

Witness Name: John Robert
Boulton-Jones
Statement No.: WITN3501001
Exhibits: WITN3501002-013
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOHN ROBERT BOULTON-JONES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 May 2019.

I, John Robert Boulton-Jones will say as follows: -

Section 1: Introduction

1. My name is Dr John Robert Boulton-Jones and my date of birth is GRO-C 1968. My current work address is Gastroenterology Department, Queen Elizabeth University Hospital, 1345 Govan Road, Glasgow, G51 4TF. I have worked as a consultant physician and gastroenterologist for Greater Glasgow and Clyde Health Board since November 2003. At the time of the events discussed in this response I was based at the Victoria Infirmary, Glasgow. This hospital has subsequently shut since the Queen Elizabeth University Hospital has opened.

Section 2: Responses to criticism of Maria Armour

2. Thank you for providing me with a copy of the evidence provided by Maria Armour to the Infected Blood Inquiry and for asking for my comments. Before addressing the specific criticisms, I would like to make some general comments to allow the evidence to be put in context. The events that I have been asked to comment on took place in 2005 – 2006 and I have no direct personal recollection of the consultations mentioned. All my comments are therefore based on the contemporaneous clinic letters and my recollection of how we would have treated patients with Hepatitis C at the time.
3. The criticisms I have been asked to comment on are as follows:

- At paragraph 6 of her witness statement, Ms Armour states she had regular appointments where her blood was taken for routine tests. On one occasion in 2004 she states that I unexpectedly told her that I had "some good news and bad news" for her. The bad news being that she had Hepatitis C. At paragraph 9 she states that she felt the way I informed her of her infection was 'disgusting'.
- At paragraph 7, Ms Armour states that she was given no information about hepatitis C at my clinic and she was left alone to deal with her condition for many years.
- At paragraph 9 Ms Armour states my attitude towards her was 'terrible' and she was given no leaflets or further information about managing her infection.
- At paragraph 10 Ms Armour states that she was given no information about the risks of others being infected as a result of her infection.
- At paragraph 13, Ms Armour states she believes that the blood I had drawn from her was tested for Hepatitis C without her consent.
- At paragraph 18, Ms Armour states that in 2009 I told her that I was not going to offer her the Hepatitis C treatment as I did not think her body could cope with the treatment. She states that there was no discussion about this decision and no discussion about what she could do to make the treatment more tolerable for her. She says she felt like it was a 'vicious cycle' as she was too ill to have the treatment for the infection because of the infection. She also states that this was the first time that treatment options were discussed with her.
- At paragraph 22, Ms Armour states that whilst studying for a health qualification, she learnt that Hepatitis C is a life-threatening condition that affects every part of the body. She states that this was a contrast to what I told her as I only focused on the liver and did not emphasise the seriousness of the infection.
- At paragraph 23, Ms Armour states that her medical records contained a letter from me which stated that she had contracted Hepatitis C via intravenous drug use. I subsequently sent her another letter indicating that this error had been corrected.

Evidence about MA being told she had hepatitis C at my clinic.

4. The patient states that I did not voluntarily give her any information about hepatitis C. I do not accept that this is the case. This view is based both from my review of the contemporaneous case notes and because it is not my practice to hide things from patients. The diagnosis was made on the basis of blood tests taken at the preceding clinic attendance and she was told the results at the very next clinic visit I had with her (WITN3501004 and WITN3501005). We therefore had no consultations where I was aware that Ms Armour had hepatitis C and she did not.
5. From the review of the contemporaneous clinic letter (WITN3501005) we appeared to have had a long discussion about how she may have caught hepatitis C. As this was not particularly relevant to the future treatment and because elsewhere in her evidence it comes across that she was very concerned about how she may have caught hepatitis C, I suspect this part of the discussion was driven by her. Treatment for hepatitis C did not and does not vary with method of infection.
6. I decided to carry out more tests for the hepatitis C (genotype and viral load) before deciding on a treatment plan for this patient (WITN3501005). This is because at the time there was a big difference in both the length of treatment required and the likely success of treatment depending on the hepatitis C genotype. There are 2 genotypes

that are common in the UK – namely genotypes 1 and 3. Patients with genotype 3 had higher success rates with the treatments used at the time and required less time on treatment (usually 6 months against 1 year + required for genotype 1). Therefore, this information would be required before we could give her the full information about the implications of and likely success of treatment.

