

**Witness name: Leroy Scarlett**

**Statement No: WITN2644006**

**Exhibits: WITN2644007-28**

**Dated: 11 June 2019**

**INFECTED BLOOD INQUIRY**

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**SECOND WRITTEN STATEMENT OF LEROY  
SCARLETT**

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**I, Leroy Scarlett, will say as follows:-**

1. My name is Leroy Scarlett. I make this second written statement in response to a supplementary Rule 9 request letter sent to me by the Inquiry, care of my solicitors, Leigh Day. I am due to give oral evidence to the Inquiry on Thursday 13 June 2019 in Leeds. This statement should be read in conjunction with my first written statement dated 22 February 2019.
  
2. In this statement I give evidence on the following matters:
  - a. The circumstances around my operation in July 1982 when I believe to the best of my knowledge that I had was given blood or blood products, which led to my infection with Hepatitis C ("HCV");
  
  - b. The fact that my medical records (both hospital and GP records) from the period 1979 to 1984 (that is to say, the five-year period around my operation when I was believe I was infected with HCV) are missing, and my repeated attempts and efforts to obtain them;
  
  - c. The impact of not having medical records of my operation on my ability to receive financial compensation, and the response of the Skipton

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Fund and, more recently, the English Infected Blood Support Scheme ("EIBSS"), to my applications in view of my missing records;

- d. The care and treatment that I have received, or failed to receive, for or on account of HCV, including the missed opportunity to diagnose my HCV in 2003, my participation in a clinical trial for HCV treatment, and my inability to access dental treatment; and
  - e. Other matters that I refer to in my first written statement and on which I now provide further context or information in order to assist the Inquiry.
3. I append some key supporting documents to this statement and I state their corresponding Exhibit Numbers in the body of this statement.

### **The circumstances of infection in 1982**

4. I explained in my first statement that I believe that I was infected with HCV during an operation in July 1982 when I was 22 years old to remove a ¼ inch piece of glass that had become lodged behind my knee. The circumstances around that operation are as follows.
5. In 1982, I had moved from Nottingham to Manchester in an attempt to better my life. As a tall, young black Afro Caribbean man, I could barely walk out on the streets after a certain point in the day without being stopped or arrested by the police. This was unfortunately typical at the time in a place such as Nottingham. I therefore moved to try and get away from this environment.
6. On the night of 13 July 1982, I was involved in an incident where I had been attacked and hit by a car. I was disorientated following my accident and I found myself running away from some men who were chasing me. I felt

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frightened. By the time these men caught up with me, it turned out that they were police officers. They simply arrested me without asking who I was or what I was doing. Although I protest to this day that I had done nothing wrong, I was later accused of being a burglar. They took me to the police station. I remember that I was very scared.

7. Somehow, following the accident, I kneeled on some glass and a  $\frac{3}{4}$  inch piece of glass managed to go into my knee and ended up right behind my knee cap. I must have stood up and straightened my knee without realising, so that the glass became lodged deeply in my knee. At the police station, one of the officers noticed my injury and I was subsequently taken to hospital, Manchester Royal Infirmary ("MRI"). I required an operation to remove the glass.
8. I emphasise at this stage that, since there are no medical records available for my operation (please see paragraph 31 of my first written statement), I set out the following dates and events to the best of my knowledge. I was taken to hospital in what must have been the early of hours of the morning of the 14 July 1982. I was booked in to have an operation and that required me to be starved for a certain period of time before I went under anaesthetic; I believe approximately 24 hours. The operation took place on either the 15 or 16 July 1982.
9. There are several points I would like to bring to the attention of the Inquiry that I think are significant. First, at the time of my operation, I was in the custody of the Manchester police force (now Greater Manchester Police) following my arrest. I was transferred to the MRI before they had charged me with any offence. The police were running out of time to either charge me with an offence, or release me, as is required by law. Therefore, I recall that they had to apply to the magistrates' court to extend this period of time to keep me in

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custody pending my operation. I remember that the magistrates made the point that it was unlikely that I would be able to run away with my knee as it was.

