

Witness Name: Regina Alice Cheptanui

Statement No.: WITN6966001

Exhibit: **WITN6966002-004**

Dated:

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF REGINA ALICE CHEPTANUI**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 January 2022.

I, Regina Alice Cheptanui, will say as follows: -

#### **Section 1. Introduction**

1. My name is Regina Alice Cheptanui, my date of birth is GRO-C 1946 and my address is known to the Inquiry. I am a British Kenyan. I was born in Kenya, and moved to the UK in 1972, and I then lived in Barbados from 2002 until 2016 when I moved back to the UK.
2. I intend to speak about my infection with Hepatitis C ("HCV") that I got as a result of receiving a blood transfusion shortly after I had given birth in November 1973. In particular, I will speak about the nature of my illness, how the illness affected me, the poor treatment I received and the impact it had on my life and, especially, my mental health.

3. I am happy to give my statement to the Inquiry, and I do not wish to be anonymous.
4. The Inquiry Investigator has explained the Inquiry's statement of approach and 'Right to Reply' procedure. I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
5. I wish to acknowledge that as time passes, memories can fade and so I have provided my witness statement to the best of my knowledge.

## **Section 2. How Infected**

6. I gave birth to two of my children in Kenya as a home-birth with the assistance of a qualified mid-wife and I required no blood transfusion. In 1972, I moved from Kenya to the UK. Soon after I arrived here, I became pregnant with my daughter.
7. In GRO-C 1973, I gave birth to her. Unfortunately, during child-birth, I incurred a huge amount of blood loss. In response to that, the hospital gave me a blood transfusion. Please see **Exhibit WITN6966002**, which is my medical history from delivery, noting "transfused 2" in 1973. I was also told at the time that I was going to receive a blood transfusion. It was a scary experience because I had just recently moved to a foreign country and so much was going on.
8. I remember before the birth there was not much interest in me as a patient and I think that was partly because of my ethnicity. I believe that this may have contributed to the following events and me having required a blood transfusion. I am lucky that this was not my first birth and so I had some idea of what to expect. After the blood transfusion, I felt fine – there was nothing to indicate at the time that something was wrong with the blood.

9. But then in 1994, things changed. Whilst I was at work, my manager asked me if I wanted to go and donate blood. I was particularly keen to do so because I had previously benefitted from a blood transfusion and so I wanted to give back. I donated blood at Southampton General Hospital. Then suddenly, on a Saturday morning, I received a letter telling me not to donate blood again. They said I had "jaundice". As I was worried to death, I immediately went to the hospital. The doctor looked at my eyes and said "there is nothing wrong with you". I did not accept this answer and so, he did another test on me and reiterated that everything was okay. At that point, I went home reassured and thought nothing more of it.
10. Later, I then received a letter from the hospital telling me that I had Hepatitis C and they wanted me to go in for a biopsy on my liver. It came as a massive shock. I attended the appointment at hospital, and I was told that they wanted to 'inject and pinch' my liver to test it for Hepatitis C. I told them "no one is touching my liver in that way". It sounded really frightening. They asked me if I had received a blood transfusion and that this may be the cause, which caused me further concern, and so I refused the investigation. After that I did not have any further hospital appointments and no treatment was offered to me. I was confused by the whole situation, and assumed that because I never heard from them again that I did not have Hepatitis C.
11. Although, during this time, my GP carried out a blood liver function test for the duration of one year. But I was never told why I was having the liver function test, nor was it made clear to me and my GP never told me that I had Hepatitis C. I can also recall being told that my liver was 'okay' once they ended the liver function testing.
12. I moved to Barbados in 2002. I then moved back to the UK in 2016 and joined St. Mary's GP Surgery in Southampton. In 2018, my GP told me that he needed to do a review of my medication. I thought it was just going to be a review of my blood pressure. When I went there, he asked me

what medication I was currently taking for Hepatitis C. That took me by complete shock. I told him that I did not have Hepatitis C and so I have taken nothing. I then remembered the previous talk of an investigation more than twenty years ago to “pinch my liver”, which I told them about but that I was then told by my previous GP surgery, that my liver was ‘okay’.

13. My new GP then told me that according to my records, I have Hepatitis C. They decided to do a test for HIV and HCV, and that test concluded I had Hepatitis C. It was a complete shock to me. I was so annoyed that my previous doctors had never followed this up with me or explained to me properly what was going on.

14. After finding out that I had Hepatitis C, I was referred to Dr Wright, Consultant Hepatologist at Southampton General Hospital in 2019. They conducted liver tests on me, which now, consisted of just a scan. I was told that my liver was badly infected and that I had three million viruses’ attacking my liver. At this point, it was around forty-five years since my blood transfusion. When I was diagnosed in 2019, they did not explain the risks of HCV. Although, I was told that I might have contracted the infection from contaminated blood.

