Witness name: Samantha May
Statement no.: WITN0912001
Exhibits: WITN0912002
Dated: 16th September 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SAMANTHA MAY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 June 2019.

I, Samantha May, will say as follows: -

Section 1. Introduction

Q1. Please set out your name, address, date of birth and (if you wish) a short description of your current professional circumstances.

1. My name is Samantha May, born GRO-C 1962. I live in London. My address is known to the Inquiry. I work full-time as the Helpline Information and Support Service Manager for The Hepatitis C Trust ("the Trust").

Section 2. How Affected

Q2. You have been asked to provide this statement because you have had professional involvement with others who have been infected with Hepatitis C through blood or blood products. It would be helpful if you could set out at

the beginning of your statement, and before you address the issues listed below, some information about your role at the Hepatitis C Trust.

2. The Trust is the UK charity for people infected and affected by hepatitis C and is a patient-led organisation.

3. Our Helpline Information and Support Service provides up to date, reliable information and emotional support, delivered in a 'patient friendly' manner within a safe and confidential environment to anyone affected by the hepatitis C virus ("HCV"). By way of brief background, the Trust was registered as a charity in 2001.

4. Four people who had HCV, created a patient-led charity because they were aware from their own personal experience that there was no information or support available for people that were infected at that time.

5. The Trust was initially focused on providing support and reliable information, in a way that was non-judgmental, non-stigmatising or full of medical jargon and ensuring people infected with HCV were aware of their rights and treated fairly, by advocating for them at all levels.

6. In the early days, after HCV was specifically identified in 1989, there was a complete lack of accurate information, no provision for emotional support and a stigma was often attached to those who were infected. So in 2001 the Trust launched a website, and in 2004 a helpline, to help remedy this.

7. Until 2004, there was no specific provision for financial support for those infected by way of blood/blood products, or for their families.

8. The majority of people who had HCV at that time, regardless of their route of transmission, were extremely frightened, confused and isolated as a result of their diagnosis.

9. Since we started, the Trust has evolved and constantly adapted to people's changing needs with support and information as required. In our early years particularly, aside from the helpline and website, this included provision of a wide range of support groups for different group's needs, health and lifestyle workshops and other social and information events for people to meet others living with HCV and enabling them to have direct contact with gastroenterology specialists and other professionals. This meant they could receive up to date information on the illness, its treatment, lifestyle guidance and link in with other networks, to get the best information possible, all delivered in a friendly, informal and supportive atmosphere with others.

10. We have also always provided newsletters to keep people informed and to provide people with a platform to share their experiences and feel less isolated. Current circulation is just under 4000 people.

11. We have grown rapidly since we started, and over the last five years in particular. This is as a result of a much more positive landscape opening up for people with HCV, due to better education and diagnosis, especially among people at greater risk, and because of the arrival of new, safe, tolerable and highly effective treatments.

12. Much of our current our work is focused on building awareness of HCV, finding those most at risk, the majority of whom remain undiagnosed, and supporting them to access treatment. We work across the UK to support the achievement of HCV elimination by at the latest 2030, in line with World Health Organization and NHS goals.

13. Our current work specifically includes:

- Providing information and support through online and printed materials, and through our Helpline Information and Support Service.
- Working directly with drug and alcohol providers, hostels, prisons, pharmacies and homeless services across the UK, delivering peer led

services to raise awareness of HCV, encourage testing and support those testing positive along the care pathway. We also provide overall blood borne virus awareness training to staff and other professionals.

- Working on policy and supporting professional networks: we provide the secretariats for HCV Action, to bring together health professionals, and for the All Party Parliamentary Group on Liver Health.

14. Over the last 17 years since the helpline launched, the scope of that has also grown, to include not just those directly infected or affected by HCV, but also to provide a reliable resource for a wide range of people, including the general public, the media, medical profession, employers, researchers, students, employers and many others, on any matters relating to it.

15. I intend to speak about my professional experiences as the Helpline Information and Support Service Manager for the Trust, specifically in connection with those infected or affected by HCV, by way of NHS infected blood or blood products.

16. I was employed by the Trust in July 2004 to launch a UK-wide helpline, utilising a team of volunteers who all had/or had had, HCV themselves. The thinking behind that was that by supporting and empowering them personally to gain a better understanding of HCV for themselves, they could then use and share their experience with others, whilst also regaining their confidence by learning skills in the workplace and also to help them feel less isolated.

17. Prior to this I volunteered for the Trust for a short while, having benefited personally from their support following my own diagnosis of HCV in 2002.

18. I was not infected with HCV through an infected blood transfusion or blood products.

19. The initial purpose of the helpline was to provide reliable, up to date and patient friendly information, emotional support and ensure that people were aware of their rights.

20. We would advocate for them where necessary and/or empower them to ensure they had the tools to make lifestyle decisions to maintain their health. This was particularly important, as the treatment available at the time (interferon and ribavirin) was not always available to everyone, often not successful, and often left people with additional problems.

21. In the early days of the helpline, the people who called us were greatly stigmatised as a result of their condition and how they were treated by others, subsequently leading them to be hugely isolated.

22. They had been given poor and confusing information, had little or no support and particularly if they were on treatment, were significantly struggling on a daily basis to manage the physical and mental side effects alone. Our call rates were low in number in the early days, but were often lengthy, detailed and involved a high level of emotional support.

23. We were often people's only actual resource for any support or information.

24. As both our own profile as an organisation and that of HCV has risen over the years, the number of people that engage with us and seek our services has grown incrementally each year. We have had more than 54,000 (as at September 2021) contacts (via telephone, email, post, personal appointment and social media) since the helpline's launch in 2004.

25. The work of, and publicity surrounding the Infected Blood Inquiry, has generated many more calls from the general public and others, in particular about blood transfusions, prior to September 1991.

26. Although we have continually and consistently received calls from people infected in this way, the numbers of callers in the early days were few and the majority of those were from those who had injected drugs, whether just once, or many times.

27. Over the last 5 - 10 years however, we have increasingly heard from people who had just been diagnosed, often because they were only recently becoming more noticeably or seriously unwell, as a result of their infection with HCV following blood transfusions, decades ago.

28. The views, comments and experiences I speak of in this statement are from the interactions and observations I have made in a professional capacity. I will speak of common themes and 'general' experiences. I do not intend to speak about any particular individual's specific experience. I do not have legal representation in regard to the Inquiry.

Q3. I have been asked to comment on the experiences and the number of people with HCV who were infected by way of blood products and blood transfusions and who engage with the helpline at the Trust.

29. Our current records system holds data that can be individually identified from January 2018. This allows us to count the number of people who have contacted us since that time. Between January 2018 and June 2021, more than 3,800 people contacted us in total, at least 947 of whom had received infected blood and/or called to discuss a related issue such as the support schemes or the Inquiry (this will be an underestimate as it excludes anonymous callers). With such complex issues, contacts with this group of callers can be on multiple occasions for example we facilitated 4,600 contacts with this group during this period. It's important to note, however, that the route of transmission is not always known, or captured in the course of a call. Moreover, we do not always hear the outcome of results from someone we have encouraged to go for a test for example, so they may not have known they had HCV when they spoke to us and would therefore not have been categorised as having contracted it through blood or blood products in our records.

30. I believe we would have had considerably more contact from people in these groups and the general public overall in 2020 had Covid-19 not emerged and had such an overwhelming impact on testing and treatment services across the UK, our own work, and also on media coverage about the ongoing Inquiry.

a. Blood disorders

31. We receive calls both from people who contracted HCV by whole blood transfusions and from people who contracted it through blood products. Our records do not record a distinction between these groups, but the majority of our callers are certainly from those who had blood transfusions rather than blood products.

32. The helpline has had contact with people who have had various blood disorders including people with haemophilia A and B, Von Willebrand Disease, thalassaemia, and sickle cell disease. The percentage of callers from any of these groups has always been very small in comparison to people who received whole blood transfusions.

b. Infected by transfusion

33. I believe the reason the number of people who have a hereditary blood illness who engage with us is less, is because the large majority of them will have been diagnosed with HCV in the early 1990s, long before the Trust was established in 2001 and launch of the helpline in 2004. They are therefore most likely to have known they have been living with an HCV diagnosis for many years and, I very much hope, had already developed and established their own support networks and knowledge of the virus from their doctors, other organisations and each other. There are also specific charitable organisations who support these groups, such as the Haemophilia Society, UK Thalassaemia Society and Sickle Cell Society. This is not the case for people who got HCV from a blood transfusion for example during childbirth, during an operation, or after an accident.

34. In terms of client demographics there is generally an equal spread in the gender of those that seek our help on infected blood. However, when awareness is raised about a particular issue this may change. For example, when in 2007 our late patron Anita Roddick highlighted her HCV infection by way of blood transfusion during childbirth, there was a huge increase in calls from women who had given birth and received a transfusion.

35. Generally speaking, the majority of people contacting us who've had infected blood or blood products are in their 60's and above and they will have lived with their HCV, for many years, regardless of their route of transmission, before being diagnosed.

36. It is important to note that it has only been in recent years that ethnicity data has been collected. Recent reporting shows 91% of our callers describe themselves as white British, less than 2% describe themselves as Black or Asian heritage.

Q4. Risk of infection

37. I have been asked to provide my views and experiences on the information and advice those who received infected blood/blood products about the risk of infection prior to receiving the blood product/transfusion or treatment.

38. I cannot recall a single caller who has talked about being given any kind of information from medical staff about the potential risk of HCV in blood/blood products, in advance of being administered with them. Of course many of these people will have been given blood/blood products before HCV was identified in 1989.

39. Some people have said that they did have their own personal awareness of a risk of "Non A - Non B hepatitis" (NANB) back in the 1980s, but did not realise/understand, that this was something potentially of serious concern. However, we have had a handful of callers over the years who reported being

personally concerned about the potential risk of HIV prior to receiving blood transfusions, as a result of their own general awareness on the subject.

40. I believe they had a general awareness of HIV because of the national high profile media campaigns in the late 1980s/early 1990s. This has never been the case for HCV and generally awareness of it remains much lower than for HIV.

