Name of witness: Professor Sharon Peacock
Public Health England
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Exhibits: 9
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INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF PROFESSOR SHARON PEACOCK

STATEMENT OF TRUTH

I believe that the facts stated in this witness statement were true at the date the statement was provided in draft to the Inquiry [21 November 2019]. I believe that they remain true except that: (i) there may be updates related to, for example, additional documents provided to the Inquiry since the date of the statement; (ii) PHE staff may have changed between the date of the statement and 1 April 2021 when PHE ceased to exist and the UK Health Security Agency ("UKHSA") came into being; (iii) many changes will have occurred since UKHSA replaced PHE including my role. Since the date of signing this statement, I have been employed by the University of Cambridge as a Professor of Microbiology and Public Health. I have included an Addendum at the end of the witness statement which provides some key updates.

I, Professor Sharon Peacock CBE FMedSci, Public Health England, Wellington House, 133-155 Waterloo Road, Lambeth, London SE1 8UG will state as follows:

1. I am Director of the National Infection Service ("NIS") directorate in Public Health England ("PHE"). PHE is an operationally autonomous executive agency of the Department of Health & Social Care. It exists to protect and improve the nation's health and wellbeing, and reduce health inequalities.

2. I have been employed by PHE since April 2019. I am also Professor of Public Health and Microbiology at the University of Cambridge, and honorary consultant microbiologist at the Cambridge clinical and public health laboratory based at

Addenbrooke's Hospital. I was awarded a CBE for services to medical microbiology in 2015. I was elected as a Fellow of the Academy of Medical Sciences in 2013.

3. I make this witness statement in connection with PHE's involvement with the Infected Blood Inquiry ("IBI") **[Addendum note 1]** and further to a request under Rule 9(2) of the Inquiry Rules 2006 dated 10 October 2019. This request asked four questions. I deal with each in turn below, having sought input from appropriately qualified persons with the relevant knowledge where appropriate **[Addendum note 2]**.

QUESTION ONE

4. Question One requires PHE to provide evidence of the following issues and matters:

> *Please see the attached "Organogram of PHE entities". Please confirm and comment on the accuracy and completeness of the illustrated structure of PHE and which current and historical organisations it has responsibility for. In particular, please confirm how the organisations labelled "Other connection/arrangement still to be determined" on p.2 fit into the overall structure of PHE. The Organogram is provided as a guide only and should it contain inaccurate information or missing entities, please let us know in which way our understanding does not reflect how the organisations are currently, and historically structured.*

5. I answer Question One as follows. The document referred to by the IBI as the "Organogram of PHE entities" [RLIT0001894_002] is comprised of two diagrams. The first shows the organisations that came together to form PHE on 01 April 2013 and so might more accurately be referred to as an 'organogram of the organisations that came together to form PHE', the majority of which no longer exist.

6. To the best of my knowledge this first diagram is correct, except in relation to the following points:

   a) for the box titled "Other" it should be noted that the entities listed here did not transfer wholesale into PHE, only some of the public health functions and services they provided did;

   b) for the box titled "Public Health Observatories (PHO)" it should be noted that some of the PHOs also incorporated what were previously known as the

regional cancer registries and that all these registers transferred into PHE when it was established;

c) for the box titled "Public Health Observatories (PHO)" it should be noted that the internal structure of PHE has evolved since 2013 and that the "Knowledge and Intelligence Teams" are now referred to as the PHE 'Local Knowledge & Intelligence Service'.

7. The second diagram that comprises the "Organogram of PHE entities" [RLIT0001894_002] shows the organisations that, at various points in time, came together to form the former Health Protection Agency ("HPA"). The HPA transferred into PHE on 01 April 2013. To the best of my knowledge this second diagram is correct, except in relation to the following point:

   a) for the box titled "Other" it should be noted that the European Centre for Disease Prevention and Control is an agency of the European Union and wholly separate from the former HPA and PHE currently.

8. To assist the IBI, I have provided a copy of the current PHE 'Leadership Organogram' which shows the main PHE directorates and senior leadership team [WITN7520002].

QUESTION TWO

9. Question Two requires me to provide evidence of the following issues and matters:

   Please provide a complete account of the Public Health England archives and repositories including those storing documents and information in hard copy, electronic copy and any other form.

10. I answer Question Two as follows.

Background

11. PHE employs approximately 5,500 staff working in 11 directorates, the largest of which by headcount is NIS. NIS is PHE's scientifically-led service that aims to protect the population of England from infectious diseases. It does this by detecting outbreaks, analysing causative pathogens, and effecting interventions, both immediately, and through longer-term preventive measures.

