Witness Name: Julie Stanborough
Statement No: WITN7688001
Exhibits: WITN7688002-7688017
Dated: 06 June 2023

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JULIE STANBOROUGH

I provide this statement on behalf of the Office for National Statistics in response to a request under Rule 9(1) and (2) of the Inquiry Rules 2006 dated 13 April 2023.

I, Julie Stanborough, will say as follows: -

Section 1: **Introduction**

1. I am Julie Stanborough, Deputy Director of Health Analysis and Life Events, Office for National Statistics, 2 Marsham Street, London, SW1P 4DF. My date of birth is GRO-C GRO-C 1976 and I hold a Diploma in Official Statistics.

Section 2: **Statistics and Monitoring Cause of Death on Death Certificates**

2. The Office for National Statistics (ONS) and its predecessor organisations noted at paragraph 4 have been responsible for publishing statistics on cause of death as recorded on death certificates over the course of the relevant period (1970-present).

3. Throughout this period, the process of death registration, which involves transcribing the causes of death on the Medical Certificate of Cause of Death (MCCD) into the official register, has been carried out by local registration officials acting under the authority of the Registrar General.

4. The processing of these records into statistical outputs was carried out by the Office for Population Censuses and Surveys (OPCS) from 1970 to 1996 and thereafter by

the ONS (which included the former OPCS). The Statistics and Registration Service Act 2007 (SRSA) replaced the legal entity the ONS with the Statistics Board, known as the UK Statistics Authority. The ONS operates as the executive arm of the UK Statistics Authority. I am only able to respond to the matters raised in the Rule 9 request in relation to the work of the ONS.

5. The ONS produces and publishes statistics that serve the public good. These include an annual count of the number of deaths by various characteristics in England and Wales and information on the number of deaths registered in England and Wales over time and by cause at an aggregate level.

6. More detailed data and analyses (including microdata requests and access to individual level data) is made available to other government departments (such as the Department of Health and Social Care (DHSC) and its agencies) and medical researchers in academia. This data can be used to monitor diseases and infections that contribute to mortality; however, a cause would only be mentioned on the death certificate if it contributed to the chain of events that led to death. For this reason, the data is not used to monitor the prevalence of a disease or infection as it would only be noted in cases where it contributed to the death. For example, if someone had diabetes and it did not contribute to their death then diabetes would not be mentioned on the death certificate.

7. The ONS's Deaths Registered Weekly in England and Wales release [**WITN7688002**] can be used for surveillance and is published 11 days after the end of the week of interest (for example, deaths registered to week ending 12 May 2023 would be published on 23 May 2023, providing there were no bank holidays). This looks at high-level numbers of deaths and provides a limited number of breakdowns, including a division between deaths due to respiratory diseases and others.

8. Reporting cases or deaths involving infectious diseases is generally the responsibility of the doctor who treated the patient or certified the death. There is a list of notifiable diseases that need to be reported to the UKHSA (and its predecessors). A list of diseases and how to report them can be found on the Gov.uk website, this includes acute infectious hepatitis but not HIV/AIDS.

9. The systems used by the ONS are not designed to identify short-term trends in particular infectious diseases or to monitor trends in real time (for example, by date of occurrence). In the past analysis has mostly been carried out on an annual basis. However, to support the better understanding of the Covid-19 pandemic, the ONS

began publishing more data. For example, the deaths registered weekly in England and Wales publication was expanded to include weekly numbers of deaths due to, and involving, Covid-19.

10. In addition, the amount of information and breakdowns provided were increased to inform the public and support urgent decision-making about prevention and treatment by government and NHS bodies at all levels. This included expanding our deaths registered weekly in England and Wales release to include breakdowns of deaths involving Covid-19 by sex and age, as well as more detailed analyses of deaths involving Covid-19 in monthly and ad-hoc publications.

11. The pandemic was an exceptional situation. Generally, government agencies to whom we supply extracts of death records apply their own specialist expertise and systems to use the data for surveillance of specific diseases.

12. The UK Health Security Agency (UKHSA) and previously Public Health England (PHE) monitor infections and diseases as part of their notifiable diseases reports [**WITN7688003**] which are published online. The details, format and frequency of data about deaths provided by the ONS to the UKHSA (formerly PHE), NHS bodies in England, and corresponding agencies of the Welsh Government, have varied over time with the development of IT and changing user requirements. For example, the ONS currently sends weekly extracts of death records to UKHSA and Public Health Wales which they analyse for their surveillance purposes.

13. It has not been possible to identify in searches of ONS records any reporting of concerns to any government bodies or departments on the subject of HIV/AIDS and hepatitis.

Section 3: **Medical Certificates for Cause of Death (MCCD)**

14. The information that the ONS gathers on cause of death comes from the MCCD (except for coroner cases) via the death registration. The MCCD is normally completed by a doctor who was in contact with the patient during their final illness. The informant was (until the Covid-19 pandemic) provided with a physical copy of the MCCD to take to the local registration office. The local registrar, after making certain checks, exactly transcribes the cause of death information from the MCCD to the official death register. The registrar also collects some information directly from the registration informant (usually the next of kin) for example the deceased's full name, age, sex and last known

address to record in the register. The combined information is sent to the ONS for statistical purposes. The document often referred to as the 'death certificate' is a certified extract of the death register. There has been no significant change to this process during the relevant period (1970-present), except that it has over time moved from a manual to a digital system.