10. Another significant detail is that, when I was first arrested, I gave a false name: "Asher Bangarele". I must emphasise that at that point, I was scared and had been arrested following an attack on me. When I was signing my first consent form for the operation, I started to sign my real name, "Leroy", and this aroused suspicion. When I felt safe, I admitted my real name. I resigned my consent form for the operation with my proper name and gave my national insurance details. Eventually, I was charged with an offence (I believe of burglary). I recall that I was given bail on the condition that I could prove who I was, to appear at a further date. I ended up staying in the hospital recovering from the operation for about ten days.
11. I was given bail and one of the conditions of my bail was that I had to go back to live in Nottingham. I went back to Nottingham after I was discharged from the hospital. I had to appear at court in Manchester. However, because my leg was bad, I could not travel to Manchester. I remember that I got arrested for breach of bail as a result. I was eventually convicted and ended up in prison in, I believe, 1982-1983. Although I have not been a saint in my lifetime, and I will stand up and admit to my wrongdoings, I will always protest my innocence in relation to this particular charge. The police wrongly assumed that I was a burglar when they chased me through the streets. However, the fact is that I ended up in prison for a crime I did not commit.
12. While I was in prison, in the year following my operation, I recall that my leg was still bad and I was regularly taken out of prison to the hospital to receive rehabilitation treatment. I was given various other treatments while I was in prison.

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13. I provide the above additional detail for several reasons, which I hope will assist the Inquiry. First, around the time of my operation, I was interacting with multiple public authorities: the MRI, the police, HM Courts and Tribunals Service and HM Prison Service. I am now informed that MRI has destroyed my medical records from the time of my operation, and there is a gap between 1979 and 1984 (please see below) in my otherwise complete GP records. However, this seems particularly strange to me given that there are multiple public authorities that ought to have been aware and had records of my operation. Secondly, the circumstances of my operation were unusual given that I was in custody at the time. The absence of my records is particularly strange in this context. Thirdly, I am quite clear that following my operation I went through quite extensive rehabilitation treatment for my knee, during which time I was in prison for at least part of the period. It is simply inconceivable, therefore, that there will be no medical records for this period of my life, when at every other stage I have full GP records (as the Inquiry will be able to determine from the records provided pursuant to the additional Rule 9 request).

14. I am sure that I must have been infected with HCV during this operation. I was put under general anaesthetic to have the operation. When I regained consciousness after the operation I was told what had happened by the nurse. I was naturally very suspicious of the circumstances. Although it was a long time ago, I am quite clear that the way the nurse explained the process to me made me believe that during the operation blood of some form had been put into my body. I cannot remember whether she said that was by way of a blood transfusion or blood products; it is forty years ago now and all the more difficult to remember without the benefit of my medical records. This recollection is strengthened by the fact that I can recall when there was a lot of fear about AIDS, I was worried about the fact I had been given blood from

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somebody else. There were two other things that are now particularly significant to me and reinforce my understanding that I was given a blood transfusion or blood products, although I am not a medical professional so I cannot fully assess their significance. The first is that I was told after the operation that I had something called, "sticky blood". I understand this to mean that my blood clots particularly quickly. This is consistent with my experience. If I do ever bleed, I do not bleed for very long and my blood will clot almost straight away. Secondly, I recall that I was told after my operation what my blood group was. I have since forgotten this and nobody has had cause to tell me again. This would make sense if I had been given blood. The nurse caring for me also told me about the operation and the procedure required to remove the glass. I remember I remained in hospital for about ten days following the operation, so my understanding is that it was a significant procedure. I also required rehabilitation for a long period after.

15. Furthermore, as well as believing based on my conversation with the nurse that I had been given blood or blood products, I am very clear that there is no other possible route by which I could have contracted HCV. I confirm that I have never taken drugs intravenously, nor have I had any piercings or tattoos. Nor have I ever shared a razor. I am a very robust person generally. I have not had another operation in my lifetime since this one and there are no other possible routes of transmission of HCV. I also began to experience HCV symptoms shortly after this operation (which I discuss in further detail below at paragraph 45).

16. I attach as **WITN2644007** some photos that I have since provided to the Skipton Fund showing the scar that I have been left with following my operation. When I walk my knee still clicks.

