

Witness Name: Professor Ellen Nolte

Statement No.: WITN7686001

Exhibits: NIL

Dated: 17 March 2023

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PROFESSOR ELLEN NOLTE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9 March 2023.

I, Professor Ellen Nolte, will say as follows: -

Section 1: Introduction

1. My name is Ellen Nolte. Date of birth: GRO-C 1967. My professional address is 15-17 Tavistock Place, London WC1H 9SH. I hold the following professional qualifications:
MSc Biology ('Diplom-Biologin'), University of Bielefeld, Germany, 1992
Master of Public Health (MPH), University of Bielefeld, Germany, 1996
Postgraduate Diploma of the London School of Hygiene & Tropical Medicine by research in Public Health & Policy, 2001
PhD in Public Health Medicine from University of London, 2001.
I am member of the Faculty of Public Health (Membership through Distinction, 2018).
I am also member of the UK Society for Social Medicine.
2. I am Professor of Health Services and Systems Research at the London School of Hygiene & Tropical Medicine (LSHTM). I am also Deputy Director of the Policy Innovation and Evaluation Research Unit (PIRU) at the LSHTM. PIRU is a collaboration between the LSHTM, the Care Policy & Evaluation Centre at the London School of Economics and Political Science, and Imperial College London Business School. The Unit aims to improve evidence-informed policy-making and its implementation across the Department of Health & Social Care, National Health

Service, local authority social care and the field of public health. The Unit is funded by the National Institute for Health and Care Research (NIHR) Policy Research Programme (reference PR-PRU-1217-20602). In my role as Deputy Director I support the Director (Professor Nicholas Mays) in the running of the Unit; I deputise for the Director as required and lead individual projects. I am the lead for international policy and programme comparisons and evaluation; co-lead for identification of overseas policy innovations (horizon scanning); and co-lead for health services policy and programme evaluation.

3. I am not a member (past or present) of any committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference.

Section 2: Department of Health Study

4. I have been asked to describe the study commissioned by the Department of Health and Social Care through the National Institute for Health and Care Research about psychological support for individuals historically infected with HIV and/or hepatitis C as a result of treatment with NHS blood/blood products and affected families, including:
 - a. Timeline
 - b. Consultation with people infected and affected
 - c. Consultation with providers of specialist psychological support to people infected and affected in Wales, Scotland and Northern Ireland

- 4.1 The Department of Health and Social Care (DHSC) approached PIRU on 25 March 2022 to explore the possibility of the Unit undertaking research to help inform the Government's response to the Infected Blood Inquiry (IBI). The IBI had highlighted concerns around the lack of psychosocial support for people who have been infected with HIV and/or hepatitis C as a result of treatment with NHS blood/blood products and affected families during the 1970s and 1980s. Little is known about the current psychological needs of survivors and their relatives but there is awareness that this group might require additional support because of the ongoing Inquiry. For further explanation of the context please refer to the eighth witness statement by William Vineall, dated 14 December 2022, [WITN4688076 at paragraphs 1.2-1.23].

4.2 In response to the request for research, PIRU developed an outline for a potential research project on the topic, which was shared with the Unit's Senior Research Liaison Manager in the Science, Research and Evidence Directorate at DHSC on 13 April 2022. The project outline was refined following feedback from, and meeting with, the policy team at DHSC and the NHS Business Services Authority on 22 June 2022.

4.3 PIRU commenced the study in August 2022, with a proposed end date in May 2023 (please see [WITN4688076 at paragraph 1.24]). PIRU has requested the end date for final reporting of the results be moved to mid July 2023 because of delays in data collection.

4.4 The aim of the study is to assess the nature and scope of the need for psychological support for individuals and their families affected by NHS-supplied infected blood and blood products.

The objectives are:

- (1) To assess the current need for psychological support for individuals historically infected with HIV and/or hepatitis C as a result of treatment with NHS blood/blood products and affected families, and how this need changes as the IBI concludes and the Government responds to its recommendations.
- (2) To determine the extent to which existing psychological support services are able to meet the needs of individuals historically infected with HIV and/or hepatitis C and affected families, and explore the routes they are taking in order to access support.
- (3) To understand the experiences of individuals historically infected with HIV and/or hepatitis C and affected families when accessing psychological support services, and the barriers or enablers they encountered in doing so.
- (4) To assess the experiences of practitioners providing psychological support services to individuals historically infected with HIV and/or hepatitis C and affected families, and their understanding of how to meet the specific needs of this group.
- (5) To explore what else would be needed to meet the psychological support needs of individuals historically infected with HIV and/or hepatitis C and affected families.

4.4 The study has two elements, exploring: (i) the demand for; and (ii) the supply of psychological support to individuals historically infected with HIV and/or hepatitis C and/or their families. The study relies on document review and in-depth interviews.

(i) Understanding demand for psychological support

To understand the demand for psychological support services among infected/affected individuals, the study is using two routes to recruiting study participants for interview (over the phone, via video or in person) to share their relevant experiences and what they believe should be done in terms of improving access and support.

First, we consulted support organisations (Hepatitis C Trust, Terrence Higgins Trust) who helped advertise our study among their newsletter subscribers, inviting them to get in touch with the research team if interested in participating in the study. This recruitment phase took place from December 2022 to February 2023. A total of 19 infected individuals or family members expressed interest in the study and were interviewed in January-March 2023.

Second, we draw on the 2022 Service Satisfaction Survey of England Infected Blood Support Scheme (EIBSS) beneficiaries conducted by the NHS Business Services Authority from November 2022 to January 2023. The survey included an additional question inviting interested survey respondents to participate in further research. A total of 366 survey respondents indicated their willingness to participate in further research. We are in the process of contacting interested survey respondents in the following groups:

- a) individuals who have accessed psychological support using the 'EIBSS counselling and talking therapy funding' scheme;
- b) individuals who have accessed psychological support through other routes (NHS, charities, private); and
- c) individuals who have not done either.

We aim to sample a total 40-45 study respondents spread across these groups.

(ii) Understanding supply of psychological support

We are in the process of inviting providers and commissioners of mental health services in England for interview to understand their perceptions of the existing offer of psychological support to people historically infected with HIV and/or hepatitis C and/or family members of affected individuals, and their views on how these should look like to meet affected individuals' needs. We aim to approach 8 to 10 people. In addition, we seek to interview providers and commissioners of psychological support services for infected/affected people in the devolved nations (Northern Ireland, Scotland, Wales). This process is also ongoing.

4.5 PIRU expects that data collection will continue until the end of April 2023, with data analysis to be undertaken concurrently until the end of May and reporting by mid-July 2023, as noted above.

Statement of Truth

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

Signed _____

GRO-C

Dated 17 March 2023