Q5. Other infections

Human Immunodeficiency Virus (HIV)

41. The majority of people who call us do so because of their HCV; we don't routinely ask them about other conditions such as this, and these wouldn't necessarily come up during the course of a call. This makes commenting on the numbers difficult. Broadly speaking, however, the number of people who we have spoken to who told us they have also been diagnosed with, or were speaking of, someone with both HIV and HCV following treatment with blood/blood products is relatively low. Perhaps twenty. This may be because HIV was so devastating in the early days that many people who were infected through blood and blood products unfortunately died long ago, before our service was established.

Hepatitis B

42. I can recall one person who contacted the Trust following a diagnosis of hepatitis B (HBV) which they believed they specifically contracted by way of a blood transfusion. It is unusual for us to hear from people who have contracted this virus overall.

VCJD

43. We have had a couple of callers discuss their general concerns around VCJD.

Q6. Information to manage their HCV infection

a-c. What information has been provided to them (prior to engaging with the Trust and who provided that information? Do you have a view on how adequate the provided to them has been to understand and manage the infection? Do you have a view on whether information was provided in a timely manner to those infected? If not, when should they have been provided with information?

44. I have been asked to comment on the type of information, how it was communicated, how adequate the information has been to manage their infection and whether or not it was provided in a timely matter following a HCV diagnosis. The short answer is, rarely was it very good in our experience, and rarely was much information provided and, where it did appear, it often came too late. Back in the 80's and 90's of course much less was known about blood-borne viruses, how these viruses affected people and the ways they were transmitted. Probably driven by the initial confusion and fears around HIV, early information was often over cautious about HCV (or NANB).

45. Unfortunately it was often also delivered in a heavy handed, judgmental and frightening manner and presented as hard fact. This meant that a lot of incorrect information or 'urban myths' about HCV and its subsequent confusion with other viruses was passed on.

46. The situation is much better nowadays overall, but information is still often lacking or confusing. As a result, many people have over the years sought information from a variety of different quality resources from across the world, much of which is unreliable, not up to date, or conveyed in a negative and sometimes frightening way.

47. Most of the people who call us who contracted hepatitis C from blood or blood products may have gone undiagnosed for decades. We probably also hear many of

the worst examples; where the health service has really failed someone they will come to us for help and some of the examples we've heard of the years have been extraordinary. Often, people have received their diagnosis from a GP after many months, years and even decades of investigations, and the GP will most likely have had quite limited experience or knowledge of HCV.

48. For people diagnosed in the 1990s and early 2000s, when this was even more isolating and knowledge even more limited, this is particularly true. But people are still being diagnosed – from January 2018 to June 2021 we were contacted by 46 people who'd just been diagnosed with HCV and whose only identifiable risk factor was a blood transfusion in the UK.

49. The majority of settings we hear about where people get diagnosed (regardless of their route of transmission) is from GP surgeries, sexual health clinics, IVF clinics, hospitals, drug services, as a result of going to donate blood and increasingly in prisons. But for people who received infected blood it tends to be the GP diagnosing them.

50. In drug services and prisons there has been a step change in the last 10 years, a majority of people are provided with information and support. However, this will be mainly people to who've injected drugs. Outside of these services not only is professional awareness very poor but it is generally very unusual for people to be given written information to take away in other settings.

51. It is important to note that HCV awareness amongst GP's has been and remains particularly poor, as a main route for diagnosis for those infected by infected blood or blood products this has always been of great concern.

52. The consistent and typical feedback we have always got from people, whether they have had a recent diagnosis or were diagnosed twenty or more years ago, is that we 'were the only people that could answer all their questions' and that they

have ‘learnt more about hepatitis C by speaking to us in one call, than at any point since (their) diagnosis from others.’

53. One of the particularly common questions we often got asked in the past at the Trust when someone called us was: “Is it the same as HIV, am I going to die?” This provides an insight into the level of fears and worries they have had about the potential impact of their HCV diagnosis and its confusion with other viruses.

54. It is so important, with any illness, to communicate the possible likelihood of progression, risk of infection to others and for people to explore the possible ways they may have caught the infection in the first place.

55. With HCV it is additionally important to be aware of the sensitivity of someone’s diagnosis, due to the stigma and confusion about it that continues to exist. Information should empower people in coming to terms with their diagnosis and management of their HCV, not stigmatise, confuse or cause additional and unnecessary fears.

56. Being able to provide a patient-centred response, especially with potentially sensitive illnesses like HCV, also goes a really long way to helping people to relax, be open and able to have a frank but supportive, informative and empowering exchange.

57. In my experience people are given very basic, if indeed any at all, information at the time of a typical HCV diagnosis. Many of the people we talk to with HCV haven’t been given even an understanding around risks of transmission, to enable them to feel confident and comfortable enough to manage the very small potential risk they may pose to others.

58. People are often left scared and feel very isolated during this vulnerable time. There is also a risk of misinformation and misunderstanding that does not help their understandable and well-founded worries or fears around their HCV diagnosis. For example, fears about their possible infectiousness to others, that they are going to

die prematurely, or that others (partners, friends, families, employers, colleagues or others) will think negatively about them if they disclose their status to them.

59. This in turn leaves many of them with a greatly reduced access to their usual/every day support networks.

60. This can often lead to people with HCV taking extreme steps such as leaving their partners, stopping their sexual relationships, resigning from their jobs or generally becoming extremely isolated by cutting themselves off socially from others.

61. We've also repeatedly heard from people who found out about their infection in the 1990s that they were advised of excessive risk prevention measures such as not sharing towels, crockery; as a result people developed obsessive compulsive behaviours, repeatedly cleaning or bleaching items in their homes, or even feeling afraid to leave the house, such was their fear of passing it on in some way.

62. It's clear from these calls that this was often due to the misinformation and the 'fear of god' being put into them by these unnecessary instructions from healthcare professionals. I know many felt like they were something "dirty", and described themselves, as "a walking toxic hazard" or a "leper" as a result of feeling like everything they touched could potentially be a risk to others.

63. I know from our interactions with callers that with the right information about HCV, conveyed in an open and sensitive way, they feel much better equipped to manage their condition and any fears about it in a more appropriate or balanced way. This additional stress and fear is unnecessary and completely debilitating for them and for those around them, causing a variety of problems.

64. There is a huge amount of misinformation about transmission. I believe many people that have caught their HCV through blood transfusions have had the cause

overlooked as a result of this, or alternatively believe, or are led to believe, wrongly, that they may have caught it from sexual contact.

65. We have heard from people whose doctors have assumed they've been using drugs, or that they've been seeing sex workers, and then informed their spouses or partners of this asking them to come in and be tested. This type of treatment from medical professionals can be devastating, and can destroy people's personal relationships at exactly the time they need them the most.

66. We know that people often, naturally perhaps, think HCV is something they must have caught recently and don't make a connection, and/or are totally disbelieving that it could possibly have been a decades long undiagnosed infection, especially from a blood transfusion they may have received as a baby, child or adult, many, many decades ago.

67. There may be many people out there, including some we have spoken to, where it is entirely possible that they didn't seek tests, follow-up or treatment as they were made to feel so bad about their diagnosis, and felt shamed or treated badly. Of course there are so many diseases and conditions for GPs and other medics to be aware of that they can't possibly be familiar with all of them. However, with the accessibility of information through NHS online and basic medical good practice and patient care there is no reason why diagnosing someone with HCV should cause them additional significant upset or trauma.

68. And in the case of those who did get their HCV from blood transfusions, they are often not made aware of the blood support schemes or encouraged and supported to contribute their experience to the work of the Inquiry. HCV information should include information on this, the blood support schemes and on the Inquiry itself, in the same way that the NHS vCJD pages highlight the vCJD compensation scheme.

69. I have no doubt from the many thousands of people we have spoken with, that some GPs and other medical professionals' ignorance about HCV has caused additional problems for people by giving little, no, or just plain wrong information about it.

70. In turn this ignorance also prevents more people from getting diagnosed in a timely way and that many, and often multiple earlier opportunities have been missed or overlooked as a result. For example, we continue to hear from people on the helpline who are having to go back to their GPs, sometimes several times, to actually get a test, or even worse are refused one altogether.

71. We still hear from people who, had a past transfusion, hear about the risks linked to historic blood transfusions, seek testing from their GP only to be told they "do not need to worry about that" or that they "are not the 'sort of person' who gets HCV". Sometimes, this is also conveyed in a way that makes them feel like they are time wasters, they are not taken seriously and even laughed at, told to "get off Google", and generally made to feel like they are a hypochondriac.

72. Many people are reluctant to question doctors' opinion or decisions, especially older people. Others may be vulnerable or lacking in confidence to question or challenge them, and others still, are concerned that they "will rock the boat" and affect any courses of action or future contacts with health professionals.

73. One of our many concerns is that as a result, they are dissuaded from having a test and will just walk away and then not get a diagnosis until it is too late, when the disease has progressed further as a result. We have heard from many people who have been back and forth to their doctors for many years or decades with different symptoms. Later they find out they also have cirrhosis, liver cancer or other serious complications as a result of a long term and undiagnosed HCV infection.

74. I believe if there was a better understanding and awareness of HCV and the risk of infection via blood transfusions decades ago amongst both the general public

and medical professionals, it would ensure people in this group (and many others) are identified, and/or come forward themselves to be tested.

75. In addition, for those who received a blood transfusion, who may have lived the last few decades unable to work due to being ill and not knowing why, there would be the possibility of accessing the financial support that they and their families are entitled to receive to provide them with at least some security.

76. I am also aware that some people's experience was that they only find out they tested positive for HCV many years or decades after the test was actually conducted. While there are many reasons why this gap could have occurred, a typical situation we have heard of is, it being mentioned in passing by a new doctor unexpectedly in the course of being examined for something else. For example, "Oh I see you were previously diagnosed with hepatitis C". Then the patient is doubly shocked, not only to find out they have HCV, but also that no one had bothered to tell them about it.