12. From the date of the first Rule 9 request from the IBI to PHE (28 November 2018), the efforts expended to identify documents of potential relevance to this request have focused on the NIS directorate. This is because of its responsibility for providing public health services that fall within the scope of interest of the IBI.

13. NIS provides many of the national public health services that were previously undertaken by the former HPA and, prior to that, the Public Health Laboratory Service ("PHLS"). The directorate is comprised of a number of divisions. The relevant divisions in respect of the matters raised in the Rule 9 requests from the IBI are the Blood Safety, Hepatitis, Sexually Transmitted Infections ("STI") & Human Immunodeficiency Virus ("HIV") Service and the Microbiological Laboratories Service.

Records management

14. Each PHE directorate is directly responsible for ensuring that processes are in place to manage its documents and records. A PHE-wide Records Management Policy [WITN7520003] setting out this requirement is in place. This policy is supported by a corporate Records Retention & Disposal Schedule [WITN7520004] and a suite of record management guidance and training materials.

15. The Records Retention & Disposal Schedule [WITN7520004] sets out the expected period for which different types of records will be retained by the directorates, and the expected disposal action at the end of the relevant period. This corporate-level schedule can be augmented by more detailed schedules that are specific to a particular service or function. For example, the NIS Microbiological Laboratories Service is expected to comply with the PHE Records Retention & Disposal Schedule [WITN7520004] and the current version (5th Edition) of the Royal College of Pathologists guidance on The Retention and Storage of Pathological Records and Specimens [RLIT0001474].

16. PHE does not have a corporate-wide Electronic Document and Records Management System. Instead, the directorates are responsible for implementing processes to manage the records they create and use effectively and efficiently as required by the PHE Records Management Policy [WITN7520003]. These processes must ensure the confidentiality, integrity and availability of these records across the whole of the record lifecycle from creation, use, retention and appraisal through to disposal.

17. The electronic documents and records created and used by the NIS directorate are stored either in dedicated parts of the PHE information technology ("IT") network provided for use by the divisions that comprise the directorate or in dedicated SharePoint sites located on the PHE IT network. Any hardcopy documents and records retained by the NIS divisions are held either in storage rooms, filing cabinets or are archived offsite with Restore, PHE's record storage service provider. There is no unified, central inventory of all the records held by the NIS directorate; rather, inventories, where these exist, are held locally by the NIS divisions.

18. The other PHE directorates manage their documents and records in a manner comparable to the NIS directorate.

19. When PHE was established in April 2013, it inherited an archive of records from its predecessor organisations. These organisations are as described in response to Question One of this statement. With specific regard to the public health services provided by the NIS directorate, a large volume of records was inherited from the former HPA and PHLS. The size and condition of this archive of hardcopy records is as described in the responses provided below to Question Three of this statement.

20. In responding to the Rule 9 request of 28 November 2018, PHE performed searches to identify and provide to the IBI relevant documents. The scope of these efforts is also set out in the response to Question Three below. In responding to the present Rule 9 request, the NIS directorate has identified that there is one archive that it has not yet reviewed, and which may contain records of potential interest to the IBI. There are approximately 500 archive boxes stored offsite with Restore, PHE's offsite record storage provider.

21. The above archive was not inspected as part of the initial record review, for which I apologise on behalf of the NIS directorate. At the time of the Rule 9 requests, PHE was in the process of changing its offsite record storage provider from Iron Mountain to Restore and this archive was inadvertently omitted from the record review.

22. The NIS divisions responsible for these archived records are currently reviewing the local inventories they hold and recalling all boxes from Restore that may contain records of relevance to the Rule 9 requests so that they can be inspected and submitted as appropriate. PHE would be grateful to discuss the process that will be of most assistance to the IBI in this regard. However, PHE will use its best endeavours to recall and review these archives by 20 December 2019 **[Addendum note 3]**.

QUESTION THREE

23. Question Three requires PHE to provide evidence of the following issues and matters:

> *As discussed in the meeting, please confirm the methodology and approach PHE used to perform the searches locating the documents provided to the Inquiry under the previous three Rule 9(2) requests, including all those laboratories, health centres and any other groups, committees or organisations contacted by PHE.*

24. I have provided below descriptions of the methodology and approach taken to performing the searches for the documents previously provided by PHE in response to the Rule 9 requests.

HIV/Blood-Borne Viruses (Including Hepatitis) Document Search

25. This search was led by Dr Nick Phin, the Deputy Director for the Tuberculosis, Acute Respiratory, Gastrointestinal, Emerging/Zoonotic Infections, and Travel and Migrant Health ("TARGET") division in the NIS directorate. Dr Phin was also interim Deputy Director for the NIS Blood Safety, Hepatitis, Sexually Transmitted Infections & HIV division between April 2018 and January 2019.