7. I have also recorded in my letter from that clinic consultation that we discussed the small risk of sexual transmission of hepatitis C and so I do not accept that we did not discuss the risks of others being infected (WITN3501005).
8. On the basis of the clinic letter I consider that we discussed many aspects of her hepatitis C and I therefore would dispute the comment that I did not voluntarily give her any information about her hepatitis (WITN3501005).
9. On the next two occasions the patient was seen in my clinic she was seen by junior doctors working alongside me at my clinics (which was a reflection of the fact that the pressures on the service at the time meant it was a consultant delivered rather than a consultant led service). On the next occasion she was offered treatment, but declined and so was not referred on (WITN3501007). On the last occasion she was seen in my clinic treatment was again discussed with her and on this occasion she accepted and was referred on to the specialist clinic (WITN3501008).
 - a. The patient states that she had been coming to my clinic since 2002. This is factually inaccurate. I first saw her in March 2005 (WITN3501003), having only taken up my post in November 2003. She was referred to me with gastrointestinal symptoms. There was no suggestion in the referral, or from her initial history or symptoms that she that there was a liver problem. As part of the standard work up for patients with bowel issues we performed a panel of routine bloods including liver function tests. These results showed that her liver function tests were persistently mildly abnormal. To further investigate this abnormality further, we had detected we arranged a battery of tests looking for multiple potential causes of persistently abnormal liver functions tests (known as a liver screen) which included checking for hepatitis C.
 - b. In relation to point 8 where the patient states that she feels she should have been told immediately that hepatitis C had been diagnosed I can confirm that this did indeed happen – ie she was told of the diagnosis at the next clinic visit she came to after the results of the liver screen became available (WITN3501005).
 - c. She says that she found the way I told her she had hepatitis C was "disgusting". My impression reading the other comments in point 9 is that she felt the way she was told was insensitive and disrespectful. This is difficult to answer because it is a subjective opinion, but I strongly refute that it is my clinical practice to treat patients in a such a way. As evidence for this, I would point to my appraisals which include unselected patient feedback where this has never been raised as an issue. I have also never had these types of criticisms fed back to me through the Hospital's complaints' process or informal feedback from colleagues.
 - d. The patient says that she was told "the good news is that you don't have cancer. The bad news is that you have hepatitis C" (paragraph 6 of witness statement). This is a gross oversimplification of a consultation where a lot of information was

imparted as mentioned above. The consultation, as shown by the contemporaneous record (WITN3501005), fell into two parts. The first was to go through the investigations she had had for her GI complaints (which was the problem she had initially been referred to me with) and which were normal. As she said in her own testimony she was worried about cancer and I would have been able to reassure her that this was not the case. Although I cannot recall the conversation, I have recorded in the notes that we had made the diagnosis of irritable bowel syndrome (which is a diagnosis of exclusion – ie it is made when other causes have been excluded) and that the treatment options would be symptomatic. This would have been discussed with her. The second issue was hepatitis C, which was a new diagnosis and, like her, one that I was not expecting. We had a discussion about hepatitis C. I have referred to it elsewhere in the report and so will not repeat here. Therefore, although the one liner that she records is actually factually accurate it reduces the full consultation that we had to absurd levels and does not reflect all the other things that are recorded as having been discussed. As can be seen there was a lot of information imparted in this consultation and it is well known that patients only retain a fraction of the information discussed, particularly if they receive information that they were not expecting. I may have tried to summarise the whole consultation using a formulation along these lines as I would have wanted her to know that her gastroenterology symptoms were not a cause for worry, but that her hepatitis C would require further intervention and follow up.

- e. It was not my routine practice to have a nurse sit in with me in clinic and I would normally only ask for a nurse if I felt that I should have a chaperone for either a difficult consultation or if I had to perform an intimate examination. I have not recorded that a nurse was present and, as mentioned, cannot recall the consultation from my memory.
- f. In Paragraph 10 of her witness statement she reports she was given no information about the risks of others being infected. This is incorrect as I have specifically recorded that I discussed the small risk of sexual transmission (WITN3501005).
- g. In paragraph 7 of her witness statement she says she was given no information by me voluntarily about the hepatitis C and was left alone to deal with the condition for many years. There are two parts to this criticism and my response is as follows. She was given really quite a lot of information about hepatitis C. I do accept that treatments were not discussed but, as mentioned, this would in part have been because I did not have all the information required to fully explain what treatment would entail and the likely success rates as genotype was not available at that stage (and it was not standard practice to ask for a genotype with a liver screen as most patients that have a liver screen performed do not have hepatitis C). I do accept that much of this information would not have been retained and that the comments that we did not have or use information sheets in the clinics for hepatitis C is a valid criticism. Leaflets were not available in our unit at the time. At the time we were a small unit and, I believe, understaffed with both consultants and specialist nurses compared to other local units in the city. My clinics were therefore general gastroenterology and not specialist liver clinics. I had also only been in post since November 2003 and so at this stage was still new in post. Over the next few years we argued for and achieved consultant and specialist nurse expansion which allowed us to set up more specialist clinics including hepatitis C clinics. The