17. Furthermore, there are some records referring to surgery to my knee. I exhibit

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as **WITN2644008** a letter from my doctor, dated 4 April 2018, prepared for the purposes of an EIBSS appeal, demonstrating that I had an operation to my right knee. I also refer to a "New Patient Check Questionnaire" (**WITN2644009**) dated December 1993, which states that I had an injury to my right knee aged 21/22 in my past medical history.

### **Missing medical records**

18. In my first written statement, I said that my medical records – both my GP and hospital records – were missing between 1979 and 1986. In fact, for the purposes of the preparing this statement, I have found one isolated record from 1984 (**WITN2644010**). However, there are no medical records at all for me between 1979 and 1984. This is also clear from my Patient Summary record, which appears to have been generated in or around 2002 by my GP at the time (**WITN2644011**). As I explained above, during this time I had my operation, was having regular rehabilitation treatment for my knee following my operation, and for part of this time I was in prison. It seems inconceivable to me that such significant medical events would not have been recorded on my GP records at the time. Yet, no record exists. I do not know whether any records for this time period were taken out of my records, or, if so, who might have tampered with my records.
19. I have made significant efforts since I was diagnosed with HCV in 2009 to obtain my records – GP and/or hospital records – from 1982 when I had my operation. However, I have simply hit a brick wall. This has had practical consequences for my ability to receive financial assistance (which I explain below) and it has also had a damaging effect on my health and my relationship with my GP and GP surgery. I have worked hard to rebuild this relationship and I am pleased that we are now in a better place.

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20. I feel that I have made every attempt to obtain my records, entirely by myself, with no help from anybody else. When I first discovered that my records were apparently incomplete, for the reasons I give above, I thought, "this is not possible". Naturally, at first I thought it was somebody in my surgery. I have grown up seeing the files and files of little wallets behind the doctor's desk. I was therefore under the impression that GPs kept all your records throughout your life. I was completely shocked when I realised that my records had apparently been edited and that there was no reference to my operation or rehabilitation. There were no GP's own notes, nor copies of follow-up letters from the hospital about my further treatment. This was all missing.

21. My relationship with my GP suffered as a result. I felt like I was continually asking for my GP's assistance to find the records (as my GP records demonstrate) and that I kept being dismissed. It felt like I went into battle with my GP surgery. They took all my complaints about my missing medical records as a personal insult. Over time, I have tried on multiple occasions to ask calmly whether my GP surgery could initiate an investigation to try and find my records, given that they would have been aware of the necessary process in a way that I was not as a layman. However, when my efforts were met with what I perceived to be inaction or dismissal, I admit that I did on a number of occasions become frustrated. However, I think it is unfair that my surgery painted me out as some kind of "maniac" and accused me of being intimidating or aggressive. I am a tall, black man, and I understand that, as a result, this can make some people more prone to finding me "intimidating", regardless of my actions. I feel that my frustration, insistence and assertiveness when faced with the serious problem of my missing medical records was misconstrued and mischaracterised.

22. For example, I attach as **WITN2644012** a letter dated 22 February 2012 that I consider demonstrates how I was treated by my surgery at a time when I was



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undergoing treatment for HCV and was also struggling to obtain my medical records. This letter refers to the fact that I had come into my surgery on 22 February 2012 to try and see a GP. It states that I was offered the chance to see a Practice Nurse triage and then I *“stormed out of the surgery saying that [I] would go to the hospital as [I was] suicidal.”* It states, *“You were aggressive from the very start and your behaviour wasn’t acceptable towards me. This kind of behaviour isn’t acceptable and will not be tolerated in the surgery”*. I was obviously going through an extremely difficult period. It baffles me that a patient who told his surgery and doctor that he was suicidal and would go to the hospital would receive a letter that day effectively telling him off for being aggressive.