15. A death must always be registered, but since it may be certified by a doctor or by a coroner depending on the circumstances, mortality statistics effectively come from a combination of four sources:

    a. Details supplied by the doctor when certifying a death, on the MCCD, as described above. For example, whether the body was seen after death, cause of death, when the deceased was last seen alive and whether a post-mortem was carried out.

    b. Details supplied by the registration informant to the registrar, as described above. For example, occupation of deceased, sex, last known address, date and place of birth, marital status, date of death and place of death.

    c. Details supplied by a coroner to the registrar following investigation, for example, cause of death (following post-mortem), place of accident (following inquest); in the case of deaths certified after inquest, the coroner supplies the registrar with all the particulars that would otherwise have been supplied by the registration informant.

    d. Details derived from information supplied by one of the other three sources, for example, age of deceased is derived from date of birth and coded cause of death.

16. When a death is certified by a doctor, the content of the MCCD is transcribed exactly into the official death register. Therefore, as far as the cause of death is concerned, there is normally no difference between the original MCCD and the 'death certificate' extracted from the register. When a death is certified by a coroner, the coroner determines what cause of death to certify in line with the findings of their investigation. The cause of death provided by the coroner is recorded in the official death register. Since the proceedings of a coroner's inquest and findings can be lengthy, not all the information considered by the coroner will necessarily be recorded at the point of registration.

17. Information on how to complete a death certificate [**WITN7688004**] is not currently provided by the ONS. The ONS has previously worked with the General Register Office (GRO) to produce guidance and training materials, however following the Coroners and Justice Act 2009 this responsibility now sits with the DHSC and the Royal College of Pathologists.

18. The ONS published information on how it processes and codes mortality data in the exhibited Quality and Methodology Information (QMI) [**WITN7688005**] and User Guide [**WITN7688006**]. The processes followed are based on the recommendations of the World Health Organisation (WHO) and the codes and coding rules contained in the International Classification of Diseases (ICD).

19. Until 1992 the process of coding the text of the causes of death into the ICD was carried out manually by trained coders. Since 1993 an automated system has been used to carry out simpler coding operations, whilst trained coders complete more complex cases (including infant deaths and coroner's cases). Since 2022 the coding software the ONS have used is known as IRIS version 5.8, which operates based on internationally agreed decision tables that reflect the most recent version of ICD-10 (the current coding system) and automatically codes over 80% of death registrations. This system converts specific terms from the MCCD, which we receive via the death registration, to ICD codes. These are then used with selection and modification rules to assign the underlying cause of death.

20. Part I of the MCCD (obtained through the death registration) consists of three lines, referred to as lines Ia, Ib and Ic. These begin at the 'top' (line Ia) with the condition that immediately led to death, followed when relevant by the conditions that led to the condition in line Ia. Thus, if all three lines are completed with one condition per line, we can say that line Ic led to line Ib which in turn led to line Ia (or that line Ia was due to line Ib which in turn was due to line Ic). All the conditions written in Part I must make up a sequence of events or chain of medical causation. Part II of the MCCD allows the certifier to note, in addition to Part I, any conditions which contributed to the death but do not form part of the direct sequence of events. For example, a pre-existing chronic illness might have made the deceased more vulnerable to the influence of the condition that actually led to death, and so would be noted in Part II.

21. The selection of the underlying cause of death is generally made from the condition or conditions entered in the lowest completed line of Part I of the MCCD. If the death certificate has not been completed correctly, for example if there is more than one cause on a single line with no indication of sequence, or the conditions entered are not

an acceptable causal sequence, it becomes necessary to apply one or more of the selection rules in the ICD-10.

22. Even where the certificate has been completed properly, there are conditions, combinations, or circumstances when modification rules have to be applied to select the correct underlying cause of death. For example, on some death certificates when two or more causes are listed and then linked together, these may point to another cause (not mentioned directly on the certificate) as underlying (an inferred underlying cause). This happens in a small minority of cases (less than 0.01% of deaths) and most commonly relate to diseases of the circulatory system and certain combinations of drugs. In other cases, the underlying cause of death can be selected from Part II of the MCCD.

23. In summary, the purpose behind the selection and modification rules is to derive the most useful information from the death certificate and to do it uniformly. This way data will be comparable between places and times and each death certificate will produce one, and only one, underlying cause of death.

Section 4: **Collating information on deaths**

24. The ONS and its predecessors (GRO and OPCS) have processed mortality data over the relevant period. The GRO who collect the data used to be part of the ONS, however this function moved to the Home Office in 2007.

25. The list of organisations that ONS can share registration data with is set out at section 42(4A) of the SRSA. The full list of recipients has changed over time, but current recipients include UKHSA and NHS Wales. Additionally, de-identified registration data may be shared with, or accessed by, individuals who are approved researchers (section 39(4)(i) SRSA) for public good research.

