gravity was a major challenge and many people experienced relationship breakdown. In some cases, families were able to work through this, but in others the relationships never recovered. One man, who lost his brother to HIV when he was 20 and his brother was 23 said: *"growing up, he was my best friend - we were inseparable in the school holidays. His HIV diagnosis when we were teenagers drove a wedge in our relationship; it was something that we never discussed properly and we were never close after that. That's one of my biggest regrets and I feel the guilt to this day."*

One mother whose son was infected with HIV when he was very young commented: *"We have nothing else to compare this to. Our child was infected and it took the joy out of our lives. Psychologically we became different people, we cut off from others and the depression we carry has at times almost torn us apart. In my darkest days I even chose the music for our son's funeral."* Although this couple feels lucky to still have their son, they have had to endure his constant struggle with his illness.

Two people spoke about how the hepatitis C infection had affected their closest personal relationships, including the decision whether to have relationships: *"I decided it was too much of a risk to have a partner. Having to keep it to myself has been very hard but I didn't want to discuss it with anyone else unless it was absolutely essential."*

"Being infected with hepatitis C has totally changed my life. I have not been able to marry and have children. It's hard to go on a date with a woman and tell her you've been infected and that she and any children you have could be infected too."

The medical advice in the 1980s for men co-infected with HIV and hepatitis C was to abstain from any sexual activity which involved exchange of bodily fluids. Two of the men interviewed remained celibate throughout their 20s after receiving this advice. One married later, but the other has never felt able to be in a relationship for fear of infecting a partner. Advice on sexual activity

was not clear for people infected with hepatitis C and everyone interviewed described significant stress because of this.

Another man said that the major impact of being infected as a young man, was not feeling able to have a sexual relationship. He felt he must be honest and mention the infection early but this stopped any relationship progressing. By the time he was infection-free he was into his 30s. He worries that having a partner is unlikely given the stigma about viral infections, and the need to keep himself safe from infections from a potential partner.

Several people interviewed had not had sexual activity for years: others who were in established relationships said that the need to control the infection affected their enjoyment of sex, and even after the hepatitis C was cleared many felt nervous about it recurring and took appropriate steps.

Some couples spoke with immense sadness about limiting their families because of hepatitis C. In some cases, this meant having to wait until the infection was cleared, by which time their fertility had diminished. Others felt so broken by the experience that they did not have the emotional resources to contemplate having further children or indeed being a parent at all. One woman infected with hepatitis C had planned her life, assuming she would have children. The infection led her to believe she could not risk having a child which remains a cause of deep sadness.

People who had been infected also experienced shrinking horizons through not being able to travel. Many people spoke about the loss of their true self – their former confident, outgoing and active personalities, the lost ‘happy go lucky’ person and their abandoned aspirations. One woman who wrote about her experiences before she died noted: *“I’m left with a possible death sentence; this virus had destroyed my plans for the future and I have lost the ability to dream.”*

One woman diagnosed with hepatitis C during her second pregnancy spoke of the trauma of her son’s birth: when he was born he had to have his stomach emptied via suction to ensure that no blood had been ingested. The midwives took him to the other side of the room to do this so while the new mother could see her son she was not able to hold him. Eventually they were both moved from the labour suite, and she was placed in a side room because the hepatitis C infection meant she could not mix with other mothers.

One person said: *“This put my life on hold. It was like marking time. Playing with my children stopped as I was scared to hurt them. My precious children needed protection so I distracted myself in order to protect them. It made my relationship difficult and I lost them and me. I don’t have emotions, I just shut down.”*

People with underlying conditions, in particular thalassaemia and haemophilia, developed friendships with others with the condition who were

having blood transfusions or treatments at the same time. They recounted the horror of watching these friends with HIV and hepatitis C dying: *"We were like a little family in and out all the time. It was hard seeing them dying."*

Stigma and shame

Many people lived with an enduring sense of being blamed and feeling shame about the infection, which was compounded by the national mood about viral infections in the late 1970s and 1980s: they felt that hepatitis C was linked in people's minds with HIV and AIDS, and the prejudices and moral panic associated with those conditions.

