Witness Name: Katie Cusick Statement No: WITN7273001 Exhibits: WITN7273002-WITN7273006 Dated: 14 November 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KATIE CUSICK

I, KATIE CUSICK, Head of Acute Programmes within the Specialised Commissioning Directorate of NHS England, will say as follows:-

Section 1: Introduction

- 1. My name is Katie Louise Cusick. I am based at NHS England at Wellington House, 133-155 Waterloo Road, London SE1 8UG. My date of birth is **GRO-C** 1978.
- 2. I am Head of Acute Programmes in the National Specialised Commissioning Directorate at NHS England. The work of the Directorate was described in the first witness statement of Claire Foreman dated 14 February 2020. The specialised services commissioned by NHS England are grouped into six national programmes of care (NPoC) which coordinate work across a group of services. I oversee the work of the commissioning teams within four of the six NPoCs, which includes the Blood and Infection and Internal Medicine Programmes of Care. The Internal Medicine NPoC includes the Hepatobiliary and Pancreas Clinical Reference Group (CRG). CRGs consist of clinicians, commissioners, public health experts, patient and public voice (PPV) representatives and professional associations which offer specific knowledge and expertise to advise NHS England on the best ways that specialised services should be provided.

- 3. I have not been a member, past or present, of any committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference.
- I make this statement in response to a Rule 9 request from the Infected Blood Inquiry ("IBI") on 16th September 2022.
- 5. In producing this statement on behalf of NHS England ("NHSE"), I have sought generic advice and information from clinical and NHSE colleagues without disclosing the content of the Rule 9 and have sought specific advice relating to the Rule 9 from NHSE's Information and Intelligence team, the outcome of which is detailed below.

Section 2: Ongoing Liver Care

In the statement provided to the Inquiry by Claire Foreman [WITN3953053], Ms Foreman set out the arrangements for follow up for a patient with cirrhosis. The Inquiry has received evidence that access varies geographically. Please comment on this and provide any updated information on this issue.

- 6. I am not aware of any specific work undertaken by NHS England relating to geographical variation in follow-up care for patients with cirrhosis (as opposed to follow-up care for patients with all types of liver disease). Follow-up of patients with cirrhosis may occur both in primary and secondary care. Although there will always be some warranted variation in service models, depending on the demographics and prevalence of liver disease in each locality, all patients should receive the same high quality of care, access to expertise, procedures, treatments, and outcomes irrespective of where they live.
- 7. I am aware of the following information that may be of relevance to this request:
 - A document produced on behalf of the NHS England Specialised Commissioning Hepatobiliary and Pancreas Clinical Reference Group (CRG) titled *Health Inequalities Stocktake – Liver Disease* (WITN7273002) ("the Report"). The Report in turn draws on the *Liver Disease Profile Data*

and the 2nd Atlas of variation in risk factors and healthcare for liver disease in England mentioned below.

- Liver Disease Profile Data published by the Office for Health Inequalities and Disparities.¹ The liver disease profiles provide an interactive data tool with data on liver disease and risk factors at different level of English geography and selected indicators by sex, age, and deprivation.
- The 2nd Atlas of variation in risk factors and healthcare for liver disease in England² published by the Office for Health Inequalities and Disparities. The Atlases of Variation help to identify unwarranted variation and assess the value that healthcare provides to both populations and individuals.
- Secondary Uses Service (SUS) data held within the NHS England National Commissioning Data Repository relating to first admissions to hospital where a diagnosis of cirrhosis was recorded and associated follow-up activity within specialist services. The Secondary Uses Service is the single, comprehensive repository for healthcare data in England which enables a range of reporting and analyses to support the NHS in the delivery of healthcare services.
- Ongoing National Institute for Health and Care Research (NIHR) research relating to the Management of patients with chronic liver disease admitted to hospital as an emergency.
- I comment further on these documents below in this statement.

Health Inequalities Stocktake – Liver Disease document

8. The final draft document *Health Inequalities Stocktake – Liver Disease* was presented to and approved by the Hepatobiliary and Pancreas CRG on 14th June 2022. The Report was prepared by Sarah Morgan, Public Health Registrar, with oversight from Angeline Walker, Public Health Consultant, as part of their role providing Public Health expertise to the national Hepatobiliary and Pancreas Clinical Reference Group (CRG).