practice now would be that a patient with newly diagnosed hepatitis C would be seen in a clinic with a specialist liver nurse who would be able to spend more time on the counselling. We now have written information available. I would add that the same criticism would have been applicable to patients with other conditions that came to my clinics at the time and that we have also worked to address these deficiencies.

10. Consent – as mentioned above we only checked her for hepatitis C as part of a liver screen because of abnormal liver function tests that were picked up during routine testing for the gastroenterology symptoms that she was referred to my clinic with (WITN3501004 and WITN3501005). A liver screen was and is standard investigation for patients with persistently abnormal liver function tests. With the exception of HIV testing at the time, I do not believe that it is or was standard procedure to seek specific consent for all individual blood tests that are performed in clinic. The patient states that she does not know if she was being tested for research purposes. I can state categorically that she was never put forward for or entered into any form of research for hepatitis C while under my care. I am not, and have never been, involved in any form of research into hepatitis C. Guidelines are quite clear that anyone being entered into research would have to give fully informed consent before taking part. I follow these guidelines if I am ever recruiting patients into research studies, and I have done so for patients with other conditions.
11. It is worth noting that the patient feels that the hepatitis C had a major impact on her quality of life. If I had not noted and acted on the abnormal liver function tests and made the diagnosis at that time, she may still be undiagnosed or been diagnosed at a much later date when she may have developed liver complications. If this had happened i.e. I had not picked up the hepatitis C diagnosis at that time, I would predict that that would be the criticism being levied against me by this patient and now being considered by this Inquiry.

Impact of hepatitis C

12. It is quite clear from the patient's testimony that she has had a great deal of difficulty coming to terms with her hepatitis C. I do acknowledge that due to the configuration of services at the time, we did not have access to psychological counselling from clinics which was, and remains, an issue which I believe is due to psychological counselling remaining a scarce resource within the NHS (and it is worth noting that this applies to patients with other conditions that I also look after). If I felt that patients needed or asked for counselling I would have advised her to go to her GP for referral to the community services and would have included this recommendation in my letter to the GP. I did not do this because I suspect the patient did not raise the issue of counselling with me.
13. In point 29 of her testimony she states that neither her GP nor I offered her counselling. It is clear, however, both from the patient's testimony and from the case notes that she did access counselling services. She approached her GP (as described in point 16). She also had counselling from the Brownlee as documented in a psychiatric letter from 2005 (WITN3501006). She also saw the psychiatry services after her overdose in 2005 (WITN3501006). At this time she described multiple stresses including family and work issues as well as concerns about her health issues. Furthermore, when she was at the

liver clinic she was seen by the specialist psychiatrist prior to starting treatment in 2009 (WITN3501013). I do believe that the services could have been better configured at that time to allow psychology input into clinics, but unfortunately this was not available then. Since the patient was seen by us we have reconfigured our services so that specialist nurses are in clinic and available to give information and counselling about the disease (although they are not trained psychologists). Despite this service not being available at the relevant time, the patient was able to access counselling support services early after diagnosis through other routes including the routes that we would have recommended if she had asked us for counselling.