One woman was acutely anxious about anyone finding out that she was infected. The receptionist at her GP surgery was a fellow parent at her son's school. She went through agonies every day wondering whether this receptionist had told other parents about her infection. This became such a crippling anxiety that the family felt obliged to move house. They moved 25 miles away to an isolated small village, away from the support networks provided by her mother and mother-in-law.

Another infected woman who worked with vulnerable people in the care services found herself in a difficult position when she attended training in infection control in 1991, and realised that others on the course had preconceived ideas about HIV and hepatitis C. This made her realise how difficult it would be to share information about her health with colleagues.

One woman infected with hepatitis C had been a blood donor prior to her diagnosis. She now works in a predominantly male environment where a mobile blood donor unit visits the work premises. Her male colleagues mock her for not participating as they assume she is too frightened to give blood.

One man was ostracised by some in his community by, for example, people getting up and leaving the room when he came in. Another man spoke of getting abuse in the street because of his skin colour and being called *"junkie"*.

One family talked about a sign in a local hairdressing shop in the 1980s that said: *"No Homosexuals or Haemophiliacs"*. A man with haemophilia described how he has to have his own glass at his local pub.

A number of people spoke about the pressure of keeping a secret for so long, especially within their families, and the guilt of not feeling able to tell their closest loved ones the truth. One infected man explained he didn't tell anyone about his condition as it would be selfish to share that burden with others. This sentiment was widespread.

People who had been infected wanted to protect their loved ones from this information as far as possible. They felt that continuing public ignorance about

hepatitis C and infected blood aggravated the issue. Where they had shared their status through necessity, they all felt it imperative to make clear their infection was as a result of infected blood and not caused in another way. They hoped that the publicity for the Inquiry would raise awareness and help to quash ill-informed myths.

Impact on education and work

One young woman gave up university after a year because her father was so ill with liver disease that each time she came home felt like the last time she would see him, and the strain became too much. Two people who learned of their infection when still teenagers gave up on their education because it seemed a pointless investment if their lives would be short.

One family described a “*battle*” to ensure their son was given the right education following his infection. He missed a lot of school during his treatment and when he returned his friendship networks had fractured. His parents asked for an assessment of his educational needs but the local authority refused. Only after his parents took the appeal to the highest level could they get him the support he needed.

It was not uncommon for children with haemophilia in the 1970s and 1980s to be educated at ‘special schools’ for pupils with additional health needs. Two men educated in one of these schools had good memories of this time. They were supported in managing their haemophilia and injected themselves to avoid hospital visits where possible. The introduction of new clotting products gave them freedom not previously experienced, but in retrospect they all commented on the catch-22 of the long-term implications of the resulting infections.

Two women with thalassaemia had different school experiences, which may be due to the 15 year age difference. The older woman found that thalassaemia led to fear and exclusion by other children. She required frequent blood transfusions, was absent from school for a significant amount of time and does not recall any additional support during these years. The younger woman had a much more inclusive time at school and felt just like one of the other pupils.

Although the younger woman was well supported at school and college, her experience at work was not as positive. One of her employers required her to make up the hours missed for transfusions, resulting in long days and further exhaustion. This was not sustainable so she chose to move on. Fortunately, her current employer is supportive and flexible.

Many people had chosen not to share their health information with their employer unless necessary. This was usually if they needed to be away from work with long-term absence for treatment. Some chose to do so and felt supported, whereas others knew that it would affect their employment

prospects and would expose them to further stigma. In these instances, people spoke about avoiding work conversations about health and times when they felt compromised in doing their job properly. One man talked about a customer falling and cutting her head in his shop. He felt unable to help and was frozen to the spot. He then felt bad for not doing anything, and knew that his colleagues had observed this but were not aware of his infection.

Several people spoke about their determination to keep working. Sometimes this was about wanting to contribute to society and not allowing the illness to take yet more away from them. For others it was a financial issue – they could not afford not to work. They also spoke of the negative impact of continuing to work: a life consisting of working and sleeping, coping with excessive pain, and requiring joint replacements to keep going. Several people had to reduce their working hours or change careers, and others were unable to contemplate working at all, because of their physical or mental health. This reduction in working capacity was also described as a loss to wider society; the nursery nurse who retired at 49; the nurse who retired at 52; the teacher who had to retire early because of her mental health.