77. It is also important to note that there are people who have been diagnosed with HCV but who for a range of reasons have not been made aware of the possible implications of the result when they do get it. Also we hear from many who were diagnosed in the early days, who were given a bleak picture of treatment, or told that there their infection was "dormant" or "not active" leading them to think that nothing could be, or needed to be, done.

78. There are many people who were diagnosed at that time who "fell off the radar" as a result and have not been monitored or followed up with since.

79. In the past there were also people who had the antibody test but not were followed up with a PCR, so may have mistakenly believed they had hepatitis C when they may in fact have spontaneously cleared, or others that believe because their liver function tests are "normal" that it is not affecting them in any way. It makes me wonder if the diagnosing doctor had explained or prepared them fully as to what

testing positive for HCV meant and what the potential gravity and impact of that diagnosis could be.

80. There are many more who believe they “must have been tested”, or that their doctor has tested them “for everything”, not understanding the wide range of tests a GP may do and that HCV will not be included in “routine tests”.

81. Even when diagnosed patients get to hospital, many are unclear about what their results mean – ultrasounds and FibroScan’s are frequently confused with each other and people often struggle to understand the scoring system – one man believed he was stage 4 and was terrified after going home and misunderstanding scoring systems on the internet that indicated that meant advanced cirrhosis. In fact his result was 4kpa, which meant his liver was actually in great shape.

82. In the past, many people advised us that they thought that an undetectable result early on in treatment meant they were cured and then discontinued the treatment as a result, because they found the side effects so challenging when in fact a cure was only defined 6 months after the treatment had ended.

83. Others put undue importance on their viral load results and panic if it is high, or equally feel more reassured if it’s low, they often don’t understand that the amount of viral load does not have a bearing on the progression of their disease.

84. All of this additional confusion and worry could be avoided if clear information was given to patients about the tests they are having, and why, and what the results mean – and by checking the patients understanding of that, or providing them with written information to refer to in case they do get confused.

85. Given the increased awareness of HCV following the start of the Inquiry, and NHS England seeking to eliminate HCV by 2025, ahead of the World Health Organisation’s goal of 2030, there is now a much greater impetus to diagnose

people who were given HCV through a blood transfusion as there is with other risk factors.

Section 3: Consent

Q7. I have been asked to comment on the matters around consent. In particular, whether patients were treated or tested:

a-d. without their knowledge or without their consent or without being given adequate or full information or for the purposes of research?

86. I have never heard of anyone who believes they have been treated for HCV without their consent, knowledge or for the purpose of research. As I have said above, I have heard of people, in particular those who received blood transfusions, having been tested for HCV without being made aware of this and who then often only found out they were tested, usually by chance, often many years or decades after they were actually tested.

Section 4: Impact

Q8. The lives of people we speak to who were given HCV through blood or blood products are impacted in a vast number of ways.

a. Mental and Physical

87. The people we engage with have suffered significantly both mentally and physically as a result of being infected with HCV and as a result, so have their partners and families. Of those contacting our helpline who have received infected blood, 57% have reported additional physical or mental health needs; more than a third of which related to depression, anxiety or other mental health conditions. Someone diagnosed in the 1990's would certainly have had very little information, support or general awareness when first diagnosed, nor access to it from other sources like ourselves.

88. During this period particularly there was such confusion about HCV and it would rarely have been discussed openly, or if it was, have been dealt with sensitively by others. Our callers have described their experiences in the 1990s particularly, as terrifying.

89. I believe a lot of those who were diagnosed and/or treated back then are justifiably distressed and angry as a result of how they were made to feel by both medical professionals and others. Things have got slowly and steadily better over time, but we still consistently and continually hear stories of people who are treated poorly and feel stigmatised by the medical profession and others. This then has a massive impact on their mental health, confidence and sense of self-worth.

90. The older interferon and ribavirin combinations of treatment also greatly affected people psychologically. Interferon is a chemotherapy treatment with enormous side-effects; ribavirin too brought a further raft of side effects when added.

91. It was a long and arduous treatment at best, usually from 6 – 18 months, many people spent a full year on treatment and suffered many physical and mental side effects and overall had only a 50/50 chance of working. These got worse the longer the treatment lasted, and sometimes people did it 2, 3 or even more times, because they were so desperate to clear it, even though the chances of it being successful after the first round were yet further reduced.

92. Many people were totally unprepared for and/or unaware of the physical side effects, let alone the psychological ones before starting on it. It affected their ability to work, their relationships with others and often even their understanding of themselves. Even when it finished, the side effects would continue for months or more afterwards, and for some people, never went away at all.

93. For others, new physical and mental health issues emerged and any existing or underlying ones were hastened, in addition to those from their original infection, the

negative ways they have may been treated by others, and/or simply as a result of the treatment side effects.

94. We continue to hear, even today, from people who did this treatment decades ago who feel strongly that it has had a considerable and ongoing impact on them physically and mentally in many different ways.

95. The physical and mental health impact of HCV itself usually depends on a number of factors: the length of infection, when they were diagnosed, how they were treated, what information they had and what support networks (if any) were available to them.

96. The majority of people with HCV develop worsening symptoms over years and particularly decades, but some may feel very ill much sooner.

97. It is well known and reported that HCV alone can cause depression, along with physical symptoms like fatigue.

98. Their lifestyle may also be a contributing factor to how they feel and their quality of life, extent of liver damage etc. If they are diagnosed soon after infection and are given support and good information, then they at least have a choice and opportunity to make informed decisions about managing their lifestyle to help slow down progression of the disease. But with many people finding out so late, being given frightening information, treated insensitively and so on, then the combination of all these factors will impact on how they respond and their ability to cope.

99. For those who received infected blood/blood products who are only just being diagnosed now it means they have had HCV for a minimum of 30 years. This means they are much more likely to be suffering with advanced liver damage, increasing symptoms and other complications or conditions will be starting to emerge.

100. Psychologically, it is very distressing for someone to find out they have had HCV for 30 years or more, worrying about the damage to their body over that length of time along with often overwhelming concerns about others they may have inadvertently put at risk.

101. People then often feel very angry and let down by their GPs and are completely outraged that no attempts were ever made by the NHS to find them and diagnose them earlier. These feelings of anger can be even stronger if they had tried to repeatedly seek medical help during that time with any symptoms that were likely related to their HCV, or that warning signs were there with other historical blood test results, but the possibility of HCV was overlooked and their problems were put down to other causes.

102. Paradoxically, some report feeling relief when they finally get diagnosed with HCV as they finally have a name and explanation for why they felt unwell and feel justified at last. Many of these people will have previously been labelled as hypochondriacs or over anxious, not only by their GPs and other medics, but often by family members as well.

103. As with any serious illness, one of the questions people may have is "how long am I going to live for?" This is a difficult and confronting issue for anyone to deal with, but even more so with an illness that is also often perceived as stigmatising and therefore so difficult to talk about.

104. It can also take a mental toll on them and cause great stress and anxiety wondering how they will tell their family, partner, friends or others. Often people receive the diagnosis, and will leave the appointment not really understanding what they've got or what it means. They are not aware of their rights and many people feel that they are obligated to tell others to not put people at risk as they feel it is a "legal or moral duty". Of course people want their loved ones to be tested for peace of mind, but also do not want to unnecessarily scare them.

105. This feeling of responsibility to protect others can weigh very heavily for some and cause great anxiety. For many people, the possibility that they may have passed it on to others can put enormous stress on their relationships – as there are misconceptions about HCV being sexually transmitted, their partner may feel they have been cheating on them. Or they simply up sticks and leave as they no longer want to have a sexual relationship due to the fear of putting themselves at risk. And indeed, sometimes the person with the HCV infection decides to terminate a relationship, because they are so frightened of passing it on, or being a burden. It is a lot for both the infected and affected person to take on board physically, mentally and emotionally.

106. A HCV diagnosis is of course a shock for anyone, regardless of their route of transmission. When it is something they are concerned about or aware they might have, they are at least a little pre-warned and more mentally prepared for a possible diagnosis. But when they find out by accident, during routine appointments, or whilst being investigated for other more likely or better known conditions, when donating blood or during IVF, for example, the psychological impact is even greater.

107. For these people it comes as a great shock. This would certainly apply to most people with a long or even short term infection of HCV, regardless of their route of transmission. There is a disbelief that someone can have something potentially so serious and life threatening and not know about it, and also for it not to have been previously identified in the course of previous medical examinations they may have had over their lifetime.

108. If they have caught their infection from a blood transfusion, there is also the additional disbelief and outrage that they have not been actively tracked down in the past and advised of the risk they had been at and the multiple lost opportunities where they could have been called in for testing much earlier.

109. If they had been, they may have been able to make lifestyle adjustments or accessed treatment earlier to stop or slow down the progression of the disease, or taken steps to protect or inform others if necessary.

110. There is also great anger and trauma caused by the simple fact that many will then go on to understand as they learn more about their situation and that of so many others, that so much more could have been done to protect them from being infected in this way in the first place.

111. I believe that the timing of a HCV diagnosis has also significantly affected people. The Trust did not exist in the 1990's, when the large majority of people with haemophilia were diagnosed, but as we have heard from their testimony throughout the Inquiry hearings, the way people were treated or regarded at that time was absolutely brutal.

112. Those we have spoken to latterly have described the extremely confusing and often frightening circumstances at that time when getting their diagnosis. This, along with the dearth of clear information for them, their partners and families, would certainly have created a very bleak landscape for them, from the very start of their journey with this illness.

113. That coupled with the overwhelming trauma of prematurely losing partners, family members and others in their close knit community to HIV and/or HCV and/or coupled with the effects of such punishing treatments for both these conditions at a time when so little was understood and so much stigma was created has clearly been psychologically devastating for many.

114. Even people that have had a more recent diagnosis but who then realise that they were in fact infected years ago simply can't reconcile that they may have been living with such a debilitating and serious illness for so many decades without knowing and they fear for their family and anyone they have been in contact with over many years. They will revisit many different situations where they worry

(usually completely unnecessarily) that they may have passed it on inadvertently in sexual relationships, or to their children in some way or times they have injured themselves at home or used someone's toothbrush or razor. They have great anxiety and panic about how many people have they could have infected.