26. The search undertaken by Dr Phin involved the following two stages:

a) stage 1: senior PHE staff responsible for microbiological laboratory activities and for the surveillance of relevant diseases, particularly hepatitis and HIV, were contacted and asked to review any historical material;

b) stage 2: the archive of files, correspondence and meeting notes relating to business services, investigations and policy advice covering the subject and period of interest stored in the PHE offices in Colindale, North London, was reviewed.

Stage 1

27. The first stage of the search involved Dr Phin contacting by email other senior staff in PHE responsible for functions relevant to the scope of the Rule 9 request dated 28 November 2018 from the IBI. [Two emails from Dr Phin to these colleagues are provided as WITN7520005 and WITN7520006]. The persons contacted, all of whom responded even if providing a nil response, were:

a) Professor Noel Gill, Head of HIV and STI, Blood Safety, Hepatitis, STIs & HIV division, NIS;

b) Dr Kate Soldan, Head of STIs (HPV and Chlamydia Prevention Programmes) Blood Safety, Hepatitis, STIs & HIV division, NIS;

c) Dr Sema Mandal, Medical Consultant Epidemiologist, Blood Safety, Hepatitis, STIs and HIV Division, NIS;

d) Dr Mary Ramsay, Deputy Director, Immunisation and Countermeasures, NIS;

e) Dr Neil Woodford, Deputy Director, Microbiological Laboratories service, NIS;

f) Andrew Mumford, Deputy Director for Microbiological Laboratory Operations, NIS;

g) Dr Samreen Ijaz, Clinical Scientist, Virus Reference Laboratory, NIS;

h) Alex Sienkiewicz, Director of Corporate Affairs & PHE Porton Site director.

Stage 2

28. The second stage of the search involved a physical inspection of the archive of hardcopy documents held at the PHE Colindale site. In addition to hosting the microbiology laboratory service, this site had been the administrative headquarters of the former HPA and PHLS for many years. Any files, correspondence and meeting notes relating to business services, investigations and policy advice covering the issues raised in the Rule 9 request are considered most likely to have been archived in Colindale (except for those archived offsite with Restore as described above in response to Question One).

29. The Colindale archive is located in the basement of the corporate services building. Entry is card-controlled and only card holders with the required clearance can access the area where files and documents are kept. The conditions are not ideal, as although the area is dry, it is very dusty and there is evidence of water damage to some files, probably caused by leaks from the many pipes that travel through the area.

30. The archive consists of seven, rolling stack-type, archive shelving units. All the stacks are double-sided. For six of the stacks, each side consists of three, six-foot bookcases with five shelves and three, six-foot bookcases with four shelves. One smaller stack has one, six-foot bookcase with five shelves and four, six-foot book cases with four

shelves. All files and documents are either in folders or box-type files labelled with the topic on the spine or front.

31. The stacks are divided into sections covering publications, finance, time sheets, human resources, contracts, correspondence, reports, meeting notes and minutes. Dr Phin and Gwynn Morris, the Head of Business Operations for the TARGET division headed by Dr Phin, spent time reviewing material in the stacks that contained correspondence, reports, meeting notes and minutes. The remaining sections listed above were not reviewed. Some material was grouped in the sections which were reviewed into topic headings but most required manual examination of the contents of each folder.

32. The original request from the IBI did not provide a specific time period for which documents were required, so 1970 to 1995 was chosen. The following broad search topics were used in the initial trawl of the documents in the archive (i.e. documents which appeared to contain any information likely to be relevant to any of these categories were retrieved):

    a) Hepatitis, including:

        i. A, B and C (please note that the hepatitis A files were later put to one side as this is predominantly transmitted by food and water and in some instances sexual contact);

        ii. serum hepatitis;

        iii. infectious hepatitis;

        iv. hepatitis non-A and non-B;

    b) AIDS/HIV/HTLV III;

    c) Creutzfeldt Jacob disease (CJD);

    d) scientific groups, including:

        i. national and/or regional meetings of virologists;

        ii. senior PHLS staff meetings at national level;

    e) PHLS headquarters correspondence.

33. This approach resulted in a large number of documents being identified. These were then reviewed in detail by a team of eight staff who reviewed each individual document. Any references to infected blood testing, the introduction of testing, blood or blood transfusion, and haemophiliacs in relation to any of the infections of interest in any documentation were logged. In cases where the relevance to the Rule 9 request was uncertain, a senior Blood Safety, Hepatitis, STI & HIV division scientist assessed whether this should be included or not. All documents of potential interest were then listed in an inventory, digitised and provided to the IBI. PHE would welcome the Inquiry's inspection of the archive if that would assist **[Addendum note 3]**.