23. I also note that my GP records show that, following a conversation with my doctor on 3 October 2014 where I was evidently frustrated and upset about my medical records, I received a diagnosis of *“paranoid ideation”* (**WITN2644013**).
24. I also have found references to paranoia in records from other clinicians responsible for my treatment and care. For example, an email on 15 May 2014 from my specialist nurse to my consultant hepatologist (who supervised my care and treatment during my participation in a clinical trial of Ritonavir and Ribavirin) (**WITN2644014**), states, *“I have just had Leroy Scarlett ranting at me for the last hour about noticeably paranoid beliefs regarding him acquiring Hep C. Whilst none of it was directed at me he was quite intimidating and I am quite concerned about him. He says he wishes he was dead but is not actively suicidal.”* The email refers to my missing medical records and states, *“Leroy now believes there is a conspiracy against him and that this information has been deliberately removed from his medical records.”*
25. I am disappointed, but not surprised, to discover these references to paranoia

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and to me being intimidating or aggressive. Even if I did appear frustrated and angry at times, I do not think that this was unreasonable. I would also like to point out that, at this point, I was experiencing symptoms of HCV such as brain fog, cognitive impairment and personality change, as well as going through gruelling treatment. All of these things interacted with and exacerbated my very reasonable frustration that my records had just disappeared. It is disappointing that medical professionals did not recognise this and treat me with more compassion. In hindsight, I also feel angry to see those comments from my specialist nurse. After all, those clinicians would have made a significant amount of money out of my voluntary participation in their drug trial. I would have thought that I would be treated with more respect.

26. I also exhibit a letter from me dated 10 October 2014 (**WITN2644015**), which demonstrates one of my many calm and polite attempts to engage with my surgery to seek their assistance with finding my medical records. I feel this shows that the various references to me as aggressive, intimidating and paranoid are somewhat unfair, one-sided or at least are not fully reflective of the whole situation.

27. I also hit a brick wall when trying to obtain my hospital records. When I was told that my records did not go back to 1982, I felt like someone was having a joke with me. As a patient, I could not believe this blasé attitude.

28. In 2010, when I was preparing my Skipton Fund application, I contacted the Medical Legal Department of MRI (run by Central Manchester University Hospitals NHS Foundation Trust) to obtain the hospital records of my operation in 1982. I received a response dated Wednesday 24 November 2010 from Heather Swirles who confirmed that "*in line with National Guidelines, Health Records are retained for 8 years since the Patient's last attendance.*" (**WITN2644016**).

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29. Subsequently, I made a further Freedom of Information Request to MRI in Summer of 2018, for the purposes of my EIBSS appeal, seeking "information of all knee operations concerned with removal of foreign objects from knee from 1 July to 31 July 1982". I received a response stating, "*The Trust can confirm we are unable to provide data for this request as our records do not go back that far.*" (**WITN2644017**) I understand that my solicitors, Leigh Day, have received further confirmation in January 2019 from Heather Swirles at MRI that my records have been destroyed (**WITN2644018**).
30. I sought my prison medical records in 2011 but it was confirmed to me by Humber NHS Foundation Trust on 18 July 2011 that my inmate medical records had also been destroyed (**WITN2644019**). There is a note on this letter saying that the Prison Records Department had been able to confirm that back in 2005 I was provided with a copy of all my records including medical records. I can confirm that at no point did I receive my records from 1979-1984. I was informed that the relevant period of retention, in accordance with Health Service Circular 1998/217, and as set out in PSO 9020 was "10 years after conclusion of treatment or death".
31. I also sought the assistance of my MPs, Graham Allen MP and Alex Norris MP, to obtain my medical records. On 24 July 2012 Anne Milton MP, Parliamentary Under Secretary for Public Health, contacted Graham Allen MP about my situation (**WITN2644020**). This letter was unhelpful, stating only:

*"The Skipton Fund can approve claims only where claimants can provide the necessary supporting evidence that they meet the Fund's eligibility criteria. It is for the Fund to decide, on the balance of probabilities, whether an applicant has provided enough evidence to support their claim for a payment. Officials have contacted the Skipton*

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*Fund and established that evidence other than hospital records can be considered when claims are made. Examples are:*

- *GP records;*
- *Letters from solicitors or police – Mr Scarlett was involved in a road traffic accident and there may have been criminal proceedings; or*
- *Any 'look-back letter' Mr Scarlett may have received from NHS Blood and Transplant about a possible infection from a blood transfusion."*

32. As I explain below, I cannot see that the policy stated by Anne Milton MP was the one applied by the Skipton Fund or, subsequently, EIBSS. Instead it appears to be that documentary "proof" of a blood transfusion is *de facto* required in order to meet their criteria. She also does not engage with the fact that I was missing my GP records from the time of my operation.