115. Some also realise that they would have had it when they donated blood many years ago, before screening for HCV started and their own diagnosis was known.

116. People may then recall the doctor saying that results of liver function tests were abnormal years or decades before their diagnosis or start to realise that how they may have been feeling over many, many years is in fact connected with HCV, and this often causes them to worry about the extent of the liver damage they may have or other harms to the body that may have occurred. They start to believe that any ill health they may have is in some way connected with their HCV diagnosis.

117. Generally, the people we speak to (prior to their HCV diagnosis) have faith in the health system, hold doctors in high esteem and trust them. When they get diagnosed and realise that warning signs weren't picked up, or were in some cases ignored and realise that they have been missed, misdiagnosed or dismissed as a hypochondriac or over anxious, this then really undermines their confidence in the health system and professionals going forward.

118. We speak to many people who are then extremely reluctant to have tests or appointments for other things as a result of this total loss of faith and trust in their doctor's ability putting them at further risk of physical and mental health issues by not seeing medical help.

b. Medical Complications from HCV

119. There can be many types of complications and HCV is now clearly established as more than just an illness that affects the liver. However, the most common complication we hear of is cirrhosis of the liver and liver cancer. Cirrhosis usually

starts to occur after at least 25 years of an HCV infection. For some people it may be faster or slower depending on their lifestyle and/or any other health conditions they may have which may limit or accelerate this. Generally speaking, someone who has had HCV for 30 years may well have developed cirrhosis of the liver. There are, however, some who have had it for longer who have little or no liver damage.

120. General vague and intermittent symptoms we commonly hear reported are physical and mental fatigue (brain fog), digestive problems e.g. stomach pains and/or bowel problems, aching muscles and joints, depression and anxiety.

121. Other types of specific health complications which we commonly hear about are: fibrosis, type two diabetes, rheumatoid arthritis, thyroid problems, Non-Hodgkins Lymphoma (NHL) and also much less common connected issues such as Lichen Planus, cryoglobulinemia and Sjögren's Syndrome. While these conditions could also be caused by other factors, they are all things we have heard about consistently over the years in connection with HCV infection. There is also evidence that HCV can lead to an increased risk of gallbladder disease, chronic heart disease (CHD) and Parkinson's disease.

122. Many people will not have any symptoms of HCV for many years, even decades, or they will be vague and intermittent and easily put down to other causes. Equally some will develop them very early on and they will be constant and greatly affect their quality of life.
Whilst treatment can now safely and quickly cure them, that does not necessarily mean that their symptoms all resolve.

123. For some with advanced liver damage (cirrhosis), even after a successful treatment, they should continue to be monitored on a 6 monthly basis, as there are a variety of specific problems that can arise from that. Some of these are life threatening in themselves and will require a range of medical interventions to

manage (ascites, varices, encephalopathy, oedema) and also liver cancer (hepato-cellular carcinoma or HCC).

124. Although thankfully, with the advance of new treatments, the necessity for liver transplant (as a result of HCV causing cirrhosis) is ever decreasing. However, for some, this will still be their only option if their liver starts to fail as a result of decompensated cirrhosis, or for some, HCC.

c. Path the HCV diagnosis may take

125. HCV is diagnosed in different settings but for the infected blood population it would typically take place at a GP surgery, and from there a referral to a gastroenterologist or a hepatologist at the local hospital.

126. Historically this would mean a raft of tests would take place over many weeks, even months. These would include blood tests to establish liver function, a liver biopsy which was intrusive and often very painful to establish the extent of any liver damage and/or, an ultrasound scan.

127. Today, further, more detailed, blood tests, ultrasound and/or a FibroScan would then be carried out before starting treatment. Although this is generally done much quicker than it was many years ago, it can still feel like a very long wait for people to find out more about their specific situation (e.g. do they have fibrosis or cirrhosis) and to get started on treatment. New treatment lasts for eight to twelve weeks, and there may be a few monitoring appointments whilst that is underway. In the past people were monitored much more closely with weekly, fortnightly and then monthly appointments during the course and then again, 6 months after it had finished.

128. Once a patient is linked in with a hospital, they are usually overseen by a HCV specialist nurse. They are able to build a rapport with a patient as they are able to offer reliable information, understanding of their situation and also to provide them with a level of support and continuity. It is unusual for a patient to see a consultant

more than once or twice, unless there is some medical complicating factor that requires it.

129. In the past, if treatment did not work, there were no other options for medical care, other than to monitor the patient, with blood tests and/or a scan, usually once a year at the hospital (or more frequently if they had cirrhosis). Other than those appointments there would be no contact with a consultant or nurse for support or information in between times.

130. As GPs are not always knowledgeable about HCV, this would often leave the patient with no reference point for support or information about any concerns in between.

131. While HCV is curable, depending on the damage to the liver and other possible complications, some people will still have to manage the consequences of the illness or older treatments and also the psychological impact of it for the rest of their lives. If they have been successfully treated however and have not got cirrhosis, it is usual for them to be discharged and they are left to manage any ongoing concerns they may have alone, or by consultation with their GP, who is unlikely to understand their previous condition, the treatments for it, or the problems that are associated with it, which can be very frustrating and difficult for the patient. The health impacts associated with interferon and ribavirin could be severe and permanent, as described above.

132. As those that have had HCV for a long time are much more likely to develop very serious medical complications such as cirrhosis or liver cancer, or those who have had to have a liver transplant as a result of their infection, there will be ongoing and lifelong hospital appointments to monitor them.

133. Unfortunately, we still hear from people who have just been diagnosed. This leads us to believe that there are many more out there still to be diagnosed, and this is why it is imperative that they are identified and treated as soon as possible to

reduce at least some of the potential long term physical and mental health consequences.

d. Types of Treatment

134. In the 1990s treatment was solely with interferon, a treatment also used for cancer, initially taken three times per week.

e-f. Obstacles and access to treatment

135. Treatment availability was dependent on the genotype of HCV that someone had, and how advanced their liver damage was. For some genotypes, treatment was not offered at all.

136. With new treatments available now, all genotypes of HCV can be treated and it is provided, regardless of the level of liver damage.

137. In 2000, pegylated interferon (PEG-INF) was introduced. This was a subcutaneous injection once a week and was accompanied by ribavirin in tablet form. This was no doubt a significant improvement to the previous treatment regimens at that time in terms of effectiveness, and had an overall success rate across the different genotypes of 50%. However, it still remained a long and very punitive treatment in terms of side effects.

138. Following that, in around 2012, one of two other drugs were added to the pegylated interferon and ribavirin combination - Telaprevir or Boceprevir - and later, Viekerax and Exviera. At that time these drugs were welcomed as they again improved the success rate, but for some people it was actually even worse in terms of side effects as each of these drugs had their own side effects on top of the ones already caused by interferon and ribavirin.

139. Now a range of totally new Direct Acting Antivirals (DAA's) tablet only treatments have been available for more than 5 years. These all have very high success rates with little or no side effects; troubling side effects are very rarely reported. Treatment length has also been greatly reduced, usually 8 – 12 weeks at most.

140. When the first of these 'new treatments' became available, they were initially offered to those with very advanced liver damage. Treatment enabled some people to improve sufficiently to come off the transplant waiting list.

141. For several years access to these treatments, which were very expensive, was restricted, irrespective of NICE approving them. Hepatitis C treatments are delivered through Operational Delivery Networks (ODN) a hospital hub and spoke model, across England there are 22 ODN's. Each ODN was given a run rate, specifying how many people they are able to treat over a set period of time. In the early days these numbers were small compared to those in need of treatment. Many people were very angry at this, in particular those who had received infected blood and blood products, who had perhaps completed multiple earlier treatments without success and had lived with their infection for many years.

142. Many people who contracted HCV through NHS blood understandably felt strongly that they should be prioritised without any delay.

143. The impact of knowing that there is a new treatment that will cure your illness but that you will have to wait for it, cannot be underestimated. The demand for these new treatments was such that private 'buyers' clubs' were set up.

144. Over the last few years, further new combinations of treatments started to be available, and restrictions and barriers have been lifted.

145. It is now the case that anyone with HCV can swiftly access the new treatments available, regardless of the length of their infection or the extent of its impact on

their physical health and the NHS is currently fully committed to ensuring that everyone with HCV gets treated.

146. When the most recent new treatments first became available, starting with Harvoni, we frequently heard from our callers that their consultants told them they were "lucky" to receive this new treatment and they should be "grateful" due to the initial high cost. Many were told to be careful not to lose it, as it was "£1,000 per pill".

147. I believe it is unacceptable to make these references to cost to anyone infected with HCV, or indeed any illness. I do not believe that a cancer patient would be told they are "lucky to get this chemotherapy", or are advised of the cost of that in the lead up to their treatment. It is up to the National Institute for Health and Care Excellence (NICE) to appraise different treatments and manage the cost, to provide the most clinically and most cost effective options. Nobody should be made to feel uncomfortable about the cost of any treatment they are fully entitled to access.

g. Mental and Physical Impact of Treatment

148. Interferon and ribavirin are each a punishing medication in terms of both mental and physical side effects.

149. I am aware that many people chose not to have them due to their concerns about these side effects. I am also aware some people simply couldn't take them, because they had other medical conditions such as heart problems or serious mental health problems which could have been made worse by them.

150. Overall, the various combinations of interferon and/or interferon and ribavirin and the physical and mental impact they caused, affected people to varying degrees. For many of those on treatment with interferon and ribavirin it was common to have symptoms which included depression, anxiety, low or irritable mood and for some, swinging personality changes or suicidal thoughts.

151. People noticed they were more volatile, aggressive, outwardly violent and lacked the tolerance and control they would normally have. As an example, many would describe situations where they, completely out of character, would lose control of their emotional feelings because “it took so long for the kettle to boil” when they were making a cup of tea, or they “had to wait to be served in a shop”. Many had feelings of paranoia and their reactions would be totally disproportionate to the situation they were in, they often describe feeling like they were “going mad”.