CJD Document Search

34. This search was of the archive of electronic documents stored on the part of the PHE IT network provided to the staff working in the CJD team of the Blood Safety, Hepatitis, STI & HIV division of the NIS directorate. It was led by Dr Katy Sinka, the head of the team.

35. A list of the documents in this archive was made by Dr Sinka on 07 February 2019 and included 40,862 electronic folders and documents with a date range from 1998 to 2019. This list is available to the IBI if requested.

36. This archive is a repository of documents concerning the former HPA and later PHE's operational role in the public health aspects of CJD and variant CJD ("vCJD"). It includes documents relating to:

    a) the secretariat of the national CJD Incidents Panel (which met between 2000 and 2013);

    b) HPA/PHE operational activity in risk-assessing individuals and group of patients for potential exposure to CJD, and tracing and notifying individuals at risk of vCJD;

    c) vCJD-related research;

    d) public health follow-up of individuals with a risk of iatrogenic CJD;

    e) supporting references and information resources.

37. Among these documents were a large number of items of personalised correspondence sent to individual vCJD patients, their GPs and the local health protection consultants. These were all identical in content, save for the information

personalising the letter to the patient; master versions of these letters were included in the evidence supplied to the IBI by PHE.

38. These letters relate to approximately 180 patients, who were allocated into groups defined by their direct or indirect link via blood transfused to or donated from a person who was diagnosed with and died from vCJD. No correspondence is held by the CJD team for individuals treated with plasma products for bleeding disorders.

39. The search process carried out in relation to the 40,862 electronic folders and documents involved the progressive review and exclusion of items considered not to be likely to contain information relevant to the Rule 9 request from the IBI. The exclusion criteria used were:

    a) document subject matter not related to blood or plasma products;

    b) document subject matter related to blood generally but not to implicated or infected blood;

    c) initial drafts of documents for which a final version was available;

    d) duplicate documents.

40. This search process identified 1,042 documents that were considered likely to be of interest and these were submitted to the IBI in early 2019. A further 29 'Department of Health & Social Care vCJD Risk Assessment Documents' were submitted at a later date at the request of the IBI.

QUESTION FOUR

41. Question Four requires PHE to provide evidence of the following issues and matters:

> *As explained in the Inquiry's Terms of Reference, we would like to confirm how PHE collects data on Hepatitis C and HIV infections so that the Inquiry may ascertain the likely numbers of people who have been infected through the use of infected blood or blood products.*
>
> *i. Our understanding is that information relating to Hepatitis C infections is stored in the Hepatitis C National Register in the form of anonymised data on patients who have acquired their infections on a known date. It is referred to on the government website. We understand this Register*

to be separate and distinct from the Hepatitis C Patient Registry. Please confirm:

a) the main functions of the Hepatitis C National Register and the Hepatitis C Patient Registry;

b) how, in both cases, the Hepatitis C data collected is sourced, updated and used.

ii. In relation to information contained on the HIV National Register, please confirm:

a) how the HIV data is sourced, updated and used;

b) an appropriate point of contact at the HIV National Register who can assist the Inquiry with any further investigations

42. I have provided below descriptions of the hepatitis C virus ("HCV") and human immunodeficiency virus ("HIV") data that PHE holds.

Hepatitis C National Register of Known Date Infections

Background

43. The Hepatitis C National Register of Known Date Infections ('the Register') was established in 1998 to provide epidemiological information on the natural history and clinical outcomes of patients with HCV in the UK.

44. The Register contains data on patients who acquired their HCV infections on a known date. Approximately 1,200 individuals are enrolled and followed in the Register. Most of these patients are transfusion recipients who received potentially HCV infected blood prior to the introduction of blood supply screening in 1991 and were identified during the National HCV Lookback exercise in 1995. Other cases recorded on the Register include patients with evidence of seroconversion for antibodies to HCV between serial blood donations (within a defined window period) as well as those who acquired their infections in childhood.

Data collection

45. The Register, which covers the whole of the UK, records the following information on patients with HCV:

a) details of the source of the infection and background demographic, risk and clinical information for each patient;

b) follow-up data on each patient's current clinical status, test results, HCV management and treatment, and risks of progressive HCV-related liver disease;

c) information from any referred sera or liver biopsy sections;

d) linked notification data on any cancer diagnoses or death notifications taken from Office for National Statistics and Health & Social Care Information Centre (known as NHS Digital) systems and their equivalents in the UK Devolved Administrations.