Section 6. Treatment, Care and Support

Attitude of healthcare professionals to infections

People described a range of experiences from more sensitive and expert care to brutally delivered information, inappropriate questions, and poor quality care.

Some people with underlying health conditions, such as haemophilia or leukaemia, said that their illness could have been life limiting and that treatment with blood products was pioneering. They appreciated that medical science had advanced the treatment of their condition and believed that the use of infected blood was not due to clinicians but to organisational decision makers.

Many people described their consultants as “*lovely*”. They shared examples of medical and nursing staff going the extra mile to support patients with home visits, ‘open door’ access and attendance at funerals. One woman who was widowed when her husband died due to hepatitis C infection says she does not know how she would have survived without the support of the consultant. Some described their consultants as being active and vocal campaigners about infected blood, and working hard to find new treatments to tackle hepatitis C. The great majority of people with hepatitis C described a positive relationship with their specialist nurse, who provided a flexible and practical response to the challenges they faced.

One family described a very positive experience of care for their uncle who had haemophilia and was under the care of the same two consultants and a very dedicated nursing team throughout his life. This team were like a second

family as their lives revolved around visiting the unit. Given the extent of his haemophilia, the family felt the team did an amazing job keeping him alive into his 60s. When he died aged 65 he was the oldest haemophiliac in his home city.

Another positive account came from a man who had received infected blood during treatment for Hodgkin's lymphoma. In 1995 or 1996 he was contacted by his consultant who was extremely apologetic that the infected blood had been given at the hospital where the consultant was now working. This man was very keen to emphasise that the specialist care received for Hodgkin's lymphoma and hepatitis had been excellent and that his GP welcomes him *"like a VIP"*.

One man with haemophilia had a mixed experience when he visited the local surgery for treatment of a bleed. In the treatment room some blood remained on the surfaces and a nurse immediately started to deep clean and disinfect the area. However, the GP told her to stop, and that tidying up could wait.

Several people described limitations to the knowledge about their conditions, especially alongside other conditions, and described having to research this for themselves to inform clinicians. This was more common in more rural areas, compared with positive experiences in cities which had specialist centres linked to research establishments.

Where specialist facilities were not available, people described being treated in clinics alongside drug and alcohol users or with cancer patients. If they lived in an area with low incidence of hepatitis C, this also limited their ability to establish networks and gain support from others affected. In other areas, existing services have supported the development of networks and specialist support, for example one couple described an excellent service from a social worker with a specialist support role for people with hepatitis C. They said *"We would not be where we are today without her. She has helped us to deal with financial and emotional matters. We rely on her and everyone deserves this support"*. Where such services and networks did not exist, people spoke of feeling isolated and abandoned.

A number of people experienced thyroid problems as a hepatitis C complication. One woman described how she had thyroiditis, triggered by the infection and its treatment, but the medical team had very little understanding of the condition. The consultant acknowledged that she was their first patient with hepatitis C related thyroiditis and they were grateful to her for providing them with a review paper on this condition.

After successful treatment to clear hepatitis C one man moved to a new city for a fresh start. His haemophilia treatment also transferred to a new hospital. The doctor he saw said casually *"I see you have hepatitis C"*. This was a terrible shock as he thought the infection had returned. Six months later, he was told that this had been a clerical error; his record should have said that he

was positive for hepatitis C antibodies, but this had been copied wrongly as 'positive for hepatitis C'. He felt that it was important that the whole team, both clinical and administrative understood their responsibility for ensuring that information was correct, and in failing to do this they had "*put him through months of hell*".

One woman who had scoliosis discovered later in life that she had received infected blood during an operation in 1981, when she was 14. In 1994 she was living in Australia when she had blood tests as she was feeling lethargic and experiencing low mood. These tests showed she had been infected with hepatitis C. She recalls that the doctors in Australia were very relaxed about the condition and regular liver function tests were arranged together with advice about personal hygiene. In 1997 she returned to the UK for an extended visit. She visited a GP for regular liver function tests. The GP was alarmed by her hepatitis C status and queried the patient's information, thinking that hepatitis C was contracted from dirty water.