152. People could turn from being a bit off, low or grumpy, to being absolutely raging and completely unreasonable. This could come out of nowhere and many people described it as feeling like they were “a psychopath”. These mood changes became known as ‘Riba Rage’ and were caused by/exacerbated by, the ribavirin.

153. Many, many people on this treatment also developed severe depression and anxiety while on interferon and ribavirin, and had significant and troubling “dark thoughts” that were extremely difficult for them (and those around them) to deal with.

154. In my experience the people who engage with us who have taken interferon and ribavirin commonly reported physical side effects, including overwhelming bouts of fatigue, flu like symptoms, insomnia, loss of ability to concentrate, stomach/digestive issues, loss of appetite, and dry mouth.

155. Written down, these terms don’t really convey the absolute hell they actually caused: the “fatigue” could be so severe people would have difficulty lifting their leg to get into a bath, getting out of a chair, or going from one room to another. The “flu-like” symptoms meant they felt beat up all over, sore and aching from head to toe, with alternating bouts of extreme chills or raging fevers. The “insomnia” would mean that despite being constantly physically and mentally exhausted it was literally completely impossible to sleep, sometimes for days on end and people reported feeling “totally wired” despite their exhaustion. “Lack of concentration” meant they

couldn't follow a TV programme, read a book, or remember what they were doing from one moment to the next. "Stomach and digestive issues" could mean pain and a tendency to anorexia by being totally unable to eat or feeling sick resulted in marked and rapid weight loss and sometimes even sudden loss of control over bowel movements. "Dry mouth" meant that their tongue would literally stick to the roof of their mouth and they would have to drink fluid or suck sweets constantly to relieve that.

156. The combination of all these physical and mental side effects, which for some came and went and returned over the duration, and for others just steadily increased as treatment progressed, was unquestionably challenging and debilitating for them and made it often impossible to continue working, studying, or doing any of their normal activities.

157. They often withdrew emotionally from their partners and other family members causing great distress for everyone.

158. Loss of libido affected their sexual relationships with their partners and during the whole of treatment and even when it ended, women who took ribavirin were unable to conceive for six months afterwards and men were advised to continue using condoms due to the risk of ribavirin causing birth defects. For some this resulted in their plans for starting a family being delayed for a year or more, or sometimes, forever.

159. Most people have found that many side effects lasted months after treatment has finished, even when the drugs had technically left their system. Many would say that some side effects never fully resolved.

160. The majority of our callers who have done interferon and ribavirin report feeling that they were "never the same" or that it "knocked the stuffing out of them" and that it "changed how they felt forever".

161. They also attributed a wide range of subsequent new physical and mental health problems to effects of this treatment alone.

162. Another physical side effect that is common is a range of skin issues, particularly following treatments that included Telaprevir and Boceprevir along with the interferon and ribavirin. These medications caused very dry skin, even after intensive moisturising. I recall people describing how they would put cream on and it would instantly go back to being very dry. This would cause considerable discomfort with itching, scratching, skin breaks and soreness. Many reported intense feelings of burning and soreness in their anus which was awkward and embarrassing for them and extremely hard to relieve.

163. Ribavirin alone would cause dryness and itchy skin that became known as 'riba rash'. The irritation would often cause scratching and blistering and the skin would be slow to heal. It was also recommended not to sit in direct sunlight, as even after a short while, the sun could aggravate this and also the skin was made more prone to sunburn.

164. Some people would become so severely anaemic as a result of the treatment that they would have to also take Epoetin, (which again had its own potential side effects), to resolve that, just so they were able to complete the course of treatment and give themselves the best chance of treatment success.

165. While less common, I am aware some patients developed a serious skin condition called Stevens-Johnson syndrome (with Telaprevir) where the skin would blister and peel. This in itself required a separate and ongoing treatment.

166. With HCV infection, and then as a result of older treatments people often felt significantly rundown which in turn made them more susceptible to other infections and/or less resilient overall. As a result of the immune system continually trying to fight off the HCV, for many, it often took longer to fight off any other infections, or

bounce back as quickly from them afterwards. Many would say their immune system was never the same after using interferon and ribavirin treatments.

167. I am aware of many people who have been cleared of HCV following treatment, but live with an ongoing anxiety about it returning and disbelief or confidence that it has really gone, many of them persistently getting re-tested to check, or that any feelings of being unwell or subsequent ill health is connected to their previous HCV infection.

168. I have spoken to many people who have undergone interferon and ribavirin treatment. Whether it did, or did not work, or despite how well, or not, that they coped with it, the common theme is that mentally and/or physically, they "have never felt the same since".

169. In fact in our early days we heard so frequently from people suffering debilitating post treatment issues on the helpline that we undertook a survey of 500 people from April 2006 to September 2007. The survey asked questions regarding how people felt up to three years after receiving interferon and ribavirin treatment. The research found that 90% of all respondents had ongoing side effects for more than a year after treatment concluded.

170. The five most frequently reported post treatment symptoms/side effects were fatigue, joint aches/pains, brain fog, depression and mood swings. Regardless of their Sustained Virological Response (SVR), 40% of people still felt worse after treatment than before and only 31% felt better. For those who had attained SVR, 37% felt better and 36% felt worse. For those who hadn't attained SVR, 18% felt better and 50% felt worse. Attached and marked as Exhibit **WITN0912002** is a copy of the Hepatitis C Trust Post-Treatment Survey.

h. Accessing other medical treatment

171. Since 2004 when the helpline started, we have heard many people have had difficult experiences accessing medical and dental care because of their HCV status. I believe much of this is a result of ignorance about transmission and general confusion as a result of misinformation about blood borne viruses.

172. For example we have heard from many people whose dentists insisted their appointments were at the end of the day to allow for "more intensive" cleaning and sterilisation procedures to take place and indeed some people have reported having difficulty in finding a dentist prepared to treat them at all.

173. When one woman advised her dentist that there should be no concern and that she had been successfully treated for hepatitis C, he scoffed and told her "not to be ridiculous, there is no treatment for hepatitis C". We have also heard reports from women who have been refused various beauty treatments as a result of disclosing their HCV status.

174. This is all a nonsense, as universal/standard precautions and sterilisation of the environment and surgical or other tools needed in medical, cosmetic and dental settings should be in place already and are sufficient to prevent risk of HCV to either the patient, or doctors/nurses/beauty therapists and dentists.

175. A typical situation we have heard of when someone with HCV has a medical procedure, is for there to be additional barriers between the patient, staff members and equipment. For example, double gloving, or additional plastic sheeting being used on equipment. We are aware of people having their HCV infection openly discussed in front of them by medics and decisions being taken to use extra sheeting because of the "additional risk". One patient was asked to get off the operating table before a non-invasive routine procedure in the operating theatre took place, whilst additional sheeting was placed on there for them to lie on. Even when people have been cured of their HCV, these additional measures are often still, totally unnecessarily, carried out.

176. These types of situations can chip away and wear down even the most robust kind of people and those with less resilience can become broken and traumatised by these kind of experiences. They may become depressed, withdrawn and often develop obsessive thoughts about their risk of infection to others, or avoid seeking medical and dental care in the future and are frightened they will be asked about it, or afraid they will be treated negatively. When situations like this occur multiple times, there is also the anticipation by the patient that they will be treated in this way, regardless of whether they are or not, which causes considerable stress.

Q9. Their private/family/social lives

177. A HCV diagnosis impacts people's lives in many ways. Some people will be fortunate to have positive support from their family, partner, friends and employers, but others won't, or if they did the weight of their diagnosis and the problems caused by it destroys it and their relationships will break down.

178. It can add significant pressure in the family circle, for example, other family members getting tested, although the risk of infection to others is miniscule in a household situation, it is important that they are for reassurance and for everyone's peace of mind.

179. Having to get their children tested can particularly cause a lot of distress, anger and feelings of guilt.

180. HCV will have a considerable impact on people's social life and lifestyle. For example it is strongly advised that people do not drink alcohol once they are diagnosed and they may not feel they can talk to their friends about why that is, for fear of being judged or stigmatised.

181. It puts them in awkward situations if their friends challenge them as to why. For example, comments like “what do you mean you're not having a drink?” and “oh go on, just one” and feeling they have to provide an explanation.

182. Many people do not wish to disclose their HCV status to others, causing them to then withdraw and socially isolate from others, or behave differently to avoid these sort of situations where they are put on the spot.

Q10. Stigma

183. Stigma is a huge problem for people living with HCV. We have heard terrible stories about people being shouted at and abused in the street by others, and even their own personal friends, family or colleagues reacting to them in different ways following their diagnosis.

184. This prejudice and what I would describe as "urban myths" about HCV, forms the underlying basis for much stigmatisation, even nowadays, although thankfully the understanding, information and support for people is much better overall.

185. Stigmatisation is not always blatant/seen or heard – for example someone calling you abusive names, writing something negative or untrue about you, spreading rumours in the local community, or making certain assumptions. It can simply be the flicker of an eye when you talk to someone about your illness, or that they noticeably stand back a little from you, or sometimes they simply cease contact with you altogether.

186. These reactions, again chip away at people and many feel shamed, upset and frustrated by it. They may get angry, or they may turn in on themselves and believe themselves to be dirty, unclean or somehow unworthy.

187. In addition, even in circumstances when people aren't discriminated against or stigmatised people may hesitate to do things or live in the way they want to; they have been essentially pre-programmed to expect negative responses. This 'anticipated' or 'perceived' stigma often leads to them isolating themselves from others so they aren't put into any situation where it may happen again.

188. On our helpline, from the calls we have received, it often appears that stigma is more of a major issue for people in small towns and communities in more rural areas, "where everyone knows everyone", and there may be only one GP. Lots of people take steps such as visiting hospitals out of area to ensure they do not run into someone they know.

189. It was common for us to speak to people and offer to send them our newsletters, leaflets or other information but they would refuse, for fear of the letter being intercepted by someone else, or delivered through the wrong door. People would seek reassurance that we didn't send envelopes that were not securely sealed or would ask whether we had our name across it.

190. This fear of others knowing they had HCV, deterred many people from attending support groups or other services across the UK also for fear they would encounter someone they knew.