46. Patient hospital number (or other local identifier), NHS number and date of birth are collected for patients on the Register to enable:

a) linkage of follow-up HCV-related clinical information;

b) linkage to cancer registration records, deaths records, and treatment records and posting data.

47. The Register is supported by clinicians across the UK and response rates to clinical follow-up have never fallen below 90%. As HCV has a clinical course that spans decades, patients on the Register are followed until death, which means patient identifiable information is kept by PHE long-term.

48. PHE does not have any direct patient contact in order to collect or verify data or as a result of its analyses of the Register.

Further information

49. Information on the Register, including published papers, registration/follow-up forms, clinical bulletins and patient information material, is published at: https://www.gov.uk/government/publications/hepatitis-c-national-register.

Wider HCV surveillance work programme in PHE

50. HCV is a notifiable organism so microbiological laboratories across England are required by law to report cases to PHE in accordance with The Health Protection (Notification) Regulations 2010 [RLIT0001896].

51. The NIS directorate is responsible for the national surveillance of the extent of HCV in the population and for looking at the treatment and outcomes for patients with HCV. To support this work, it utilises five separate databases covering:

    a) laboratory reports of new HCV diagnoses;

    b) sentinel surveillance of blood-borne virus testing;

    c) HCV treatment monitoring and outcomes (sometimes referred to as the Hepatitis C Patient Registry);

    d) molecular surveillance;

    e) anonymous monitoring survey of people who inject drugs.

    Further information on each of these databases is provided below:-

    Laboratory reports of new HCV diagnoses

52. Since 1996, the former PHLS and PHE have received new diagnoses of viral hepatitis through a reporting system covering all laboratories in England. This data is recorded by the laboratories in an information system called the Second Generation Surveillance System ("SGSS"). This system stores and manages data on laboratory isolates and notifications and is the preferred method for capturing routine laboratory surveillance data on infectious diseases and antimicrobial resistance from laboratories across England.

53. This system is used to report new diagnoses for all notifiable organisms, including HCV. It provides a diagnosis or detection rate, although it should be noted that this does not equate to a prevalence estimate for HCV and does not provide any information on the time of acquisition. Under-reporting of new diagnoses by laboratories is known to have occurred in the past but has improved since reporting became mandatory in 2010. Currently, there are 127 NHS laboratories and one private laboratory which report to SGSS for HCV. Data for approximately 232,500 individuals who have been newly diagnosed with HCV is held on SGSS.

54. The data collected in the laboratory reports includes: patient surname and forename, date of birth, gender, NHS number, hospital number, sexual health service number and laboratory number; test type (mainly HCV antibody); and test results. Clinical information (free text or in feature codes), where available, is collected and used to indicate risk factors. Route of acquisition may possibly be inferred from these risk

factors (e.g. injecting drug user) but cannot be confirmed; the recording of this information is often patchy and incomplete.

Sentinel surveillance of blood-borne virus testing (also known as the 'HCV denominator study')

55. Sentinel surveillance of blood-borne virus testing began in 2002 with the aim of supplementing the routine surveillance of hepatitis and HIV.

56. Blood-borne virus testing data is submitted from the information systems of 23 participating NHS laboratories across England. Information on the testing carried out in these laboratories is collected irrespective of whether the test result is positive or negative which means it can be used to estimate the incidence and prevalence of HCV among those tested.

57. This data is used by PHE to enhance wider understanding of the population of patients who are being tested for HCV and the types of local health services they are using to access testing. In 2017, sentinel surveillance captured front-line testing for hepatitis A, B, C and HIV among approximately 40% of the population. There are an estimated 6.7 million records in the sentinel surveillance database associated with HCV tests relating to an estimated 3.7 million patients.

58. The data collected through sentinel surveillance includes: patient surname and forename, date of birth, gender, NHS number, hospital number, sexual health service number and laboratory number; test type (mainly HCV antibody); and test results. Ethnicity is not recorded for all patients so is supplemented using name analysis software which assigns ethnicity based on patient name. Clinical information (in free text form), where available, is used to indicate risk factors. Route of acquisition may be inferred from risk factors (e.g. injecting drug user) but cannot be confirmed, and the recording of this information is patchy and incomplete.

59. As this is a sentinel surveillance system, the data collected does not provide complete coverage of all laboratories in England. The quality of the reporting also varies depending on the specifics of the local data entry processes in each reporting laboratory meaning there is the possibility of some double-counting of patients.

60. Names and other identifying information are retained for patients with a positive test result for follow-up of chronic infections but identifying information for patients with a negative result is removed from the database held by PHE.