Another woman described how, after the birth of her baby, a health visitor wrote on her record 'mother hepatitis C positive'. She also insisted on setting up a separate file because of hepatitis C. The new mother and her husband objected to this, and received a defensive letter from a senior health visitor responsible for child protection. This letter focused on infection risks to staff and the health trust's duty of care to their staff. The couple challenged this further. The mother says she felt like a leper, and that this experience with the health visitor "*nearly killed me*".

During treatment with ribavirin and interferon one man had a subdural haematoma leading to a bleed in the brain. He had life saving surgery for which he and his wife were very grateful to the surgeon. However they recall a very insensitive comment from a nurse who said "*You ought to think yourself lucky, most people don't usually make it this far*".

One man recounted that his father had leukaemia and received stem cell treatment followed by blood transfusions. He was infected with hepatitis B, which was noted as the primary cause of death on the death certificate. His father had been told by the consultant that an error had been made, and the wrong blood taken out of the wrong fridge. This had affected eight people, seven of whom had died. The father was told he might be all right, but in fact he died three months later.

The family were distraught as their father had spent his last weeks in an isolation ward at a psychiatric hospital due to lack of provision to treat hepatitis B in the main hospital. Their father wrote an account when he was told about the infection which was formulated into a statement by his solicitor: "*I was told today by (the consultant) that the blood cells were contaminated. It has not really sunk in what has happened. Now that I have hepatitis B I cannot be cured and there is the possibility that it will be passed on to others who come into contact with my blood.*"

One woman's father needed dialysis, which he had at his local dialysis suite with a regular group of other local patients. He was infected with hepatitis B as a result of his dialysis. After the infection was confirmed he had to have his treatment in a separate room. This fuelled speculation among the other patients and it also removed his regular support network. The same man had previously taken holidays near his daughter because a local hotel had dialysis facilities, but this offer was withdrawn once the hepatitis B was confirmed.

In some instances, essential tests and equipment were not available on the NHS and people were expected to fund them privately. In 2005 one patient was told that a fibroscan would determine the progress of the disease, but there were no facilities in this country. She had the fibroscan in Paris in June 2005 at the family's expense. In 2006 a fibroscan machine was installed at a hospital 74 miles away and she had to travel there for scans for seven years before she could have them more locally, even though she lived in a densely-populated area. In June 2008 her consultant advised that due to the level of cirrhosis she needed an enhanced liver fibrosis test. Again, this was not available on the NHS and she had to pay £99 to have this carried out by a private contractor, though in an NHS hospital.

The words most frequently used by people when discussing access to treatment were "*leper*" or "*pariah*". There were many examples of people being denied treatment or isolated from other patients because of hepatitis C. Being the last patient of the day was a common experience, for instance for a thyroid operation or when having wisdom teeth removed. The individuals concerned assumed this was because of their infection. Everyone was aware that their dental records and GP records were marked with the infection status. The majority felt this was necessary to ensure safe practices were followed, though some were uncomfortable at the obvious nature of the marking. One woman spoke of "*the tyranny of the yellow sticker*" on her notes and trying to cover it up with her hand.

There were examples of GPs being supportive in challenging stigma or prejudice from others. One woman's dental nurse commented loudly on the infection status marked on the record; the dentist reassured the patient and rebuked the nurse. While most people had supportive local dentists who continued to treat them, several were refused treatment and referred to hospital dental departments. One man was so traumatised by the insensitive way he had been treated during a hospital dental procedure that he has not felt able to visit the dentist since and has resorted to extracting his own teeth.

One man with HIV and hepatitis C had a number of hospital admissions when he was very ill with pneumonia. He recalls being placed in an isolation room with full barrier nursing. The haematology consultant was visibly angry and insisted he was nursed like any other patient.

One woman described how her husband experienced some abdominal pain and was taken to a local A&E. As the doctors stood around his trolley, his wife

informed them of his hepatitis C and she described them all stepping away from him as she said this, and putting on gloves. Her husband noticed and was very upset.