191. It also impacts on the families - trying to explain to their children why they are no longer invited to play or attend birthday parties at other people's houses, or insistence by the person infected that the whole family should not speak about their infection to others.

192. If you ask anyone with HCV about the first time they injured themselves and bled after being diagnosed, they will tell you how they have felt stressed and wanted "to stand back from their own hand". Many describe excessive handwashing/bathing/washing of clothes and linen and the constant sense of "having something dirty inside them", something that they often feel other people can see. Sometimes it is in the background, or in their subconscious and they try to bury or deny it, but for others it may be highly stressful, overwhelming and intrusive to have to deal with these feelings. We regularly hear from people with severe anxiety or obsessive compulsive disorder (OCD) which they attribute to their HCV and the psychological impacts of this.

193. When someone in the family dies as a result of HCV, or with HCV but of other causes, aside from their grief and loss, we have heard from some families who have reported that they have been dealt with very insensitively by undertakers.

194. For example, some may refuse to embalm the body because of a perceived risk of infection, or even to provide a funeral service for them at all in some cases and they are asked to go elsewhere. Others have refused family members to be allowed to view or dress the body. The distress that this can cause at such an already difficult time for those left behind is unimaginable.

Q11. Impact on family members

195. We take a lot of calls from partners, family members and friends who are trying to gain an understanding of HCV so they can support their loved ones better. They also personally experience the fear, stress, confusion and sadness that comes with this diagnosis and the lack of information, guidance and support provided. This is often particularly true where people have had HCV for a long time, especially if they don't realise at first the transfusion link, as they try to understand how they got it, and also the likelihood they might have passed it on. They will go through their own personal worry when they have to undergo an HCV test. It was frightening for them to have seen a loved one go through the older treatments and the consequences of being diagnosed with an illness, tests and procedures, often many years or decades after being infected.

196. Depression, anger and a desire to isolate themselves also are all common reactions for them as well, they often feel unable to discuss the subject openly with their own networks of friends and others to gain support.

Q12. Work and Education

197. Many people's lives changed significantly, first when they got diagnosed and then again when they began the older treatments for HCV. Many have to take time off work, or reduce their capacity, and many had to give up working altogether. Others decided not to take up training, education, promotion at work, or other opportunities because they felt unwell, or now faced an uncertain future ahead of them, or simply were just trying to focus on managing their treatment. This is particularly true of people who contracted HCV though NHS blood because they'd often had it for so long before finding out about their diagnosis.

198. Some people's personal circumstances and support networks may mean they have more resilience to cope with changes to their employment than others. But no matter what type of role, number of hours, or work environment that people are in, both the symptoms of HCV and the side effects of the older treatments, affected people's physical and mental ability to varying and sometimes very substantial degrees.

199. I have heard from many people who simply gave up their job and resigned rather than admit their diagnosis – not realising, that with very few exceptions, there is no obligation to tell your employer of your status. Others felt that they would be a risk or liability to others, and others still who lost their job or were moved to other duties wholly unnecessarily.

200. All of these ongoing setbacks and consequences accumulate over long periods of time and greatly affect people's motivation and ambitions, knock their confidence and create a lot of ongoing and relentless stress.

201. Many people who have had HCV for a long period of time, reflect on what their potential might have been, if they had not contracted the virus in the first place, because of all its differing physical, mental, emotional and practical effects on them and all these cumulative barriers and difficulties that are put in their way.

Section 5. Treatment/Care/Support

Q13. For the majority of people who received infected blood, diagnosed in the 1990s and early 2000s, treatment, care and support were difficult to obtain.

202. Access to interferon-based treatments was often limited, it could take months to begin, lasted a year and the physical impacts of it were often terrible. Moreover, at the end of treatment you would still have to face the uncertainty of whether it had been successful or not, and wait a further 6 months to have the "all clear".

203. There also weren't so many specialist nurses/clinics many years ago and it was necessary to go to multiple appointments for blood tests and liver biopsies to check that you were both tolerating the treatment and getting a good response to it. This meant people often felt very isolated, very ill and had nowhere to go for support and information during what could be up to an 18 month period or more.

204. In terms of care and support, this had a massive impact on people in the past. The GP or any other medics involved in their overall care would be likely to have limited understanding about hepatitis C and the treatment for it and they would typically only have a yearly appointment at the hospital (unless they were actually on treatment, or suffering with cirrhosis), and so had limited opportunities to get information, relevant tests or support.

205. Many people went through long and very difficult treatments only to then find at the end that it had not worked for them. That left many people feeling despondent with a long wait before a different and better treatment option arrived, for some this may have ultimately meant a delay of 20 – 30 years of just having to live with their infection and being unable to do anything to get rid of it in the meantime.

206. There was no specific support set up for people who received infected blood aside from organisations like ourselves who are there for everyone with HCV, regardless of their route of transmission, or the British Liver Trust, (who deal with all types of liver disease).

207. The Haemophilia Society catered specifically for people with haemophilia and the only other options would have been some drug services and a handful of hospitals, who may have provided support or information groups for people with HCV, but they were of course unsuitable and/or inappropriate for those who had received infected blood.

208. Whilst now there is much better support online through groups on social media and a stronger community amongst those who received infected blood and blood products overall, there is not an official organisation that is specifically devoted to providing support or information to people who had blood transfusions. This community's needs are often complex, cutting across mental health and trauma, physical health needs, assistance with accessing payment schemes and support services, and simply managing long term illness. Given the background, it's understandable that people feel they deserve a much stronger offer of support than is currently available.

Q14. Counselling

209. I have been asked to comment on the availability of counselling or psychological support to those who received infected blood or blood products. There is still no specific/designated counselling or psychological support available for people who contracted HCV through infected blood in England, although a service has recently been set up in Scotland and Wales. There is also a recent discretionary payment mechanism to gain funds to cover a limited number of counselling sessions for people who've successfully applied to the Infected Blood Support Schemes.

210. While helpful, this provision is only available to people who've successfully applied to the support schemes – excluding many people whose NHS records have been destroyed. It is also typically limited to £900 which might cover 12-14 therapy sessions per year. Until recently, the application process for all of the discretionary funds was also arduous, with an expectation that beneficiaries 'prove' they had tried

alternative avenues to secure funding and, essentially, were desperate. In addition, awareness of this provision is quite low, it is not tailored to the experiences of people who contracts BBV's through infected blood/products, and likely does not overcome the reservations some infected/affected have about accessing formal mental health support. As such, there is likely to be significant unmet need under the current system.

211. Indeed, whilst the numbers accessing counselling aren't published, according to EIBSS' 19-20 Annual Report just £17,524 in discretionary payments was distributed among their 3,058 beneficiaries that year for counselling. This equates to less than £6 per beneficiary for the year.

212. Historically, the Skipton Fund and Caxton Foundation were allocated funds by the government in 2011 to assist with psychological support for their beneficiaries. Our helpline was given funding to be able to help facilitate this, by providing a confidential, safe and neutral point of contact for beneficiaries to explore the various options available to them.

213. People would contact us so we could explore with them what their needs may be. In some cases, simply speaking to us was helpful to people, it was often the first time they had spoken with someone else with HCV and we were able to answer their questions, share our experiences and hopefully give some perspective and reassurance to them.

214. For others, where it was appropriate, we would try to identify a few possible accredited counsellors or psychotherapists in their local area, who had specific experience of dealing with those with chronic illness, anger management issues, bereavement, living with HIV or (in a very few cases) HCV.

215. From there the beneficiary would follow up with the counsellor or psychotherapist directly to see if they were a good fit to work together. This usually worked really well but sometimes we would send further suggestions and

sometimes people would search themselves or have someone that had been personally recommended to them. Either way, we would ensure that they were properly accredited in their field and then facilitate the payments for them.

216. For many beneficiaries it was extremely important to them that the person they would seek counselling or therapy from would have prior knowledge and understanding of HCV and/or infected blood issues and in some instances where requested, we liaised with the therapists in advance so they understood the full context of the person's experience.

217. We would not talk about the beneficiaries' personal situation or history, just the general facts on the overall issues. This way the therapist could start work with them with a general understanding, context and background.

218. Initially beneficiaries could claim £300 for this, but as counselling or psychotherapy can often be a lengthy process, many people found it was not sufficient for their needs and costs can vary greatly from £30 to £100 or more for a session. So some people were left in the position of having embarked on a course of counselling or therapy and then the money ran out for any further sessions, which they would then have to stop, or fund from their own pocket.

219. After a year or so, the funding was further increased, first to £600 and then again to £900 per application, and later still, there was some leeway for further funding beyond that if needed, from the Caxton Foundation.

220. This initial provision made for psychological support had a very low uptake. We believe this too was because many beneficiaries were not made aware that this was even available to them and others struggled to understand what the benefit could be, or how to go about accessing it.

221. We were surprised by this as it certainly went against our experience on the helpline of the many difficult and often ingrained mental health issues people who were given infected blood were facing who were in the main, totally unsupported.

222. Counselling or psychotherapeutic support would have been incredibly helpful to so many of them and would have made a significant difference if it had been offered at the start, following their initial diagnosis. Even today we hear from people who are long term beneficiaries of the funds who had no idea this was ever available, and many are unaware of funds being available again for this now.

223. As a result of the low uptake, we sent posters around the country to haemophilia centres, hospitals, clinics and other relevant organisations and did all we could to make people aware of it through our helpline, newsletters and website. However, the large majority of those who did find out about it and actually accessed it, found out about it directly from us in the course of a call to us about other matters.

224. From our work with those affected, we believe tailored, easily accessible mental health provision would be a great resource for people to access, to help them come to terms with getting HCV through infected blood and to help them manage the issues it has created for them. However, simply providing a pot of money for someone to access it themselves is not necessarily enough to ensure that they get the help that they need.

225. Currently, EIBSS, directs people to a general mental health support line run by MIND and some NHS resources. Whilst these provide good mental health support, the specific experiences of people who received infected blood/ products is not taken into account through these services and the onus of finding appropriate support is very much left to the individual. More psychosocial support has recently been brought in to Scotland and Wales.