33. On 21 July 2017, Alex Norris MP was sent a letter by NHS England about my missing medical records, following a request by him that the situation be formally investigated. It was confirmed that "*the 2009 NHS Complaint regulations confirm that eligibility for investigation under the regulations requires the complaint to be lodged within a year of the event under consideration or knowledge of the event. Consequently, as Mr Scarlett's complaint relates to events which allegedly took place five years ago they fall outside the remit of the current regulations and therefore are not eligible for investigations.*" (WITN2644021).

34. However, I understand that Regulation 12 of the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009, which NHS England refer to, allows NHS England to disapply that time

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limit if it is satisfied that— (a) the complainant had good reasons for not making the complaint within that time limit; and (b) notwithstanding the delay, it is still possible to investigate the complaint effectively and fairly. It is not clear to me that NHS England has considered its discretion to waive the time limit at all. I would have thought undergoing serious treatment for HCV, and pursuing all other avenues to reach a resolution, might constitute a good reason for not making the complaint within the time limit.

### **Skipton Fund and EIBSS applications**

35. Given my inability to obtain any medical records for the period 1979-1984, which covers my operation, I have not been able to obtain any financial assistance from any of the Trusts, Funds or Schemes. This is despite my repeated attempts. I have provided the Inquiry with all records in relation to my applications and appeals, and I exhibit only the key documents. I confirm that the important probative evidence, such as the photographs of my knee, and letters from my doctor referring to records of my knee injury, have all been provided to Skipton and/or EIBSS.
36. On 7 April 2011, after I had made my initial application to the Skipton Fund, I received a letter inviting further documentary evidence (**WITN2644022**). It referred to the letter sent to me in 2010 from MRI confirming that my records had been destroyed:

*"I note that there was a letter included with the application from Central Manchester University Hospitals confirming the destruction of medical records, which means the only possible course of action is to pursue your prison records. If as you say they will not allow you access to the relevant information, please ask that they put this in writing and send that along with your form instead."*

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37. I subsequently received the letter from Humber NHS Foundation Trust referred to above confirming that my prison records too had been destroyed. I communicated this to the Skipton Fund and received the following response on 27 July 2011 (**WITN2644023**):

*"We have re-received your application form along with the letter from the Medical Records Department at Humber NHS Foundation Trust informing us that your prison medical records have been destroyed. We also have correspondence from the Manchester Royal Infirmary that confirms that they no longer hold any information relating to the procedures that you underwent there.*

*It is with regret that I must advise you your application has been declined due to this lack of supporting confirmation that you required treatment with NHS blood or blood products prior to September 1991 and that this was therefore the likely source of your hepatitis C infection. Of course, if you do manage to obtain any medical records which confirm that you were treated with NHS blood or blood products prior to September 1991, then please return these along with your application form and we will consider it again." (my emphasis)*

38. I requested an appeal of the above decision. On 10 December 2011, the Skipton Fund Appeal Panel refused my appeal (**WITN2644024**). The reasoning was as follows:

*"The Panel reviewed the entire file of papers held by the Skipton Fund in connection with your application and all the additional information supplied for the purpose of your appeal. We noted that there was no record of any transfusion in your notes. Our expert members were of*

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*the view, supported by the clinical records we have seen, that there is insufficient evidence to show that you were treated by a blood transfusion.*

*The Panel considered that it was highly unlikely that the surgery you underwent to have glass removed from your knee would cause sufficient bleeding to require a transfusion.”*

39. After this appeal, I corresponded with the Skipton Fund periodically, providing them with further letters of support from my clinicians and other evidence, however the Fund did not reconsider its decision.