Some people have decided not to access their own or relatives' records as they feel the extent of the information would be too overwhelming and distressing. When others tried, some were told that records of deceased relatives had been destroyed but persevered and successfully retrieved them. Seeking access to records for a deceased relative was difficult when probate had been given to another relative, since deceased. Some hospitals had been demolished and records were lost, though in a couple of cases records had been sent to GPs. By contrast, in one case the 'look back' exercise carried out by the NHS could identify the exact vial which had been infected.

Treatment for hepatitis C

People who experienced interferon and ribavirin treatments described this as gruelling, similar to chemotherapy, which lasted months and in some cases years. A small number of people said that they were given clear information to help them prepare for the impact of the treatment, for example one couple who were both being treated were able to plan so that one had the treatment before the other, whereas others felt they went into it very naively. The phrase most often heard about this treatment was: *"the worst year of my life."*

Many people described debilitating tiredness, hair loss and significant weight loss, and they also spoke of the profound impact on their mental health. Some considered suicide during this period and relationships were severely tested, with some couples separating and others considering divorce. Many of the effects of this treatment have endured, and become lifelong conditions. The treatment also resulted in the development of further physical and mental conditions.

One young woman with thalassaemia had been engaged to be married when she started the treatment in her early 20s. She had learned how to manage her condition, was working and had a lively social life so was feeling positive about her future. After starting her treatment she did not leave her parents' home for a year. The wedding was cancelled and that relationship ended. She was unable to work or consider any career prospects. The anticipated happy personal and professional future was lost. She now has cirrhosis of the liver and is deeply pessimistic about her life expectancy.

Despite successfully clearing hepatitis C, another woman has not recovered her former physical or mental health. She described the treatment as truly traumatic, resulting in flashbacks and breakdowns, which were finally diagnosed as post-traumatic stress disorder. The effects of the virus and treatment have left her with severe depression and anxiety. She becomes mentally exhausted very quickly and described this as her *"brain just stops*

working". She described the overall result of the infection and treatment as: *"an existence of survival and coping, with little contribution or fulfilment"*.

One family described how their relative had been an average weight but that the hepatitis C treatment led to a significant weight gain from size 12 to size 22. She was unable to find clothes to fit, and became embarrassed to go shopping because of the assumptions made by assistants and other shoppers. She felt that people judged her because of her weight. Her son said he felt like holding up a billboard saying it wasn't her fault.

One man described the side effects of the treatment: extreme tiredness due to disrupted sleep, hair loss, weight loss and significant mood changes – he became very quick to anger, which was unlike him. He also had some memory loss and confused thoughts: getting lost when driving familiar routes and forgetting everyday things.

Another man with haemophilia developed a psychological block against carrying out his own injections. His weight dropped to eight and a half stone and he developed lifelong rosacea. He experienced significant depression, which continued after his treatment finished, and got into a rut of *"doing nothing"*. This meant his wife took on all the responsibilities of parenting and running the home. He also turned to alcohol during this period.

One man with haemophilia was treated with ribavirin and interferon in 2001. This was not successful but for his second treatment from 2008 to 2009 the same drugs were used with a successful outcome. In the middle of the treatment he became very ill and suffered an unrelated subdural haematoma. This was not picked up by his GP but through a self-referral to the haemophilia centre where a very thorough new doctor *"saved his life"*. During this time he experienced fits and continues to need medication for this condition.

The widow of a man who had been infected with hepatitis C described how during interferon treatment he developed depression, appetite loss and severe fatigue. He lost his hair and withdrew from life – and *"he couldn't be bothered with anything"*. He also had aggressive outbursts which were completely out of character, and life for his family became about *"walking on eggshells"*. His mental condition deteriorated to such an extent that he was admitted to a specialist psychiatric hospital 150 miles away which his widow describes as a real low point for them. The interferon treatment was not successful in clearing the infection.

Many families described the stress of caring for someone with severe physical symptoms whose mental health was also affected, especially after interferon and ribavirin treatment:

- *“It was like having a different person in the house”*
- *“He became a vile person”*
- *“I was terrified of upsetting him”*
- *“She wasn’t interested in anything”*
- *“She completely withdrew from life”*

Families who had not been informed of the likely effects of treatment, did not realise the reason for the change in behaviour, thinking it was reactive depression or anxiety that they thought the person should be able to overcome. In fact, this was treatment-related depression and/or anxiety, which would endure for months or years. This lack of understanding led later to guilt for the lack of patience and compassion.