HCV treatment monitoring and outcomes

61. National HCV treatment and outcomes monitoring was established in 2015/16 by NHS England and PHE. This system is called the Hepatitis C Patient Registry & Treatment Outcome System and is held and managed by NHS England. It is sometimes referred to as the Hepatitis C Patient Registry.

62. NHS England provides an IT system on to which liver disease clinical leads working in 22 NHS England Operational Delivery Networks ("ODNs") record information on HCV patients being treated by their service. The dataset does not include patients who were treated prior to 2015.

63. The data collected by the system includes: patient name, date of birth, NHS number, hospital record number, country of birth and ethnicity; risks (in other words, the likely route of acquisition) and injecting status; patient-reported year of first diagnosis; clinical information, including genotype, liver disease stage, presence of liver cancer or transplant, and co-morbidities (including HIV, HBV, renal insufficiency, and alcohol use); referral source, setting of treatment and past and current treatments; and treatment outcome, including sustained virologic response.

64. The ODNs are expected to complete all the fields in the system for each patient treatment episode, although there is some variation in data completeness by field type and ODN.

65. PHE is granted access to this system by NHS England so that it can monitor equity, access to and outcomes for patients with HCV. Information on approximately 48,000 patients has been provided to PHE from this system by NHS England.

Molecular surveillance

66. Systematic molecular epidemiology surveillance for HCV is not undertaken by PHE. There have been specific projects undertaken in the past by its Virus Reference Department to sequence HCV infections in selected data sets for academic purposes, the results of which have been published in peer-reviewed journals. A project is currently underway to sequence HCV among participants recorded in the anonymous monitoring survey of people who inject drugs (see section below) from 2017. **[Addendum note 4]**

67. Blood donors are tested for HCV through routine screening. Samples from these donors are sequenced to genotype the viruses. This data is used by PHE to contribute

to wider understanding of the epidemiology of blood-borne viruses in blood donors. Clinical follow-up of these blood donors is taken forward by NHS Blood & Transplant. In recent years the number of blood donors in England with markers of HCV infection has declined: in 2018, only 21 donors tested positive.

Anonymous monitoring survey of people who inject drugs

68. The anonymous monitoring survey of people who inject drugs (formerly known as the collaborative unlinked anonymous survey of the prevalence of HIV and hepatitis viruses in injecting drug users) is coordinated by PHE and monitors the prevalence of HIV, HBV and HCV among people who inject drugs. It began testing for HIV and HBV in 1990 and was expanded to test for HCV in 1998. The survey recruits people who inject drugs through specialist agencies in England, Wales and Northern Ireland.

69. A biological specimen is collected and tested for HIV, HBV and HCV. A questionnaire of limited demographic and behavioural risk factor information (including drug use and sexual habits) is completed by participants and is anonymous, meaning no participant identifiable information is collected. There are approximately 64,900 records in the database since HCV testing began in 1998. As this is a rolling series of annual surveys, the same participants may take part multiple times, although their individual records cannot be linked as no patient identifiable information is collected.

Outputs

70. Some of the main outputs from the PHE HCV surveillance work programme are as follows:

    a) HCV sentinel surveillance data are reported in annual and quarterly publications at: https://www.gov.uk/government/collections/hepatitis-c-guidance-data-and-analysis#epidemiology;

    b) HCV treatment monitoring and outcomes were first reported in November 2018 in the document published at: [RLIT0001673];

    c) HCV sentinel surveillance testing, diagnoses and treatment monitoring data, along with other information, are assimilated to inform the progress reports on HCV elimination published at: https://www.gov.uk/government/publications/hepatitis-c-in-the-uk;

    d) laboratory reporting data has been used in the joint NHS England and PHE HCV patient re-engagement exercise, where information on previously

diagnosed individuals not known to be treated but thought to be alive and registered with a GP were provided to local liver disease clinical leads in the 22 ODNs responsible for providing HCV treatment; information on this is published at: https://www.gov.uk/government/publications/hepatitis-c-patient-re-engagement-exercise;

e) HCV surveillance data has been used to create a tool that can be used to estimate the prevalence, diagnosed proportion and burden of HCV at national as well as regional levels, and is published at: https://www.gov.uk/government/publications/hepatitis-c-commissioning-template-for-estimating-disease-prevalence;

f) Data tables and commentaries on the anonymous monitoring survey of people who inject drugs are published at: https://www.gov.uk/government/publications/people-who-inject-drugs-hiv-and-viral-hepatitis-monitoring.