26. The ONS also produce aggregated data requests to organisations such as the Department for Education, NHS Digital, Local Authorities, DHSC and international organisations. These are currently sent through the secure transfer system MoveIT.

27. In the past the ONS also used to send the information out through password protected compact disks. Requests for data made by organisations are published on the ONS website (under user requested data) when they are aggregated, non-disclosive data tables.

Section 5: **Quality of Information on Death Certificates and MCCDs**

28. A history of mortality data is listed in the ONS's user guide to mortality statistics [**WITN7688006**]. In 1981 and 1982 the quality of information about deaths from injury and poisoning were impacted due to industrial action by registration officers. This increased the proportion of non-specific causes recorded at that time whilst decreasing the specific causes.

29. In 1993 a revised coroner's certificate of cause of death after inquest was introduced. At the same time, the ONS's former practice of sending medical enquiries to obtain more precise information on the underlying cause of death was discontinued. This practice had applied to a relatively small proportion of deaths where the certification was unclear and was considered an unjustified cost.

30. The Coroners and Justice Act 2009 aimed to reform the death certification process by introducing a single unified system. The introduction of medical examiners [**WITN7688007**] and the scrutiny they provide is designed to improve the quality (precision and completeness) of the cause of death recorded on the MCCD, helping to improve mortality statistics.

31. There are different opinions on the accuracy of death certification in general, but only a few studies in the UK and elsewhere have addressed this question directly, such as *'Quality and comparability improvement of European causes of death statistics*' [**WITN7688008**]. The certified causes of death do not always match what might be expected from the deceased's medical records taken before death, or from pathology investigations. However, it is believed that death registration in the UK is broadly reliable, bearing in mind that the MCCD and other health-related information have different purposes and priorities (medical records exist to guide care and should document all health problems relevant at the time, whereas the MCCD records only those conditions causing death). The UK is regularly ranked by the WHO as having among the highest quality data on deaths globally [**WITN7688009**].

Section 6: **Research from Death Certificates**

32. The ONS produces a number of publications on cause of death. Currently, this includes deaths involving respiratory diseases, influenza and pneumonia, and Covid-19 as part

of the deaths registered weekly in England and Wales release. The ONS also produces the number of deaths by cause and number of excess deaths by cause as part of monthly mortality analysis [**WITN7688010**]. Annually, the ONS also reports on number of deaths by cause in the deaths registered in England and Wales [**WITN7688011**] release and share the data on NOMIS, an ONS service to provide statistics at national, regional and local levels. Ad-hoc analysis is also carried out on numerous subjects, for example on different aspects of mortality involving Covid-19 during the pandemic. The ONS also uses these data to answer Parliamentary Questions and Freedom of Information requests.

33. Accredited researchers can also access the data through our Secure Research Service (SRS), which holds de-identified individual level mortality data where accredited researchers can conduct approved analysis. However, only aggregated data that is not disclosive can be outputted from the SRS. There are a wide variety of ad-hoc cause of death reports as well as customer requested data by cause that is provided on the ONS website. In past years, information was released on causes of death as part of the DH series [**WITN7688012**]. This was discontinued following a user consultation which saw mortality publications streamlined and similar data is now made publicly available through the NOMIS website [**WITN7688013**].

34. The ONS does not, as standard, research links between chronic diseases and new viruses. However during the pandemic we completed analysis around pre-existing conditions in those whose death was due to Covid-19 [**WITN7688014**]. We have also produced several analyses on potentially chronic consequences of Covid-19 ('Long Covid'). Although not relating to new viruses, we have also done some work on comorbidities in relation to the two leading causes of death in England and Wales, Dementia and Alzheimer's disease [**WITN7688015**] and Ischemic heart diseases [**WITN7688016**].

35. I am not aware of any policies or practices to identify or record any statistical linkage of chronic diseases with new viruses. The ONS's role is to provide data and statistics for the public good, including about deaths registered, but not to monitor, investigate or control any specific disease. Epidemiological investigations have generally been carried out by other government departments or by medical researchers in academia, often using data provided by the ONS.

36. The guidance provided by the ONS (noted at paragraph 16), the GRO and other government and professional bodies over the years has always encouraged full and clear description of the causes of death and discouraged any form of obfuscation or

omission. However, it is possible that, as the Brodrick Committee noted, some such informal practices did exist. Unless a relevant cause of death is completely omitted from the MCCD, the effect of such practices on statistics is likely to be limited, because statistical analysis relies on the classification of the reported causes into the WHO's ICD, which treats all synonyms (or circumlocations) for a given disease as equivalent to each other.

37. Following searches of ONS records it has not been possible to identify any information on the draft Medical Advisory Committee paper or the letters referred to by the Inquiry. There have been a number of reports and proposals over the years to improve death certification in various ways. For example, local registrars have been provided with lists of medical terms [**WITN7688017**] that should be queried when the MCCD is presented to them. Furthermore, there has also been activity since the Shipman Inquiry (which took place between 2000 and 2005) such as the introduction of Medical Examiners whose remit includes scrutinising the causes of death proposed by the certifying doctor.

Statement of Truth

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

Signed _ **GRO-C: Julie Stanborough**

Dated _____06/06/2023_____