In great contrast, people who had been able to use the new direct-acting antiviral treatments spoke very positively about this. Everyone on this treatment had cleared hepatitis C, and few had serious side effects. The new treatment takes less time and some people felt the benefits quickly, with one woman commenting that after two weeks she knew she had been cleared.

People receiving this new treatment were all told it was expensive, which led to mixed feelings. Some felt that they were finally being valued by being given the cutting-edge treatment they deserved, whereas others felt that the message implied was *“you should think yourself lucky”*. They all felt this treatment should be available to everyone with hepatitis C through infected blood, irrespective of cost.

Liver transplants

Four people talked about liver transplants. One man had had a successful transplant which transformed his and his family’s life. His wife said it gave them nine of their best years together. Sadly, the hepatitis C could not be cleared and his new liver became infected, leading to his death nine years later.

Another family spoke with great bitterness about their relative’s experience. The interferon treatment had led to significant weight gain which remained after treatment. The liver disease progressed to cirrhosis and when assessed for a liver transplant, the assessing surgeons refused to undertake the

procedure because of her weight. The family are angry that she was infected by the NHS, that the NHS treatment caused her weight gain and this then made her ineligible for treatment which could have saved her life.

Two people spoke of being told that they could only have a previously infected liver as a transplant. In each case the individual felt they were being de-prioritised because of their infections and offered 'second-rate' organs.

Several people expressed the view that patients with liver disease as a result of infected blood should be given the highest priority for liver transplants.

End of life

Several people spoke about their loved ones experiencing traumatic deaths. One woman described this as a terrible time, as her mother "*did not have a peaceful or pleasant passing*". Her mother had multiple organ failure, and at the end the nurses had to squeeze her fingers hard to get blood, which felt very cruel.

One woman described her mother dying from liver failure at the age of 51. The daughter was very upset, leaning on the wall outside her mother's room when one of the doctors came out, tapped her on the shoulder and said: "*Cheer up, it might never happen*". She felt that this was very cruel, as her mother was so close to the end of her life. In contrast, she remembers a "*lovely doctor*" who one night gently explained that he did not think her mother would reach the morning, and what would happen over the coming hours. This felt like a respectful and compassionate discussion, which she and her father really appreciated.

Another woman spoke about her husband who had hepatitis C suddenly becoming acutely ill. His skin was yellow and he appeared to be in a dream-like state, with the symptoms of a severe hangover. The initial diagnosis was abnormal sodium levels, and he was sent home from hospital but then called back and diagnosed with hepatitis E through food poisoning.

His wife felt that his treatment at the hospital was not good. No specialist beds were available so he remained in A&E. She was very concerned about the decline in his condition, but the nurses said he was just tired. On the same day her husband started having seizures and died. The family were told by the hospital that hepatitis E is not normally life-threatening but it became so because of his underlying hepatitis C.

After the death, the family complained to the hospital about the quality of care he had received. The process took a year, the hospital said they had done all they could but the family felt "*fobbed off*". Grief and the impact of her own hepatitis C related condition meant that his widow did not have the energy to take the complaint further.

One man with leukaemia spent the last weeks of life in a psychiatric ward, because of the perceived need to nurse him in isolation. Visiting the hospital meant his wife had to travel on two different buses. His family were not informed that he was nearing the end of his life and on the day he died his wife took her usual lengthy bus route, with flowers to celebrate their wedding anniversary. It was only when she got to the ward and saw the empty bed that she was told he had died.

Most death certificates referred to hepatitis C as the cause. In one 1997 case the medical and nursing team were angry when a man who had been infected died. His niece was given the death certificate on the ward and when the registrar opened the envelope, she saw that the doctor had written 'hepatitis C' in capital letters right across the certificate, which she felt was done to ensure that the correct cause of death was recorded.

One young man with haemophilia died of an HIV-related illness in 1989 though this was not referenced on his death certificate. The cause of death was recorded as liver failure arising from blood cancer. His brother recalls there being some discussion that the doctor had "*done them a favour*" by omitting HIV from the certificate as there was such stigma about it at the time.