40. More recently, on 23 September 2018, I contacted EIBSS asking them to reconsider my previous appeal (**WITN2644025**). I provided them with a supporting letter from my GP and the Freedom of Information response from MRI. In this letter I noted: *“I have made every effort to obtain my records to back my application and in my eyes have been denied access unfairly. There is a gap in my records between 1979-1986...I fit all the criteria asked for by the Skipton Fund and feel that I was held responsible for the lack of medical records of operation to my right knee. Although there is physical evidence, it is not my responsibility for the safe keeping of these records. I have been shown no compassion or understanding and this has not helped my general health and wellbeing.”*

41. On 19 December 2018, EIBSS refused my appeal (**WITN2644026**). Again, the reasoning was as follows:

*“...your appeal was based on a blood transfusion which you may have received following surgery to remove glass in your knee in 1982. Following deliberations the Panel’s view was that this surgical*

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*procedure would be unlikely, on the balance of probabilities, to cause sufficient bleeding so as to require a transfusion at the time. This information in conjunction with the lack of records confirming the transfusion means that the Panel were not satisfied that it was more probable than not, that your Hepatitis C infection resulted from qualifying NHS treatment.”*

42. In summary, I am still hitting my head against a brick wall given the recent position of EIBSS, which is the same as the Skipton Fund. It seems irrational to me or at the very least unfair that the *lack* of medical records can be a probative factor held against me, when my records have been destroyed or lost for the entire period around my operation. It is not as if there is a complete set of GP records for this period and there is simply no mention of my operation or a transfusion. It appears that, in actual fact, what the Skipton Fund and now EIBSS require is documentary proof of the operation and the transfusion. This leaves me in what I can only describe as a “catch 22” situation, given that my records have been apparently destroyed without my consent or knowledge, and through no fault of my own.

### **Care and treatment issues**

43. I would like to expand on a number of issues to do with my care and treatment.

44. First, I would like to address what I believe is a significant delay in diagnosing my HCV (at least six years). In my first written statement, I gave evidence at paragraph 9 that there is a note in my medical records dated 12 May 2013 that refers to “Hepatitis C” (**WITN2644005**). This note appears to also refer to abnormal Liver Function Tests. I have reflected further on this record and its significance. I believe that it demonstrates a serious missed opportunity to



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diagnose my HCV at least six years before it eventually was.

45. When I first saw this record, I felt so angry. I could not think straight. It was extremely isolating for me. I cannot recall ever being tested for HCV at this time, although do recall having various blood tests. My symptoms of HCV did not appear overnight, but in fact first appeared in around 1984. A reference to me having a barium meal in 1986 shows that I was experiencing stomach problems around this time. I also displayed symptoms such as tiredness, restless legs, and insomnia. Because I was young, I carried on living my life. By the late 1980s, these symptoms were getting worse. By the 2000s when I had raised Liver Function Tests, I believe that these symptoms should have been picked up as potential HCV and that it should have been properly investigated.

46. I am terribly angry about this, particularly as there is a reference to HCV in my records. It clearly was not out of the question that I had it. I am not saying that any treatment may have necessarily worked better at that time but "knowledge is power". If I had been aware of my HCV at an earlier stage, I may have been able to do something about it. As it is, I live what I consider to be a fairly healthy lifestyle. I was a vegan for nine years in the 1980s and I have been a vegetarian ever since. I also practically do not drink. I am sure that these lifestyle choices have contributed to the fact that I am still alive now to be complaining. However, I cannot help but feel sympathetic to all those in my situation who were infected with HCV, without any knowledge of it, but carried on drinking. If you drink with HCV, it is more or less a death sentence. In my view, this is why the NHS has been so remiss. So many people have continued drinking for years without knowledge of their HCV, thereby causing irreversible liver damage and, often, death. Earlier diagnoses could have saved these people by allowing them to modify their lifestyles.

47. To assist the Inquiry, I add that, after initially not responding to

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Interferon/Ribavirin treatment and therefore stopping my course after 12 weeks, I cleared the HCV virus after participating in a clinical trial of combination therapy: Ritonavir and Ribavirin. This trial commenced in or around February 2012. By 4 July 2013 it was confirmed that I had a "sustained viral response" ("SVR") (**WITN2644027**).

48. In my first statement, I stated at paragraph 17 that I have lost my teeth since I was diagnosed with HCV and have received no dental treatment since. By way of further context, my dental problems (plaques and poor dentition) were exacerbated by the antiviral therapy I had for HCV (please see (**WITN2644028**) for confirmation of this in my GP records).