### **Section 3. Other Infections**

15. I do not believe that I was infected with any other infections other than HCV as a result of my treatment with blood. I was tested for HIV in 2018 by my GP at St. Mary’s GP Surgery and the result was negative.

### **Section 4. Consent**

16. I do not believe I have been tested for anything against my will or without my consent for the purposes of research.

17. I do not remember explicitly consenting to the blood transfusion although it was a life-saving procedure.

### **Section 5. Impact**

18. In 2002, I moved to Barbados as I was suffering from bad back problems, and my doctor told me that warm weather would help reduce the pain. I started suffering from back problems after a bad fall at work, and my workplace retired me on medical grounds. I don't know if I was unwell with my mobility partly because of hepatitis C, but it has at least been exacerbated by hepatitis C.

19. Following HCV treatment, I still suffer with bad mobility and I now walk with a stick. I often attribute this to just to old age, but in reality, I know that some of those issues might be related to Hepatitis C. It has worsened my physical difficulties, and that has reduced my quality of life.

20. Everything that has happened has greatly affected my mental wellbeing. Finding out that I had Hepatitis C made me feel dirty. Even though you know it's not your fault, you still feel really dirty.

21. When I was receiving the treatment, my mood swings were awful as a side-effect to the medication. Even to this day, I still feel miserable. I was processing not only the treatment itself but also its horrible side-effects. It was tough both physically and mentally.

22. Hepatitis C has changed me as a person. I used to be an outgoing person. Now, I don't like going anywhere, apart from to my Church. I told my community at Church that I had Hepatitis C. They were supportive and prayed for me. What kept me going was my faith, and that I had a granddaughter on the way, this really got me through my treatment.

23. Both my daughter and I feel as if our race played at least some part in why I have received subpar treatment. Even when I was bleeding really

badly in hospital, there did not seem to be enough concern about me. I felt as if I was treated as a second-class citizen. Ultimately, I was an immigrant in a predominantly white, conservative area. I think there was some unconscious bias in how I was treated and how they interpreted my levels of pain. In my country, when you have pain, you don't scream and you control your reaction to it. However, this does not lessen the amount of pain I am in and I was in a lot of pain. I told hospital staff that I was in pain, but they did not take me seriously. Different cultures handle pain in different ways and this is something that hospitals should be fully aware of. Hospitals need to have more cultural awareness, and they need to treat people more sensitively. I believe that I have been unfairly treated by hospitals generally. I also think that my race played a part in determining my application for financial assistance. Dr Wright and EIBSS made a leap in determining that I probably contracted Hepatitis C in Kenya (see the section on Financial Assistance for a fuller explanation of this point).

24. 

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GRO-C	I had two children following the blood transfusion in		
GRO-C	1973, <table border="1" style="display: inline-table; vertical-align: middle;"><tr><td colspan="2">GRO-C</td></tr></table>	GRO-C	
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 The issue is that nobody told me to get my children tested when there was clearly a risk that I could have passed it onto them during pregnancy, and they were also breast-fed. Going through that worry was a really big stress for me and my family.

25. In January 2020, I was called in for an MDT meeting and I was told that I would need treatment with Maviret (Glecaprevir/Pibrentasvir). This course of treatment was decided upon based on my genotype 4 with a Fibro Scan of 5.9kPa. Details of this treatment and decision can be found in **Exhibit WITN6966003**. This medication was not readily available and I was told me that they would have to specially source it for me.

26. I was required to take four tablets of Maviret in one dose every evening. I was warned by the nurse that it might make me feel sick and vomit. This was correct and I was sick every single day during treatment. I even had blood in my vomit. I suffered from cramps on my legs, back pain and generally felt very tired. It also affected my mood significantly. The treatment was awful. The nurse told me that if my symptoms became terrible, I should call for an ambulance. After a month of treatment, I cleared my viral load and I was informed that I no longer had Hepatitis C. During the course of this treatment, I was continuously tested (around once every week or fortnight) with a blood test and a Fibro Scan.

### **Section 6. Treatment/Care/Support**

27. I think the duty of care towards me has repeatedly not been met. Right from the beginning from when I was first diagnosed to later having treatment for Hepatitis C, I felt really let down by clinicians and the England Infected Blood Support Scheme ("EIBSS"). I have always felt as if they are not telling me everything and I have not been given proper information.

28. As I mentioned earlier, I refused to let them complete an investigation into my liver because I did not want them to 'pinch' my liver. It was too invasive for me in the context of what had already happened, but it was not properly explained to me at this time. All that was in my mind was they had given me infected blood already, and so I did not trust them to complete such a procedure on my liver. After the point of 'diagnosis' and refusing that one investigation, they never mentioned anything about Hepatitis C to me ever again.