14. In point 18 of her witness statement Ms Armour states that she continued under my care until at least 2009. This is factually incorrect. In fact, she was referred to Dr Goulding's clinic in November 2006 (WITN3501008). Dr Goulding is, as stated, a hepatologist and set up and ran a specialist clinic for patients with hepatitis C. When she was referred on she was discharged from my clinic and so I never saw her again in clinic nor was I involved in her care after this point. Therefore, she is factually mistaken to say that I saw her in 2009 and stated that I wasn't going to give her treatment because her body could not cope.
15. It is also factually inaccurate to say that 2009 was the first time that treatment was discussed with her as she reports in point 18 of her witness statement. I said in my clinic letter in October 2005 (WITN3501005) that I wanted further tests before deciding on treatment for the reasons discussed elsewhere. The junior doctor who saw her on my behalf in May 2006 has documented offering her treatment but that the patient herself felt that she was not up to it (WITN3501007). My Registrar saw her in November 2006 and discussed her case with me (WITN3501008). At that point we agreed to refer her onto the specialist clinic and liver nurses to discuss treatment with her agreement. Therefore, each time she was seen by my clinic post diagnosis treatment was considered and discussed with her. After this time, she was no longer under my care, but again it is clear from the case notes that treatment was discussed with her on numerous occasions. She had a consultation with our liver nurse specialist in January 2007 where she was given full verbal and written information about Hepatitis C (which was by now available) (WITN3501009). As mentioned in the clinical summary she was seen several times by Dr Goulding and treatment was considered, but not given, because of concerns about the patient's psychological issues and the impact treatment can have on this.
16. In point 18 of her witness statement she gives evidence that I saw her in 2009 and told her that her body wouldn't cope with treatment. As already mentioned this is factually incorrect as I was not involved with her care at that time as she was under a different consultant. From my review of the case notes and my understanding of treatments for hepatitis C I believe that the concerns of that team were not about her body's physical ability to cope with the treatment but rather her psychological ability to cope (WITN3501011, WITN3501012 and WITN3501013). She had known psychological issues and one of the well recognised side effects of interferon is depression and so the concern would have been the impact that the interferon treatment would have on her mental state. The team had to balance up the risks of leaving the hepatitis C untreated for a time (and this risk was felt to be small because the liver biopsy was reassuring) against the risks of psychological upset. Indeed, it is commented on a couple of times in clinic letters that the patient was in agreement with

holding off treatment (letters from my junior doctor in May 2006 and from Dr Goulding in January 2008, WITN3501007 and WITN3501011).

17. In the patient's testimony she gives a detailed and moving account of the negative impact the treatment had on her physical and mental wellbeing. This does reinforce the finely balanced and difficult nature of decision as to whether to give her treatment at that time that are discussed in the point above.
18. She also states that she received no treatment to help her deal with the effects of the treatment. Again whilst I was not involved with her care at this stage, I do know that the nurse specialists were in regular contact with all patients under treatment for hepatitis C. In relation to this particular patient, there are copious nurse entries in the case notes at the time showing that they were closely involved in supervising her treatment and discussing this with her. If more information about this degree of input is required, I would suggest the Inquiry speak with the liver nurses and the consultants looking after her at that time (by this time Dr Datta had taken over from Dr Goulding who had moved to another position elsewhere).
19. There is a large amount of moving testimony from Ms Armour about the impact the diagnosis of hepatitis C had on her life. It is clear that she had difficulty coping with the diagnosis and feels she has been or would be stigmatised by it. I do not feel I can add anything to this except to comment that there seems to have been a vicious cycle develop between her psychological state; her perceptions about her hepatitis C; her family life and her social life. Her perceptions of her hepatitis C treatment seems to be viewed in a very negative light.
20. In point 22 of her witness statement the patient states that I seemed to focus only on the liver and did not tell her that hepatitis C could affect her whole body. I wish to make two points here. Firstly, I was not involved with her care at the time and so did not tell her this myself. Secondly, I am not sure that the statement that hepatitis C can cause life threatening issues affecting the whole body is true. Hepatitis C affects the liver (and I accept can spill over and cause symptoms elsewhere) but the life threatening complications related to liver failure or cancer and treatment is aimed at getting rid of the infection from the liver. I therefore think it reasonable that the liver team focused on the liver. This comment is not, however, meant to lessen the psychological impacts that clearly very negatively impacted Ms Armour's quality of life and have been discussed elsewhere
21. In point 23 of the witness statement she refers to a letter in the case notes that inaccurately ascribes the routine of infection as being from intra-venous drug abuse (WITN2076008). This letter was written by my registrar at the time he referred her on to the specialist clinic. As mentioned elsewhere I had discussed the possible route of infection with the patient at the first clinical consultation after we had made the diagnosis and have recorded in the letter that I felt that it was likely to have been contracted through infected blood and I have documented clearly in the medical records that she never injected drugs. She also reported that she thought her partner may have injected drugs in the past, but I have stated that sexual transmission was less likely. This letter therefore, in my opinion, is factually incorrect.
22. I was not aware of this letter at the time because I was not involved with the patients

care after the letter was written and would have had no reason to review the case notes. I only became aware of it when the patient contacted me in 2018 to point out this factual inaccuracy. She asked me to remove this letter from the case notes. I sought advice from my clinical director as to whether I could do this and the advice that I was given was that, because the case notes are a medicolegal document I should not do so. I did, however, dictate another letter stating clearly that the 2006 letter was factually inaccurate and that we did not believe she was or had contracted the infection from intravenous drug use and let the patient know that I had done so (WITN2076006).