¹ Available at Liver Disease Profiles – OHID (https://fingertips.phe.org.uk/profile/liver-disease)

² Available at Atlas of Variation - OHID (https://fingertips.phe.org.uk/profile/atlas-of-variation)

- 9. The document was intended to provide the CRG with an overview of sub-populations adversely impacted by liver disease and where consideration could be given to modify services to address inequalities. It does not represent an official policy position of the CRG nor NHS England, and the document is not focussed on specific types of liver disease such as cirrhosis (in fact, cirrhosis is only mentioned specifically once). It also takes a population health focus on liver disease as a whole, rather than focussing specifically on specialist liver services. However, it does contain some relevant content as referred to below, in terms of the position relating to liver disease generally even if the application to cirrhosis specifically is limited for reasons of the generality of the information,
- 10. The document draws on national sources of data and evidence in relation to liver disease and inequalities and explores a number of factors that can impact on health inequalities for patients with liver disease, including: distribution of health; causes of inequalities and the potential effects of specialist liver services.
- 11. Within the *Causes of inequalities* section, the role of services (quality, access and take-up), service configuration and service quality are considered. Access to follow-up care for patients with cirrhosis is not specifically considered but the information and conclusions relating to service access, configuration and take-up for liver services generally are likely to be of relevance.
- 12. One of the *Key Messages* included within the document is that service provision may not equitably match the burden of liver disease or its risk factors and this includes a geographical mismatch between the location of services and greatest need. It also notes that there are other factors that hinder access beyond geographical location such as multiple health, social and economic issues.
- 13. The *Geographic* section of the report includes a regional comparison against the England average for key liver disease indicators taken from the Office for Health Inequalities and Disparities Liver Disease Profiles. The report states that:

'There are clear regional differences in the burden of preventable deaths from liver disease. This points to inequalities faced by populations in the underlying determinants of health, risk factors and access to prevention and treatment in respect to liver disease and, importantly, that more could be done to prevent this variation.'

- 14. Variation highlighted includes:
 - Under 75 mortality rates from liver disease considered preventable (Figure 7 within the Report) shows that, pre pandemic, the North West, North East, Yorkshire and Humber and West Midlands all had significantly higher levels of preventable mortality from liver disease than the England average;
 - In general terms, across key indicators, the burden of liver disease is highest in the North of England (Figure 8 within the Report).
 - When comparing levels of deprivation and burden across regions there is not exact alignment (Figure 10 within the Report). This suggests regions have specific combinations of risk factors, incidence and prevalence which must be considered locally, alongside service configuration, service quality and the wider determents of health.
- 15. The Report acknowledges that the pattern of health inequality is driven by a number of factors, which include:
 - The prevalence of the underlying major risk factors of obesity, alcohol, Hepatitis B and Hepatitis C. In themselves these risk factors are influenced by socio-economic issues, such as deprivation and by health behaviours including drug and alcohol use.
 - Other health behaviours connected with accessing health care, and following prevention or treatment advice
 - Health service factors including
 - o the level of investment in preventative measures
 - the configuration of services
 - o quality of services
 - \circ the timing of diagnosis (patient and health service factors)
 - o degree of adherence to clinical guidance
 - Wider determinants
 - The clear link between deprivation and risk factors for liver disease, and morbidity and mortality from liver diseases.

- Also influential, as a wider determinant, will be policy and operational decisions at all levels within government and across NHS and other services around alcohol, food, substance misuse and treatment and support for vulnerable groups.
- 16. The Service Configuration section considers information regarding the geographical availability and level of investment in liver services compared with need. It shows liver service locations mapped against liver disease admissions and liver disease mortality rates taken from the 2nd Atlas of variation in risk factors and healthcare for liver disease in England. (Figure 12 within the Report). The Report states:

'There is geographical variation in healthcare provision, access, and outcomes. Where this is not explained by the underlying burden of risk factors or liver disease this is unwarranted variation.

Distance for individuals to travel to services, along with the match of burden of risk factors and disease to service location and availability, are both important to tackle health inequalities.

Mapping for the 2nd Atlas of variation in risk factors and healthcare for liver disease in England, published in 2017, showed the location of different levels of liver disease services in relation to background levels of liver disease admissions and mortality (Figure 12). This mapping suggested service location was not always aligned with the need for greater provision of liver services in deprived areas with the highest rates of liver disease morbidity and mortality. Updated mapping would be beneficial to look at current patterns.'