A number of people spoke about the impact of losing loved ones to early and traumatic deaths. One parent who lost her child said: "*There is nothing worse than the loss of your child. It destroys your whole life. I had so much time off work I was almost sacked. It changes your personality and it's devastating. You just function day to day and there are no words to describe it.*"

People frequently spoke of grandchildren never meeting their grandparent, weddings with a parent missing, and losing their 'rock', the person they could always turn to. Widows and widowers talked about their hopes for a long retirement together being replaced by loneliness and isolation.

Some people commented that their loved ones were also a loss to the wider community: the local undertaker who was such a support to his community, the much-loved school lunchtime supervisor, the nurse who died too early at 51. One man spoke about the lost potential of his brother, a talented musician and singer, with excellent academic achievements: "*I know that, had he lived, he would have made a huge contribution somehow. He studied medicine at Oxford, then changed courses to study law and achieved a first-class degree. He was a polymath. His death at 23 meant the whole country missed out on what he could have contributed.*"

Access to psychological support

Many people felt there was a need for tailored psychological support for people infected and affected. They believed that therapists would need a good understanding of the history of infected blood and the medical aspects relating to it to fully meet the specific psychological needs of this group.

People diagnosed with HIV in the late 1970s and early 1980s could not recall any counselling or specific support. They remembered that the awareness-raising campaigns and support groups were not directed to people who had contracted the virus from blood or blood products. A number of men diagnosed in the mid 1980s felt that the help lines were for gay men and not relevant for their circumstances.

One infected person who is also a health professional was asked to co-lead a support group but was not well enough to do this. She acknowledged that the approach was well intended because of a complete lack of support arrangements locally, but she did not feel it appropriate to ask her to bring her professional skills into a very sensitive personal situation.

One woman asked for support in 2011 and was offered a group where the focus was addiction. She asked for more tailored psychological support but was told that only general counselling was available. She felt that this completely missed the point about the gap in provision nationally for infected people.

Another woman had a very negative experience of working with an NHS psychologist who told her she must have had a “*death wish*” because of her relationship with an infected person. She later sought help through the Hepatitis C Trust who were extremely supportive, and provided private counselling.

One positive experience was that of a woman with thalassaemia who had received counselling intermittently over many years. The counsellor was able to tailor the support to her particular needs at the different stages of her life, which proved to be extremely valuable.

Section 7. Financial Support

The majority of people infected with hepatitis C had been told by their consultants about the Skipton Fund. Others found out through the press or were told by relatives. Some people did not know about the availability of support or only became aware of this when they registered to take part in the Inquiry.

People spoke positively about the current schemes, but all expressed anxiety that this support might be reduced as part of austerity measures - meaning they do not feel they can rely on it for their long-term financial plans. Some felt that payment levels were inadequate for the suffering caused and that these should be brought into line with the amounts awarded in other countries.

There was one particular issue for a family who had lost their father through infection with hepatitis B, as no financial support is paid for this condition.

Everyone said that money could never compensate for their ill health and their traumatic experiences. The practical physical aspects of work had made it particularly challenging to continue in employment. Many had given up work early in their career or retired prematurely due to their ill health. One woman with hepatitis C as a result of being treated for acute myeloid leukaemia stated: *“I have been ill all my adult life. I’m always having tests. My life revolved around work as a hospital professional nurse and being a patient. I loved my work and it affected my prospects”*.

In some cases, career progression was not pursued due to illness, resulting in additional financial difficulties. Some who were still in work explained that they still suffer significantly with lethargy and need to accommodate that in their weekly routine. The financial support received allows them to work fewer days but still maintain their standard of living. Two people who were self-employed for a while found that was not sustainable in the absence of sick pay and the inability to secure insurance.

Several people spoke about periods where they could not work at all, especially when receiving treatment. One couple spoke about the impact of two years of interferon treatment. This had to be paused periodically to allow the immune system to recover, the husband could not work and the family’s savings were gone in six months. His wife worked part time, which meant they were unable to access any benefits other than a £10 reduction in council tax. They had to live off borrowed money from relatives and used a Skipton Fund lump sum to repay this.