Point of contact

71. The appropriate point of contact who can assist the IBI with any further investigations relating in the HCV data PHE holds is Dr Emily Phipps, Head of Hepatitis C and Blood-Borne Viruses/Infections, in the NIS directorate.

HIV Surveillance System

Background

72. In relation to data on patients with HIV, this information is held in what PHE refers to as its 'HIV surveillance system'. The term "HIV National Register" is not used by PHE. This is because, unlike a disease register, the PHE HIV surveillance system does not collect direct patient identifiers. The system relies on the voluntary and confidential reporting of new HIV diagnoses by clinicians and virologists. These reports are de-duplicated and matched to other data using a 'soundex' generated by reporting clinics (explained in further detail below), as well as gender and age. Importantly, PHE cannot identify individuals from the data it receives so therefore cannot identify or follow up patients.

73. National surveillance of AIDS began in 1982 with cases and deaths being reported to the former PHLS. Case reporting of new HIV diagnoses was introduced after the first test for HIV became available in the UK in 1984.

74. From the beginning of the epidemic, public health surveillance of HIV has been undertaken using multiple source ascertainment, including clinicians, laboratories and Office of National Statistics deaths records. Public health monitoring of all persons accessing HIV care services began in 1995/96 after effective treatment became widely available.

75. Case ascertainment is close to 100% with 70-80% of diagnoses reported to PHE by approximately 200 HIV outpatient clinics across England, Wales and Northern Ireland. New diagnoses in Scotland are reported to Health Protection Scotland, and paediatric HIV diagnoses are reported to the Great Ormond Street Institute of Child Health.

Data collection

76. At the beginning of the epidemic, reports of AIDS cases were sent to the PHLS by letter but by the mid- to late-1980s, paper forms from clinicians and laboratories were submitted. Around the late-1990s, a form was developed for the reporting by clinicians of enhanced epidemiological information on new HIV and AIDS diagnoses. Since 2000, electronic reporting of new diagnoses has been encouraged from both clinicians and laboratories.

77. Data on HIV patients accessing care was initially securely faxed until around 2002 when an electronic template was developed. This system was known as the Survey of Prevalent HIV Infections Diagnosed ("SOPHID"). This system was replaced by the HIV & AIDS Reporting System ("HARS") in 2013, which was rolled out to all HIV outpatient clinics by PHE between 2013 and 2015. HARS collects information on people accessing HIV care (including information on their initial diagnosis) through the uploading of data to a secure web portal.

78. There are a number of core data fields that have been collected since the beginning of the HIV epidemic. Pseudo-anonymised patient identifiers include:

a) date of birth;

b) sex;

c) soundex of the surname (an autogenerated 4-digit alphanumeric code comprised of the first letter of the surname and three numbers based on letters within the surname);

d) clinic identifier.

79. These data items are used to de-duplicate multiple reports pertaining to the same patient. They also enable an individual's diagnosis to be linked with their care records across years to enable clinical follow-up.

80. Other core data items include:

    a) country of birth;

    b) date of diagnosis;

    c) date of AIDS;

    d) date of death;

    e) first CD4 blood cell count;

    f) date of first CD4 blood cell count;

    g) probable exposure to HIV.

81. Additional items have been added as the HIV epidemic has evolved. Since around 2000, the following fields have been collected:

    a) geography of patient residence (previously postcode but now Lower Super Output Area);

    b) ethnicity;

    c) treatment status;

    d) viral load.

82. With the development of HARS, information relating to every clinic attendance is now collected together with additional clinical markers. Previously, clinics reported only the last attendance for clinical care in a given year to SOPHID.

83. Adult records of new HIV and AIDS diagnoses are linked together with the HIV outpatient attendance data to create a comprehensive cohort of all persons diagnosed and attending for HIV care.

84. The completeness of HIV surveillance data in the UK has been high since the beginning of the epidemic due to the close working relationships established between HIV clinicians and reporters and the national HIV surveillance team. The PHE HIV

surveillance system is now considered to be comprehensive of all people living with diagnosed HIV. In 2018, there were around 96,000 people living with diagnosed HIV infection and accessing care in the UK, and around 4,500 people newly diagnosed in that year with HIV.

85. As HIV has a clinical course that spans decades, patients are followed until death, which means the data held by PHE is kept long-term. PHE does not have any direct patient contact in order to collect or verify data, or as a result of its analyses of the HIV data it holds.

Further information

86. Information on the surveillance system PHE uses to collect HIV data is publicly published at: https://www.gov.uk/guidance/hiv-surveillance-systems#the-hiv-and-aids-reporting-system-hars.