17. There is also a summary (Figure 13 within the Report) of the results of the 2020 British Liver Trust survey into the availability of clinical community liver service pathways in the UK (**WITN7273003**). This shows variation in the availability of pathways for either the interpretation of liver blood tests or liver disease more generally. The aim of the study was to assess the levels of engagement with chronic liver disease management among primary care commissioning bodies and health authorities across the UK. The Report indicates the areas where there is no pathway for either the interpretation of liver blood tests or liver disease more generally; a pathway for the interpretation of liver blood tests only or pathways in development; pathways for both; and areas which did not respond to the survey.

- 18. The Report notes that the 2017 Atlas of Variation also reported variation in expenditure across Clinical Commissioning Groups (CCGs) in England for the hepatobiliary programme ranged from £2,276 to £20,372 per 1,000 population (9-fold difference). The variation across CCGs was 3-fold for non-elective admissions and 5-fold for elective care. Figure 15 within the Report shows this variation in expenditure across the country. It should be noted however that this data does not reflect follow-up care for patients with cirrhosis delivered by specialist liver services, which are currently commissioned and funded nationally. This demonstrates the limitations in applying the general data to the specific issue of cirrhosis as I have referred to above.
- 19. The CRG *Health Inequalities Stocktake Liver Disease* report also states that there is 2017 data demonstrating considerable variation in levels of whole time equivalent (WTE) hepatology staffing and the distribution of staff across providers, with almost two-thirds (64%) either based within specialist regional centres or transplant centres.
- 20. This, combined with other factors such as funding, location of services and availability of community pathways could impact on access to services including follow-up care. However, as mentioned previously, the CRG report is not specific to patients with cirrhosis or their follow-up care so caution needs to be taken when drawing conclusions from the data referenced.

<u>Secondary Uses Service data held within the NHS England National Commissioning</u> <u>Data Repository</u>

- 21.NHS England has access to Secondary Uses Service (SUS) data relating to followup activity for patients admitted to hospital between 2019 and 2022 with a diagnosis of cirrhosis recorded.
- 22. Table A below shows at an England level, the average time between the first admission to hospital where a diagnosis of cirrhosis was recorded and the first follow up activity recorded in either an hepatobiliary inpatient setting, an inpatient admission where cirrhosis was recorded, or a hepatobiliary outpatient setting. For example, of the patients first admitted to hospital with a diagnosis of cirrhosis recorded:

- 35% of admitted patients had a first follow-up in either an inpatient or outpatient setting within 6 months of the first admission, with an average time between admission and follow-up of 49 days.
- 9% of admitted patients had a first follow-up in either an inpatient or outpatient setting 6 months or more after the first admission, with an average time between admission and follow-up of 424 days.
- 56% of admitted patients had no record of a follow-up in either an inpatient or outpatient setting following their first admission.
- 23. Table B shows the same data broken down by the seven NHS England Regional geographies.
 - For the 35% of admitted patients who had a first follow-up in either an inpatient or outpatient setting within 6 months of the first admission, the average time between admission and follow up ranged from 47 days in North East and Yorkshire and 58 days in the North West.
 - For the 9% of admitted patients who had a first follow-up in either an inpatient or outpatient setting 6 months or more after the first admission, the average time between admission and follow-up ranged from 328 days in North East and Yorkshire and 506 days in the East of England.

Table A – England data

		First FU <	6months?							No FU	
		Yes			No						
Year initial admission	First FU setting	Patients count	% patients	Average time between initial admission and FU (days)	Patients count	% patients	Average time between initial admission and FU (days)	FU Patients count	Average time between initial admission and FU (days)	Patients	% patients
2019		3,481	38%	49	1,290	14%	510	4,771	173	4,288	47%
	Inpatients	2,375		47	918		512	3,293	177	0	
	Outpatients	1,106		52	372		504	1,478	166	0	
2020		2,959	35%	50	987	12%	400	3,946	138	4,451	53%
	Inpatients	2,013		50	716		404	2,729	143	0	
	Outpatients	946		52	271		390	1,217	127	0	
2021		3,327	35%	51	593	6%	287	3,920	87	5,492	58%
	Inpatients	2,251		50	419		289	2,670	87	0	
	Outpatients	1,076		55	174		282	1,250	86	0	
2022		1,721	30%	40	28	0%	199	1,749	43	4,010	70%
	Inpatients	1,089		39	18		198	1,107	41	0	
	Outpatients	632		43	10		201	642	46	0	
Grand Total		11,488	35%	49	2,898	9%	424	14,386	124	18,241	56%