29. My main issue is the lack of care and treatment I received between 1994, when they first suspected I had Hepatitis C, and 2019 when I was eventually put on a programme of treatment. I don't understand why nothing happened earlier than 2019. They were aware of my HCV

diagnosis for twenty-five years, and also having been infected nearly twenty years before that.

30. I wasn't offered much psychological support. I think they did mention counselling once to me. However, I wasn't keen on that course of action because of my previous experience with it. Previously, I was sent for an occupational health assessment by my work when I retired on medical grounds. They wanted to work out whether the pain I had in my back was just psychological. They asked me questions about my childhood which was totally irrelevant. That experience scarred my view of the utility of counselling.

## **Section 7. Financial Assistance**

31. Dr Wright at Southampton General Hospital informed me of the existence of financial assistance and advised me to make an application to EIBSS. Although, Dr Wright did say to me that I may have difficulties accessing financial assistance as I had a BCG vaccination in Kenya. He said there were fears that it may have been administered in an improper way with non-sterile needles.

32. After submitting my first application in around 2020 to EIBSS, they requested further evidence, which I then submitted to them, evidencing my 1973 blood transfusion. Unfortunately, they still rejected my application on the basis that my HCV infection was alike to the BCG vaccination symptoms in Kenya. They explained that a decision was made on the balance of probabilities, that I am more likely to have acquired the infection outside of the UK.

33. Given this concern, Dr Wright did not want to appeal the rejection I received from EIBSS. I feel like he was too resistant. He stated that "genotype 4 is most common in Africa and it is quite uncommon in the UK". I feel as if the letter I received from Dr Wright about why I am not eligible for financial assistance effectively says to me 'get it in your head'.



This letter really upset me. Please refer to Dr Wright's letter dated 10 July 2020 at **Exhibit WITN6966004**.

34. I am currently in the process of reapplying again (rather than appealing, as it past their three-month appeal deadline), however Dr Wright has made this difficult for me. I have since sent Dr Wright the forms again via recorded delivery, as he is required to complete his part in my EIBSS application, but I have not heard back from him. I believe that if I had a white surname then Dr Wright would have replied to my letter, even if he wasn't going to complete it, however he does not reply to my letter at all. It was sent to him by recorded delivery and I still have this receipt. I am really upset by this.
35. I think it is improper to draw the conclusion that I was not infected with Hepatitis C through my blood transfusion in 1973 on the NHS based on a general probability, because I also had a vaccination in Kenya.
36. Accessing the medical records regarding my blood transfusion was a very arduous process. Both EIBSS and Dr Wright have not referred to any of the evidence we provided to determine what the source of my infection was. Just because it is a rare genotype, that doesn't mean – conclusively – that I got Hepatitis C from my BCG vaccination. I don't think they've provided enough evidence to show that I didn't receive my infection from the blood transfusion in the UK.
37. I feel like I have been put aside because I have genotype 4. But that has nothing to do with Hepatitis C. I had a blood transfusion in the UK during the relevant period. The crux of it is whilst genotype 4 is rare in the UK, it doesn't mean it doesn't exist. It may have been from a BCG vaccination but equally, it may have been from a blood transfusion. My case should not be dismissed on the basis of a hunch. I feel like they want people to die before their compensation.

## **Section 8. Other Issues**

38. I hope and pray that this will never happen again. In particular, I want people to all to be treated equally. I am sceptical about whether that can be achieved anytime soon because people carry a lot of unconscious bias about the BAME community. That bias impacts the quality of the medical treatment the BAME community receive and also how we are communicated with by medical professionals.

### **Table of Exhibits:**

<b>Date</b>	<b>Description</b>	<b>Exhibit</b>
21 February 1977	Regina Cheptanui's medical record of her pregnancy history. Detailed under "abnormality in pregnancy/delivery" is "transfused 2" in the in 1973 row.	<b>WITN6966002</b>
15 January 2020	Letter from Rhea Cinco, Hepatology Nurse Specialist to Dr K Reynolds, St Mary's Surgery. Detailing Regina Cheptanui's HCV diagnosis and her course of treatment.	<b>WITN6966003</b>
10 July 2020	Letter from Dr M Wright, Consultant Hepatologist to Regina Cheptanui with Reference: MW/HW/0930222. Explaining the purpose of the NHS EIBSS, that genotype 4 is most common in Africa and that Regina is more likely to have acquired the virus outside of the UK.	<b>WITN6966004</b>

**Statement of Truth**

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

Signed GRO-C

Dated 25-2-2022