226. Many of those applying will be in poor physical and/or mental health and may find this daunting or off putting and many therapists will not have the background to HCV and infected blood issues which then requires the beneficiary to use valuable time in their sessions having to explain it to them.

227. Whilst therapists and counsellors deal with a wide range of issues generally speaking and are not experts or experienced in all the life situations their clients may have, they are of course more than equipped to deal with this. They will be used to dealing with people who have anger management problems, OCD behaviours, unresolved grief, depression, anxiety or suicidal thoughts.

228. However, we feel strongly, based on the feedback from callers that we have had, that it would be more helpful and meaningful for them if the therapist/counsellor does have an understanding of infected blood issues, given the sensitive nature of all that people have been through and their frustration of the low awareness of infected blood issues and that others "don't understand". It may also encourage people to engage more with this provision.

229. And, unfortunately for so many, there are those who are unsuccessful in accessing the blood support schemes (usually as a result of their medical records being destroyed), they are not eligible to access this additional psychological support in any event.

Section 6. Financial Assistance

Q15. I have been asked to provide my views on financial assistance available from the Trusts and Funds set up to distribute payments. In particular:

a-e. Describe when and how people found out that financial assistance was available. Describe what they have received, from which Trust or Fund and when such payments were made. Views or comments about the process of applying for financial assistance. What, if any, difficulties or obstacles did

people face in applying for and/or obtaining financial assistance? Were any preconditions imposed on the making of an application for, or the grant of financial assistance? Do you have any other observations about the various trusts and funds? In particular, do you have any comments about the amount of financial assistance received?

230. From when we started the helpline, we have ensured callers are informed about the availability of financial support from originally, the Skipton Fund, the Caxton Foundation and more recently, all the UK infected blood support schemes and we help support and guide people with their claims. From January 2017 to June 2021 we received 1817 contacts with queries relating to the support schemes; this is 11% of all our contacts.

231. Usual topics include Stage 1 and 2 payments and the Special Category Mechanism (SCM) payments, with most of the needs around support with applications, appeals and support after applications are rejected. With the Caxton Foundation our main source of queries were in relation to the counselling provision or occasional grants that people could apply for, for specific things.

232. The amounts available to claim have increased over time, from an initial lump sum/s to the addition of regular payments and a wider range of one-off discretionary payments or other grants over the years.

233. From the beginning of my time on the helpline, I have constantly been surprised that many who received infected blood/blood products were not made aware of the fact that they were able to claim from these funds immediately after their diagnosis, or in many cases, at some point even many years later. There seems to be no specific mechanism in place for alerting them to this at the point of diagnosis. Even now, albeit the situation is much better, it often goes unmentioned by doctors or nurses and people remain unaware that they are eligible.

234. Many feel very angry that they weren't made aware of the schemes earlier (and so could have benefitted more, perhaps for many years) and are grateful for us bringing it to their attention. Some, who were long-term beneficiaries, were not even aware of the additional support they could get from the Caxton Foundation when that was formed.

235. But many of the people we deal with are elderly, extremely unwell, do not use the internet, or have no family support to help them do so and they remain totally unaware that they exist, let alone that there are organisations like ourselves, who could perhaps inform them about how to apply, and/or support them with the process.

236. Even for those who do find out about the schemes, the language used and level of detail required on any of the blood support scheme application forms, past and present, is for some, so onerous that many people feel like it is making a claim for benefits or intrusive, which they describe as feeling "daunting" or "degrading".

237. Many don't fully understand what is being asked of them, but make their applications anyway without perhaps completing the form properly or with the right evidence needed. When they get turned down at the first application, they may feel unable to appeal, or not have the information that is required for a successful claim.

238. Whilst the process is a clear barrier to all applying, without question the single biggest barrier to people who received infected blood making a successful claim is the difficulty in finding their medical records to demonstrate that a blood transfusion has taken place.

239. Indeed, over many years now, the majority of those who have received infected blood find their medical records have been destroyed or are incomplete. The onus is then entirely placed on the applicant to search for further evidence, often a lengthy and time consuming process, which is difficult for many of those who are elderly and/or are affected by the long term complications of a HCV infection

and/or the treatments for it, and/or other additional mental and physical health issues. It is also psychologically extremely difficult for people who believe the NHS first gave them infected blood and then destroyed their medical records that it now assesses and frequently denies their claim for financial support.

230. Having tried to gather all and any evidence they may have the first time round, it is often unlikely they are going to find anything further. The only possibility is a private medical opinion on the likelihood of them having needed a blood transfusion or blood products for the operation/procedure/condition they had. This is costly, often difficult to arrange, and may still not guarantee success.

231. All of these things mean the payment systems can be massively biased: the people facing the biggest barriers to a successful application are those with the least resource, the least health literacy, and without the means to pay for private medical time and/or legal advice. These are often the people who need the financial support the most.

232. Other general issues we are aware of:

a. Some people may have literacy issues and no one to assist them to complete the forms.
b. We hear reports of consultants or GPs who are unwilling to complete their part of the forms, or cause unnecessary delays by not acting on them in a timely manner, or make errors on the form, causing yet further delays for them. This can take months or even years with no explanation for the delay.
c. People are forced to apply for all other options for funding before they can access any of the discretionary payments and describe being made to feel they have to go "begging" and explore other possible options, before even being able to apply for one.
d. Applications sometimes being "lost in the post", and sometimes unfortunately people have not kept a copy of the evidence they have managed to gather, often at great pains and are unable, or it is too difficult, due to them being

elderly/unsupported by others, or simply are too unwell, and/or feel it is too time consuming and overwhelming to get it again.

e. There is a lack of parity across the different schemes in the UK in terms of lump sum and annual payments and also the appeal process varies across the schemes.

f. Where applications are unsuccessful, people feel there is a lack of transparency as to why that is and so don't always understand why it has been turned down. They believe where evidence is scant that they will be accepted by the balance of probabilities, but from our experience, this is rarely the case.

g. When people have been refused on appeal, there is no further process for appealing, aside from possibly initiating a Judicial Review which requires private funding, would be hugely expensive, is still not a guarantee of success, and is extremely unlikely to be an option for the huge majority of those infected/affected.

h. Although spouses are eligible for support payments under the scheme, parents of children are not entitled to any annual support payments, and nor are children.

i. People who feel that staff (particularly at EIBSS and SIBSS) have not always been supportive, empathic or understanding of their concerns and in some cases, many who feel they have been dealt with dismissively or insensitively.

j. There is an unevenness, even with successful existing beneficiaries being made aware of the additional or newer potential grants that they may be entitled to.

233. Those who are unable/unwilling to access funds at all:

a. There are potentially hundreds, or possibly thousands, of people undiagnosed with an HCV infection through infected blood, who are of course not claiming as they remain unaware of their status and therefore have missed out and are continuing to miss out, on many years of financial support they could have accessed had they been diagnosed.

b. Those who have died already with other conditions, or possibly as a result of liver disease put down to other causes, who were never diagnosed with HCV and were therefore unable to claim, and in turn nor were their spouses, as they were also unaware that their partner was infected.

c. People who firmly believe they received infected blood <u>after</u> September 1991 when blood should have been screened, but are therefore excluded from any financial support, despite not having any other/additional risk factors.

d. Those for whom it was perhaps not clear, for a variety of different reasons following their initial diagnosis that they had in fact spontaneously cleared the virus and were only antibody positive, but who still lived for many months, years, even decades with the belief that they had actually had a chronic infection of HCV and were therefore suffering with the considerable psychological distress that would cause, thinking their health would deteriorate and/or worrying that they will pass it on to others. Certainly for some who spontaneously clear, there is sometimes what is described as "post viral syndrome" where people continue to feel run down or fatigued, so spontaneous clearance does not necessarily mean a full recovery from any symptoms they have experienced.

e. People who for a variety of reasons feel simply unable or unwilling to claim – those who don't want to reveal or share any personal information as they already feel so stigmatised. For example, the elderly, or those with multiple other physical/mental health, or other problems, who feel unable to claim as it is too much for them.

f. Those who feel the payments should "go to someone else" as they don't feel deserving, or feel that they are "taking the NHS's money". They may feel that they have a personal debt to the NHS, don't "want to cause any trouble" and that "they did the best" for them at the time of their transfusion, and despite later finding out they have been infected as a result of that, have no wish to claim.

g. Others in a fortunate financial situation who have no desire to claim, although they are entitled to, regardless of their own personal finances.

h. Those that have been dissuaded by others from claiming – that it's too complicated, too much work, too stressful for them, not to waste their time, or with the belief that that they will never be successful.

234. Appeal

Many people don't bother to appeal as they find the whole process intimidating, time consuming or feel that it is unlikely to be successful. Many have also reported that they didn't "feel believed" and are greatly offended, as "if they are trying to get something for nothing" after being turned down initially and so give up pursuing any further.

235. With the main barrier being medical evidence that a transfusion took place being "destroyed/lost/mislaid" it is extremely difficult to find a way round that and extremely unlikely it will suddenly appear elsewhere after they have explored the usual channels to try and find it in the first place. Despite the "balance of probabilities" or "burden of proof" being in their favour in most cases, it is rarely able to be demonstrated.

236. They have often spent considerable time collating as much evidence and completing forms to apply, without any support from the schemes themselves. Indeed, people often ask us why they are called "support schemes" for this reason, as no support in completing the information required on forms, or assistance with finding records is provided

237. This causes unbelievable stress, frustration, anger and disappointment to people, who have already gone through so much with their infection, treatment, ongoing physical and mental health issues. This has been described to us as the "final kick in the teeth".

238. Opinion on the amount offered

It is positive that various changes to the support provided by the schemes over the years has been extended – with increased financial assistance, the special category mechanism (SCM) payment that acknowledges the effects of the older treatments and other health conditions that followed the original HCV infection, and also the reinstatement of a specific fund for counselling. However, the current system still falls drastically short of a something that genuinely recognises and addresses the damage caused to people and their families, nor is it provided in a way that recognises this and does not demean, humiliate and make people feel like they are "begging". In line with this, it is very important that this is explicitly compensation and recognises that it is provided to compensate for damage done.