One woman explained she gave up work to care for her infected husband: *“I loved my job but I love my husband more.”*

One family had not been able to afford to pay for a funeral and had to borrow money at a time when consumed with grief. Their child had become seriously ill after an accident and a blood transfusion was needed. She died a few months later at the age of fourteen. No financial support was available.

One woman in her eighties who had moved to supported living as a result of financial hardship over the previous thirty years said if she could tell her deceased husband anything it would be: *“I hope you are proud of your sons. I know you will be. They have done so well. It’s horrendous without you.”*

Section 8. Other Issues

Messages to the Inquiry and points for the future

The majority of people interviewed described themselves as *“the lucky ones”* because they had survived. We heard this at the beginning of many interviews. Our interviewees were stoic, resilient and sensitive to the situations of those who had died, their bereaved families, and people currently ill and receiving treatment.

As experts by experience, this group of people have given a powerful collective picture, revealing clear, common patterns and themes. Their hopes for the Inquiry show similar commonality:

- People want answers as to what happened, when and why. The overwhelming need for this group is to understand the decision-making processes, and the information available at the time, which led to them or their loved ones receiving infected blood.
- They would like to see a clear timeline of when infected products were first used and when this stopped, along with an understanding of how decisions were made along this timeline to continue using those products; how risks were considered and whether this was assessed as a risk worth taking.
- They want to know what factors informed the decisions made and whether this was simply financial, in the light of other priorities.
- They particularly want to know what people in authority knew about the risks of infected blood when making strategic and clinical treatment decisions to continue its use.
- They want the people responsible to be held to account and to explain whether decisions were made in good faith on the basis of what was known, or whether there were other drivers such as finance.
- There was a range of views about accountability: some wanted to get more evidence before considering who was responsible. There were also comments such as decision-makers *“having the book thrown at them”*, or being tried for crimes against humanity.
- Some were concerned about a *“cover up”* and wanted to know if this had happened and who was responsible.
- Everyone we spoke to said the outcome of this Inquiry should be that something like this could never happen to anyone again.
- They wanted the public to know more about their experience: to replace myths with facts and thereby to reduce the stigma associated with infections. They want the public to know they were infected through no fault of their own.
- People who received blood transfusions as part of routine and emergency operations felt there was a woeful lack of information for them on hepatitis C, the circumstances in which it can be transmitted, its symptoms and treatments.

- Many people also said that they wanted health professionals to respect a patient's personal knowledge and not to dismiss them, judge them or make assumptions about that patient.
- Many people said that they would like the financial support arrangements to be reviewed to make it less of a battle for people to get help. They would like certainty that the current support will not be withdrawn.
- Many suggested that the attempts of government organisations to reach people possibly infected with hepatitis C have been ineffective. They spoke about people carrying infections they do not yet know about, and how the lack of a recall scheme following transfusions left them with a *"ticking time bomb"* for years, and an irreversible progression in their disease. They would like to see a scheme in which everyone who received blood products or blood transfusions from the 1970s until screening was fully effective would be offered a blood test.

The intermediary team would like to offer their respect to all those who found the courage to contribute to the Inquiry in this way. Their dignity, concern for others and the way they conducted themselves was admirable and humbling.

Although the aim of this process was to allow people to share their experience anonymously, some families specifically asked for their loved ones to be named in this report:

John Henry Grant Careless	1925 - 1991
Sylvia Donnelly	1926 - 1986
Jane Fitzgerald	1961 - 2015
Fay Mary Edith Howe	1939 - 1991
Giovanni (John) Lupi	1923 - 2003
Henry (Harry) Minter	1931 - 1988
Toby Stevens	1967 - 1989

Statements of Truth

I believe that the facts stated in this report are as related to me:

Name: Pam Allen

Signed: GRO-C

Dated: 15/01/2020

I believe that the facts stated in this report are as related to me:

Name: Kay Durrant

Signed: GRO-C

Dated: 15/01/2020

I believe that the facts stated in this report are as related to me:

Name: Jackie Wilson

Signed: GRO-C

Dated: 15/01/2020