23. The patient comments that the nurse, when giving her some needles for interferon treatment, asked her if she knew what to do with them and made an assumption that they had assumed that she was a drug addict (in point 23 of her witness statement). I genuinely do not believe that this assumption would have crossed the nurse's mind. The nurses are exceptionally professional in their manner and would not make that assumption about any patient. By the nature of their work they deal with people infected by the IV drug route. From my experience the nurses do not have any negative preconceptions of this patient group or treat them in any way differently from any other group of patients. I am sure that the nurse wanted to make sure she was happy that she knew how to give herself the interferon.

Section 3: Other Issues

Service Configuration

24. It is important for the Inquiry to note that the treatment options and recommendations for hepatitis C have changed hugely over the years. Currently hepatitis C can be cured in more than 95% of cases with an 8 week course of well tolerated oral medication. Back in 2005 the standard treatment involved 6 months to a year of interferon treatment given by injection along with ribavirin given orally. It is also relevant to comment that treatments and response rates do vary with genotype. The two commonest genotypes in this country are 1 and 3. Genotype 3 is much more responsive to interferon treatment with higher response rates and shorter durations of treatment required (usually 24 weeks). Genotype 1 has a lower response rates (typical 50% of patients treated cleared their virus) and needed to be given for longer (usually 48 weeks). Side effects to interferon were common and frequently the treatment was poorly tolerated. Furthermore, there was a limited number of patients that could be started at any one time due to the number of patients that the specialist nurses could support through treatment. Finally, there was an awareness that better treatments were coming. What this meant was that some patients without evidence of significant liver disease were recommended to defer treatment in the hope that better treatments may become available. These points are relevant to the management decisions taken for the patient we are discussing.
25. In response to some of the concerns raised by the patient, I should point out that services and resources available were limited. By way of example, when I started there were two gastroenterologists including myself to manage the whole of the gastroenterology service which compares to the 5 that were in post when the Victoria was merged into the Queen Elizabeth University Hospital. Because of this, at the time I was very much a general gastroenterologist and not a liver specialist. Subsequently, as consultant numbers have increased we have developed sub-specialist clinics that have

appropriate nurse specialist input. I have become more a luminal rather than a liver specialist. This is relevant because my clinics at the time were set up as general clinics and had no specialist nurse input directly into them – and indeed M Armour was originally referred with gastroenterology rather than liver problems (WITN3501003).

26. Another resource point is that we had no direct input from clinical psychology into our clinics. There is no clinical psychologist who will take rapid access referrals from us. This is an ongoing issue and applies to many different patient groups. However, if I do have a patient who I feel needs psychological input I will ask the GP to make the referral to the community services.

Summary

27. Ms Armour gives a moving account of the difficulties of being diagnosed with hepatitis C and the difficulties that this can cause. She also describes the impact that the treatments for hepatitis C that were available at the time can have. I have every sympathy with the problems she has encountered. She also does highlight some issues that we had with the configuration of services at the time and particularly around the lack of sub-specialty clinics. I do feel, however, that we made a positive diagnosis of hepatitis C and referred her on to the appropriate clinic for consideration of treatment in a timely manner. I also believe that during this period my colleagues and I were developing more specialist clinics and pathways such as the ones that Ms Armour ultimately went through. Lastly Ms Armour attributes my name to many clinic appointments, decisions and treatment decisions that I was not in fact involved in as by this time she was being looked after in the specialist clinics.

Statement of Truth

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

Signed GRO-C

Dated 10 | 11 | 2020

Table of exhibits:

Date	Notes/ Description	Exhibit number
	Case note review timeline	WITN3501002
	Letter from Dr Boulton Jones dated 10 th March 2005	WITN3501003
	Letter from Dr Boulton Jones dated 12 th July 2005	WITN3501004

	Letter from Dr Boulton Jones dated 13 th October 2005	WITN3501005
	Letter from Carolann McLaughlin dated 21 st December 2005	WITN3501006
	Letter from Dr Ruth Blair dated 17 th May 2006	WITN3501007
	Letter from Dr Gaya dated 9 th November 2006	WITN3501008
	Letter from Dr Christine Munro dated 3 rd January 2007	WITN3501009
	Letter from Carol Goulding dated 13 th April 2007	WITN3501010
	Letter dated 21 st January 2008	WITN3501011
	Letter from Diarmid Sutherland dated 9 th October 2009	WITN3501012
	Letter from Dr Wong dated 10 th December 2009	WITN3501013