		First FU <	5months?							No FU	
		Yes			No						
Region_provider	First FU setting	Patients	% patients	Average time between initial admission and FU (days)	Patients count	% patients	Average time between initial admission and FU (days)	Total Patients count	Average time between initial admission and FU (days)	Patients	% patients
East of England		523	18%	52	225	8%	506	748	188	2,113	74%
	Inpatients	204		47	132		578	336	255		
	Outpatients	319		55	93		405	412	134		
London		1,003	29%	50	277	8%	445	1,280	135	2,127	62%
	Inpatients	317		45	126		440	443	158		
	Outpatients	686		52	151		449	837	124		
Midlands		850	19%	55	295	7%	477	1,145	163	3,336	74%
	Inpatients	409		55	172		512	581	190		
	Outpatients	441		55	123		428	564	136		
North East and Yo	North East and Yorkshire		60%	47	1,553	13%	382	8,918	105	3,427	28%
	Inpatients	5,987		47	1,330		381	7,317	107		
	Outpatients	1,378		47	223		385	1,601	94		
North West		425	12%	58	152	4%	485	577	171	2,842	83%
	Inpatients	257		57	108		536	365	198		
	Outpatients	168		60	44		360	212	123		
South East		669	21%	53	186	6%	445	855	138	2,405	74%
	Inpatients	278		49	110		478	388	171		
	Outpatients	391		55	76		397	467	111		
South West		651	23%	49	207	7%	483	858	154	1,965	70%
	Inpatients	274		45	92		504	366	160		
	Outpatients	377		52	115		466	492	149		
Grand Total		11,486	35%	49	2,895	9%	424	14,381	124	18,215	56%

Table B – England data by NHS England Region

Source: SUS data held within the NHSE National Commissioning Data Repository

24. The data shown above should be treated with caution as:

- Using secondary care data, the date of first diagnosis cannot be pinpointed, rather as a proxy we can use the first admission where a diagnosis of cirrhosis was recorded.
- Follow-up activity has been assumed where either:
 - a) the patient is subsequently admitted either to Hepatobiliary specialties or where cirrhosis was recorded; or
 - b) the patient attended Hepatobiliary specialties as an outpatient.
- In either case the level of detail does not illustrate whether the full complement of follow up activities (full blood count, liver function test, clotting assessment, ultrasound scan, alfa fetoprotein assessment) were performed.

Primary Care Data

25. There may be additional data available relating to follow-up care for patients with cirrhosis within primary care but it has not been possible to analyse the data to confirm this within the timescales of the Rule 9 request. Again, it is likely that there will be limitations to being able to draw definitive conclusions from this data.

National Institute for Health and Care Research (NIHR) research

26. The NIHR funded research relating to the Management of patients with chronic liver disease admitted to hospital as an emergency seeks to provide a better understanding of three interacting complexities: the complexity of chronic liver disease (CLD) and its treatment options, the complexity of the life situation of many CLD patients, and the complexity of the healthcare system. The project's overall aim is to improve the national organisation and delivery of care for acutely ill people with CLD. It seeks to establish determinants of care processes and outcomes, recognising that these may be characteristics of treatments at patient level or characteristics of service provision at the provider level. It is a two-year research

project due to complete in October 2024. Further information is available on the NIHR website.

Section 3 – Addressing variation in access

- 27.1 now turn to the question as to what action NHS England is taking to address inequalities in accessing treatment for patients with cirrhosis.
- 28. The NHS 2021/22 priorities and operational planning guidance (**WITN7273004**) and the NHS 2021/22 priorities and operational planning guidance: Implementation guidance (**WITN7273005**) set out five priority areas for tackling health inequalities that systems were asked to give particular focus to:
 - Priority 1: Restore NHS services inclusively
 - Priority 2: Mitigate against digital exclusion
 - Priority 3: Ensure datasets are complete and timely
 - Priority 4: Accelerate preventative programmes that proactively engage those at greatest risk of poor health outcomes
 - Priority 5: Strengthen leadership and accountability
- 29. One of the priorities is to mitigate against digital exclusion, ensuring that everyone can access health services whichever mode or channel they use. NHS England will be publishing a framework for NHS action on digital inclusion by May 2023, and will develop further resources to support systems in practical action.
- 30. The *NHS* 2022/23 priorities and operational planning guidance (**WITN7273006**) reinforced the commitment to addressing health inequalities stating:

'Across all these areas we will maintain our focus on preventing ill-health and tackling health inequalities by redoubling our efforts on the five priority areas for tackling health priorities and operational planning guidance inequalities set out in guidance in March 2021. ICSs will take a lead role in tackling health inequalities, building on the Core20PLUS5 approach introduced in 2021/22 to support the reduction of health inequalities experienced by adults, children and young people, at both the national and system level.

Improved data collection and reporting will drive a better understanding of local health inequalities in access to, experience of and outcomes from healthcare services, by informing the development of action plans to narrow the health inequalities gap. ICBs, once established, and trust board performance packs are therefore expected to be disaggregated by deprivation and ethnicity.'

31.NHS England's and NHS Improvement's Equality Objectives for 2022/23 and 2023/24 were published in March 2022³. Updated equality objective 5 (Patient access and communication) focusses on addressing issues in patient access and communication:

Updated equality objective 5 [Patient access and communication]

To improve access and reduce communication barriers experienced by individuals and groups of people of all ages, by reference to protected characteristics, who need NHS services.

Targets 2022/23

- 1. To complete the review of the Accessible Information Standard (AIS) and publish the revised standard together with guidance to support compliance.
- 2. To ensure that the expectations placed on key stakeholders are clear and processes are in place to assure compliance with the AIS at a local and provider level.
- 3. To ensure relevant NHS England and NHS Improvement policies use language that is inclusive of LGBT+ people.
- 32. In respect of the specific group of patients with cirrhosis, I understand that NHS England's Hepatitis C (HCV) programme has several interventions that aim to tackle inequalities for patients with cirrhosis. These include:
 - a) Supporting access and engagement for harder to reach groups through a community van programme, services are actively going out and finding people with viral hepatitis – testing them, and where positive, commencing

³ Available on NHS England's website at https://www.england.nhs.uk/about/equality/objectives-for-22-23-and-23-24/

treatment and fibro scanning (scanning of the liver) for cirrhosis and linking them to ongoing liver surveillance.

- b) Increasing Liver Surveillance the programme has worked with NHS England's Cancer Directorate to utilise and extend its pre-existing community van programme (see above) to take testing, diagnosis and treatment for HCV out into the community to carry out active patient-finding. As a development of this work, 11 of the Hepatitis C Operational Delivery Networks now provide additional fibro scanning, as well as drug services and primary care in the community, taking services to where people are and achieving better engagement of those with cirrhosis into annual surveillance - thereby reducing or diagnosing earlier incidence of end stage liver disease (ESLD), fatty liver or hepatocellular carcinoma.
- c) Lived experience central to the patient-finding and treatment model is the commissioning of a national programme of 'experts by experience' (Peers) people who have had Hepatitis C, been through treatment and can much better engage reluctant individuals (and those that feel excluded from or judged by health services) into diagnosis and supported treatment. National research from the start of the programme where some clinical teams had Peers and others didn't, indicated that there was a 12% increase in engagement in those services that did have Peers.
- d) Targeted programmes where the HCV programme has identified specific communities with an increased risk but which are under-represented in services / treatment, it has developed specific programmes to attract and find these patients. Recent examples include targeted work with homeless populations; South Asian communities; migrant communities; Eastern European communities; Gypsy Roma and Traveller communities; and Men who have Sex with Men (MSM). A forthcoming programme in Primary Care will include people who may be unaware of the previous risk of acquiring Hepatitis C, including revisiting the population who may have been infected by blood or blood products.

All of the people that are identified through these interventions are screened for cirrhosis as a part of their preparation for Direct Acting Antiviral treatment (with the

expectation that treatment commences within 4 weeks of diagnosis), and subsequent action taken or linkage to surveillance initiated.

33. In summary, NHS England continues to prioritise the tackling of health inequalities and there are specific initiatives being taken forward by the HCV programme that aim to address health inequalities for patients with cirrhosis.

Statement of Truth

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

	GRU-C
Signed	
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Dated: 14th November 2022