239. There is a lot of additional stress and anxiety caused for beneficiaries as a result of the lack of clarity on how long the annual payments may actually remain in place, which means they cannot make plans for themselves or their families. In our view, the current system does not acknowledge the emotional impact of being infected in this way. Nor does it take into account how people's quality of life, relationships, careers, study and overall wellbeing has been eroded by HCV and the symptoms, stigma and practical problems receiving infected blood or blood products has caused them and their families - and continues to cause them, over many decades. In this context, both how the system works and how much is awarded is extremely important.

240. We believe that compensation decisions, and the body or system that manages their implementation, must be managed in line with the principles of good governance, with impartiality, accountability, fairness, and transparency at its core.

241. In setting the amount, we believe the responsible body must take account of:

a. Ensuring everyone affected is included, including recognising the devastating impact this has had not just on individuals and their partners but also their children, their parents, and their loved ones.

b. The full range of impacts for those affected – including physical, psychological, emotional, social, professional, and financial injury – both now and in the future (particularly long-term care costs for those who will need it).

c. The length of time taken for this to be addressed by the Government, and the significant trauma and loss many have further endured as a result.

d. Remains open to changing need, including people who are yet to be diagnosed with HCV.

e. There must be clear, transparent and published guidance which sets out how more specific cases should be assessed, including:

   i. Applications from people whose medical records have been destroyed by the NHS in their entirety.
   ii. People who received a transfusion after September 1991; this must be based on an expert assessment of how long infected blood/products may have remained in individual hospitals / supply chains after this date.
   iii. How probabilities should be judged, for example for someone who had a transfusion in the UK and also overseas: this must transparent and fair, and does not discriminate or rely on assessors' individual judgement or experience

242. All of this must be done in a way that is open and transparent, and which actively involves participation from those directly affected (not just through occasional consultation) and is clear and well communicated from the outset.

243. It is also vital that this is compensation, not discretionary support; this shift recognises that this situation came about through deliberate choices and that people have been severely wronged and is extremely important to the people affected.

244. Any resulting responsible body should also operate in line with the principles of good governance. This will include ensuring:

a. It is transparent, providing clear rules on eligibility; publishing data on applications, approvals and refusals; explaining assessors' qualifications to make judgements on cases; and ensuring people refused payments are told exactly why, and have a clear path to appeal which is not overly onerous.
b. It is fair to all. This will require ensuring equity in opportunity to apply, by ensuring application processes are as simple as possible and that there is support available to people to complete their applications when

needed - for example providing comprehensive guidance on how to obtain medical records, provide a mechanism for free or affordable medical opinions for people who need them, and supporting less literate or computer literate people to go through the process from start to finish

c. Fairness also means not discriminating, and in particular where someone has clearly received a blood transfusion or blood products in the relevant period and was subsequently diagnosed with HCV, HIV or HBV, their sexual or lifestyle history should not be examined and judged to decide whether they are considered the "type of person" who might have contracted one of these conditions anyway. Questions such as the current EIBSS HIV application form section 9 question for GP/medical completion - *Please give details of any other (risk and behavioural) factors that may possibly be relevant to the applicant's HIV infection, for example attendance at Genito-Urinary Medicine clinic (other than to take an HIV test), Drug Dependency Unit, association with people in or from countries which high prevalence of HIV, etc.* – should not be part of a fair and non-discriminatory system.
d. It is accountable, with people with lived experience of these issues being actively involved in its design and oversight (not simply consulted)
e. It is reliable, in that it provides long-term reassurance and clarity for those affected.
f. It should be clear how the funds will be managed over the long term and those affected should be able to plan and feel reassured about their financial future.

Section 7. Other Issues

245. HCV in the Population

I believe there are still many undiagnosed people in the general population who have HCV both as a result of injecting drug use and also those given infected blood or blood products.

246. There will be others, albeit fewer in number, who got infected through unsterile tattoos/piercings, medical treatment abroad, needle stick injuries, mother to baby, or other routes of transmission.

247. Many who either experimented with drugs, or received infected blood/blood products back in the 60s, 70s and 80s, have absolutely no idea that they would have been at risk and due to the passage of time they are totally disconnected from these past events.

248. Those who used drugs decades ago, perhaps only on one or two occasions, have pushed it to the back of their minds and are unaware of the possibility, or don't consider themselves as a "drug user" for that reason. They may not even have ever disclosed this to their friends and family all these years later due to the shame many people have around drug use, or because it's not relevant to their lives today.

249. But for those who have made a connection with their blood transfusion/s as a risk factor, they often report that they "assumed" they would have been tested for HCV in the course of other general tests in the past, or there is the expectation that they "would have been notified" by their doctor if they had been known to have been at risk in this way.

250. This, coupled with the fact that HCV is frequently symptomless for decades and/or that the symptoms for it are often attributed to so many other things, means that many people, regardless of their route of transmission, continue to be totally unaware of their status.

251. I also know that there are many who will have died with their HCV infection, without ever being diagnosed, of cirrhosis/liver failure (which often may have been attributed to alcohol use, real or assumed, in the past). Indeed we have heard stories from families where this occurred, despite their insistence to doctors that the person who died, never or only very rarely drank alcohol. Many others will have

died with a variety of other totally unrelated conditions, also without knowing they also had HCV.

252. When I started at the Trust, we had a report published that indicated that based on the prevalence of HCV in Europe (The UK vs Europe: Losing the Fight Against Hepatitis C) where they had better diagnosis rates than the UK at the time) that it was extrapolated that 466,000 people could have HCV (from all routes of transmission) in the UK.

253. This figure always stuck in my mind as we are not so different to European countries and faced the same overall risk factors back then. Public Health England's Hepatitis C in the UK report for 2020 estimates that there are 118,000 people living with hepatitis C in the UK currently, of whom around half are undiagnosed.

254. The majority of the people in these estimates would have caught it from drug use, however, I still personally believe, based on my experience at the Trust, that there are many, many people out there, who received blood transfusions and who have not been tested and many more who have died already, without ever knowing. Sadly we will never know how many and they will also never be included in the statistics on how many people were actually infected in this way.

255. General Approach

We believe it is really important that health professionals approach patients respectfully and non-judgmentally, give information in a sensitive way and also ensure that it is framed in a way that the patient can understand and to then also check that they understand. Where possible they should be signposted to support agencies or other reliable sources of information.

256. We also believe and feel strongly that there is huge value to be gained by linking people in with fellow patients/peers to discuss all aspects of living with and managing their condition and that this is often not considered. What we know from

our work is just how significant and often life changing the difference talking to someone with lived experience can make to people's ability to better understand their situation and come to terms with their diagnosis.

257. Things have improved greatly during my time at the Trust and thankfully we hear far fewer complaints from people now about their interactions with medical professionals and others, although unfortunately they still persist to a lesser degree.

258. Look Back Exercise

The Trust did not exist when the National Blood Transfusion Service ("NBTS") did a 'look back' exercise in 1995. My knowledge of what specifically occurred at that time is limited. My views are based on what I have heard from callers who were diagnosed with HCV as a result of infected blood/blood products.

259. I do not believe from the volume of people we have spoken to, and how rarely it has been referred to, that the scale of the work to 'look back' was sufficient; there are still many people unaware of their blood transfusions being a route of transmission coming forward today.

260. Through the Trust I have spoken to many people who say they were never contacted at any point about coming forward to be tested. Nor were they later made aware by others that there was a look back and are incredulous that they were not found, having lived in the same place or been registered with the same GP for decades.

261. We appreciate that some people may have moved or for other reasons weren't able to be reached and indeed we have spoken to a few, who chose not to respond to the request to get tested by the look back exercise. They reported that they did not feel it was conveyed to them in a way that made it seem important or urgent.

262. I can only recall a couple of calls where someone was actually diagnosed as a result of being contacted via the lookback exercise. I believe the majority of people

who have had a transfusion/blood products were never contacted or identified formally, but rather were diagnosed purely chance in the course of other investigations for other things.

263. Label

Even after successful treatment of HCV, for many people the weight of their previous diagnosis will follow them. Whether that is as a result of traumatic experiences impacting mental health, or reminders in medical or dental records, or affects their life/health insurance applications, even after treatment and cure, HCV continues to impact people's lives. And of course many have liver damage or other conditions as a result of their original infection.

264. Unfortunately many people still have doubts that their HCV is ever "really gone" and live in fear of it returning, believe that any subsequent health problems they may have are directly connected, or are unable to let go of the feeling that they are a potential risk to others.

265. People speak to us about how they wished others were aware that their HCV status was from infected blood/products and not assumed to be by drug use, something that many people feel is very shaming and affects how people deal with them, even if it is just by association.

266. Many talk about how they have been questioned inappropriately by medics and others, about how they may have got infected and that constantly reopens their wounds and feelings of being stigmatised.

The connection with HCV and drug use is so strong, that sometimes even when they explain their risk from infected blood to others, some people will still doubt this and continue to make assumptions about them.

267. Increasing Accurate Information

Unlike HIV/AIDs there has never been a national media campaign to raise awareness of HCV, still today there are so many people who do not even know what it is or even that it exists, they are not aware of the risk factors and as a result, have never been tested.

268. I believe a way to effectively raise the public and medical professionals' understanding of HCV would be to ensure firstly that HCV training is provided to not just medical professionals, but any professional such as police, social workers and other health care providers and, within this, that opportunities are provided during training for them to meet people with HCV, hear their stories and experiences, and start to understand the background to people's infections.

269. Whether this is through blood transfusion or blood products – understand how living with this experience impacts people's lives – or from drug use and the life experiences that often lead to it, it's incredibly important that health professionals understand holistically how differently people can come to this point, and how living with an infectious disease affects people's lives, and how they can improve their practice to support diagnosis, treatment and care. This would improve practice generally across many conditions, not only HCV.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-C Dated 17th September 2021

URN	Date	Description
WITN0912002	01/04/2006	The Hepatitis C Trust, 'The Hepatitis C Trust post-treatment survey', 2006