49. I first experienced obstacles to accessing dental treatment not long after I had been diagnosed. A crown I had had from a young age was accidentally dislodged and I went to the dentist to get it fixed. Out of courtesy, as I not been asked, I told them that I had HCV. Nobody ever explicitly told me they did not want to treat me, but their treatment of me changed. They were not as friendly. I would get an appointment booked, would have wait for a long time in the waiting room, even when I arrived early, then by the time I got to the dentist's room, they would merely talk to me about the treatment they were going to give me and ask me to come back next week. They would look in my mouth and touch me with metal tools, but they did not actually do any invasive work, which I desperately required as my teeth were progressively falling out in response to the HCV treatment. This did not help at all with my mental state.

50. Since I cleared HCV, I have had dentures fitted but no invasive work for my dental problems. I recall making mention of this to my specialist hepatitis nurse while I was on the clinical trial.

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51. I can confirm that I have not had any counselling. I know it is good to talk, but I feel that the NHS does not provide the right kind of counselling for people in my situation. It requires a professional who understands the disjointedness of having HCV and feeling like a zombie.

52. I accessed some counselling services from the Hepatitis C Trust. Nobody signposted me to the Trust; I discovered it from my own research. It was at most moderately helpful. It was a sort of peer to peer counselling. I recall being told by the person on the phone that they had HCV and were an intravenous drug user. I did not find that useful, as much as I appreciated it, because I did not fall into that category. I had not obtained HCV from intravenous drug use and so needed a different kind of support.

### **Other matters**

53. In conclusion, I would like to make some further comments.

54. First, I would like to make a practical suggestion that I hope will assist the Inquiry when it considers what recommendations to make. I feel that there should be concerted effort made to inform the public about HCV and to encourage people to be tested. For example, there could be a poster that tells someone, *"if you are displaying X, Y, Z symptoms, please approach your doctor and discuss getting tested for HCV and do not drink while you await the outcome of your test"*.

55. Secondly, I would like to express my regret that I have not felt truly part of the Inquiry. This is partly because of how I have been treated throughout my lifetime by various institutions, including the NHS. However, it is also because I am scared that, because of my criminal record and history, I will not be considered the "right type of person" to stand up and be counted. I know I am

**Witness name: Leroy Scarlett**

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not a saint, but I also think that I represent the “average person”, who has done some things they are not proud of in their lifetime but has endeavoured to reform themselves and leave that past behind. I have not been in trouble for a long time as I try always to set a good example for my sons. As such, I do hope the Inquiry gives my evidence due weight and that my evidence is not discredited because of my past.

56. Thirdly, and sadly, I cannot shake fears that I may have been experimented on or monitored without my consent. Unfortunately, my trust in the NHS and various public authorities has been eroded by the struggles I have faced with my medical records and my delayed diagnosis. I always wonder whether I was used to monitor the impact of HCV and its progression. When I was young, I was very healthy, so I would have been an ideal candidate. If this did indeed occur, if someone had simply asked me if they could monitor me for the purposes of research, I would have likely said yes. This is why I went on the clinical trial in 2012, as I do want to help with medical progress.

57. Fourthly, so far it seems that medical science has focused on HCV’s impacts on the liver, rather than its impacts on the brain. I would like the Inquiry to encourage progress in this area, as I feel there is much unknown. I was labelled as “aggressive” throughout a period where I am sure that I was displaying the mental effects of HCV.

58. Finally, I would like to express just how angry I still am about the situation with my medical records. This is indeed why I approached the Inquiry, as I want to get my story out in the open. I have suspicions that there will be a pattern and that there will be others out there like me. I have spent so long knocking my head against a brick wall trying to obtain my records. I really hope there will be a resolution through the Inquiry and that I can make a successful application to EIBSS. I would really welcome that support.

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59. Having said this, money will not give me my health back. My health was taken from me, and so were so many other privileges and rights. For example, if my children were ever to have health problems and need a blood transfusion, I cannot give them blood. The NHS was also reckless in its approach to safety. I could have put my children or partners had risk. I feel like I have a right to be angry.

60. My family will attest that since my diagnosis, over the last ten years, I simply have not been "me". I was a single father to one of my sons, and he recognises the changes in me. I have isolated myself through my anger at the situation, and this saddens me.

**Statement of Truth**

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

Signed

**GRO-C**

**Dated: 11 June 2019**