Outputs

87. Some of the main outputs from the PHE HIV surveillance work programme are as follows:

    a) Monthly updates on the epidemic were published via the national Communicable Disease Report between 1983 and 1990 at: http://webarchive.nationalarchives.gov.uk/+/http://www.hpa.org.uk/cdr/archives/HIV-AIDS_1983-1990/HIV_CDR_archive.htm;

    b) For the past ten years, annual data tables have been published each September at: https://www.gov.uk/government/statistics/hiv-annual-data-tables;

    c) The annual national reports providing statistical analyses and interpretation on the testing, diagnosis and care of HIV are published each November at: https://www.gov.uk/government/publications/hiv-in-the-united-kingdom.

Point of contact

88. The appropriate point of contact who can assist the Inquiry with any further investigations relating in the HIV data PHE holds is Dr Valerie Delpech, Head of National HIV Surveillance, in the NIS directorate.

Statement of Truth

I believe that the facts stated in this witness statement were true at the date the statement was provided in draft to the Inquiry [21 November 2019]. I believe that they remain true except that: (i) there may be updates related, for example, to additional documents provided to the Inquiry since the date of the statement; (ii) PHE staff may have changes between the date of the statement and 1 April 2021 when PHE ceased to exist and the UKHSA came into being; (iii) many changes will have occurred since UKHSA replaced PHE, including my role. Since the date of the statement, I have been employed by the University of Cambridge as a Professor of Microbiology and Public Health. I have included an Addendum at the end of the witness statement which provides some key updates.

Signature GRO-C

Name: Sharon Peacock

Date: 20th March 2023

ADDENDUM TO WITNESS STATEMENT OF PROFESSOR SHARON PEACOCK

1. Please see the statement of Dr Nick Phin [WITN7099006].

2. This response to the Rule 9 request from the IBI was assisted by the following PHE/UKHSA members of staff:

    a. Dr Helen Harris, Clinical Scientist in PHE 's Immunisation, Hepatitis and Blood Safety Department at UKHSA; (now retired)

    b. Dr Robert Kyffin, Data and Information Policy and Partnerships Lead;

    c. Dr Sema Mandal, Medical Consultant Epidemiologist;

    d. Dr Emily Phipps, Head of Hepatitis C and Blood Borne Viruses/Infections, Blood Safety, Hepatitis, Sexually Transmitted Infections & Human Immunodeficiency Viruses (no longer working for UKHSA);

    e. David Conway, Deputy Director, Harlow Business Change;

    f. Professor Geoffrey Dusheiko, Deputy Director, Blood Safety, Hepatitis, Sexually Transmitted Infections & Human Immunodeficiency Viruses;

    g. Dr Mary Ramsay, Head of Immunisation, Immunisation and Deputy Director, National Infection Service;

    h. Dr Valerie Delpech, Head of HIV Section, Blood Safety, Hepatitis, Sexually Transmitted Infections & Human Immunodeficiency Viruses. (no longer working for UKHSA);

    i. Professor Noel Gill, Department Head, STI & HIV Department, Blood Safety, Hepatitis, Sexually Transmitted Infections & Human Immunodeficiency Viruses (no longer working for UKHSA).

3. The Inquiry did inspect the archives in February 2020 (this inspection was placed on hold due to Covid19). A second review was carried out on the 29 November 2021, whereby a team of reviewers were allocated to review the archived documents. As per the Rule 9 request dated 10 December 2021 and due to the volume of documents, these were scanned by an outsourced company used by the Inquiry and in January 2021, these documents were produced to the Inquiry.

4. I have been informed that there is a paper in the final stages, the project work is complete, but the results not published.

INFECTED BLOOD INQUIRY

INDEX OF DISCLOSURE DOCUMENTS RELEVANT TO WITNESS STATEMENT OF PROFESSOR SHARON PEACOCK

Date	Notes/ Description	Exhibit number
Summer 2019	Public Health England Leadership Organogram	WITN7520002
27 February 2018	Records Management Policy v.3	WITN7520003
27 March 2019	Record Retention & Disposal Schedule v.4	WITN7520004
17 December 2018	Email to PHE colleagues requesting identification of relevant material	WITN7520005
17 December 2018	Email to Alex Sienkiewicz: requisition identification of relevant material	WITN7520006
10 October 2019	Inquiry drawn organogram of PHE Entities	RLIT0001894_002
April 2015	The retention and storage of pathological records and specimens (5th ed) from the Royal College of Pathologists (2015)	RLIT0001474
2010	The Health Protection (Notification) Regulations 2010 No. 659	RLIT0001896
2018	Hepatitis C treatment monitoring in England report by Public Health England	RLIT0001673