

Witness Name: Belinda Hacking

Statement No.: WITN4063002

Exhibits: None.

Dated: 10 October 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BELINDA HACKING

I provide this statement in response to the request under Rule 9 of the Inquiry Rules 2006 dated 8 September 2022.

I, Belinda Hacking will say as follows: -

This statement is provided in the context of my role as the Director of Psychology Services for Lothian and the Chair of the Heads of Psychology Services (HOPS) across Scotland. I work as a Consultant Clinical Psychologist. This statement addresses the specific questions requested by Matthew Hosking of the Infected Blood Inquiry, dated 08 September, 2022, and has been informed with the assistance of Dr Gráinne O' Brien, Lead Clinical Psychologist , Psychological Support Service (PSS) for inherited bleeding Disorders and Dr Sarah Gillanders, Lead Clinical Psychologist Scottish Infected Blood Psychology Service (SIBPS). It is subsequent to my initial written statement to the Inquiry of 26 January, 2020 (WITN4063001). I have not provided direct clinical contribution to the Infected Blood Psychology Network, but I have overall management as the Director of Psychology.

Section 1: Psychological Support

- 1 The Inquiry understands that since your statement WITN4063001 on access to specialist psychological support for those infected with HCV and/or HIV by blood and blood products, the Scottish Infected Blood Psychology Service has commenced operations. Please provide details of this service and give details of any feedback from users of this service.**

- 1.1 The Scottish Infected Blood Psychology Service (SIBPS) opened to referrals in September 2021 and began seeing patients in October 2021. This is a national service, hosted by NHS Lothian and based within the Astley Ainslie Hospital in Edinburgh. It has been funded by Scottish Government for an initial 2-year period to May, 2023. It has a staff resource of 1.0 wte Clinical Psychologist, which has been shared by 2 post-holders. The service has been widely advertised to those impacted by contaminated blood and blood products through liaison and close working with SIBSS (Scottish Infected Blood Support Scheme) , SIBF (Scottish Infected Blood Forum), the Psychological Support Service for Inherited Bleeding Disorders, Haemophilia Scotland, Hepatitis C Trust and the Scottish Infectious Diseases Teams.
- 1.2 To date it has received 25 referrals for psychological therapy and of those, 24 patients have been accepted for treatment. 24 referrals were made directly by patients via self-referral and 1 by a clinician.
- 1.3 The service has worked with people from a wide geographical area including the regions of Lothian, Highland, Lanarkshire, Greater Glasgow and Clyde, Fife, Ayrshire and Arran, Forth Valley, Grampian and England.
- 1.4 Scottish Index of Multiple Deprivation (SIMD) scores were calculated for all Scottish patients. Deciles were provided with decile one referring to the 10% most deprived data zones in Scotland. 2 patients resided in decile one areas, 6 in decile two, 6 in decile three, 5 in decile four, 4 in decile five and 1 in decile seven.
- 1.5 With regards to the ages of the patients seen in the first year of the SIBPS service, 1 patient fell within the 10–19-years age category, 2 within 30-39 years, 4 within the 40-49 years, 6 within the 50-59 years, 8 within the 60-69 years and 4 within 70-79 years.
- 1.6 Information collected on gender demonstrated that 14 patients identified as female and 11 as male.
- 1.7 With regards to whether patients accessing the service had been infected or affected by contaminated blood, 14 patients treated by SIBPS had been infected by contaminated blood and 9 had been affected. In relation to how the infected individual/relative had received the contaminated blood, 19 had received a blood

transfusion and 5 had received blood products. Of those affected, 5 were children, 4 were spouses and 1 was a partner.

Clinical effectiveness of the psychology service

- 1.8 Pre-treatment information was available for 21 patients and post-treatment information was available for 13. The reasons for attrition included some patients still undergoing active treatment at the time of this analysis being carried out and some patients deciding to cease treatment and therefore end of treatment data not being available.
- 1.9 When individuals first presented to the service, the main psychological symptoms recorded by clinicians were generalised anxiety, health anxiety, social anxiety, depression, grief, anger, shame, and post-traumatic stress disorder (PTSD).
- 1.10 The average CORE-10 measure of distress score at the beginning of treatment was 23 and at discharge was 13. Scores in the 20-25 range indicate 'moderately severe' distress and scores in the 10-15 range indicate 'mild psychological distress'. This indicates that distress levels improved during the course of treatment. At discharge, both patients and clinicians rated whether they believed there had been any improvement in symptoms during treatment. Of the patient responses, three said they had 'very much improved', nine said they had 'much improved' and one reported that they had 'minimally improved'. This was similar to the clinician responses in which they felt that one patient had 'very much improved', nine had 'much improved' and three had 'minimally improved'.
- 1.11 Overall, this information indicates that both clinicians and patients perceived that there had been clinical benefits as a result of the psychological treatment provided by SIBPS.

Mode of delivery

- 1.12 Data is available for all discharged patients but does not include those individuals who are still undergoing treatment. Of those discharged patients, there were a total of 184 treatment sessions provided by SIBPS clinicians between October 2021 and September 2022. 114 of those sessions were delivered using the Near Me video conference platform and 70 were delivered using telephone consultations. It should

be noted that a treatment session involves a 60-minute consultation between a psychologist and patient.

- 1.13 With regards to the treatment model used, the clinical psychologists used predominantly cognitive behavioural therapy, acceptance and commitment therapy and some more targeted interventions for grief and PTSD.

Acceptability of the service

- 1.14 Positive feedback about the SIBPS psychology service was provided by the Scottish Infected Blood Forum and Haemophilia Scotland. Given the understandable anxieties of the infected blood population about trusting an NHS service, the establishment of strong relationships with these third sector organisations was prioritised.

- 1.15 Service evaluation questionnaires were sent to patients on discharge from the SIBPS service and seven were returned. The following comments were made in response to the question 'What did you find helpful about attending the service?'

- "Speaking to someone so experienced and knowledgeable"
- "Things being explained and broken down into segments so I was able to manage my daily life."
- "Everything was done over the phone"
- "Learning calming techniques"
- "Having the protected time and space to discuss historical issues and work on many issues that are current. My therapist was incredibly kind, easy to talk to and we used many helpful tools."
- "(Clinician X) motivated me to get things done and supported me in everything I did, even while I am still sick."
- "Marshalling my thoughts and being guided back to a more rational me."
- "1. The caring support when I was upset; 2. The learning exercise of how to deal with things in my mind and 3. Becoming more positive."

- 1.16 Patients were also asked to "describe anything that was difficult, challenging or unhelpful about the service'. Comments included:

- “It is difficult to delve into your past, but this is a necessary part of the process.”
- “No problems with the service. Easy to log on on-time and to speak on the phone also.”
- “I didn’t have any problems with the service.”
- “Recording episodes throughout days. I was made aware of such daily pain and grief.”
- “Not really. Any problems with ‘Zoom’ were off-set by the convenience.”

1.17 When asked ‘Was the service easy to access’, all 7 respondents said ‘Yes’.

1.18 When asked ‘Would you recommend the service to others?’ all 7 said ‘yes’.

1.19 Patients were asked whether they felt they had benefited from the service and given the options of responding not at all, a little bit, somewhat, quite a bit or a lot. Of the seven respondents, 5 replied that they had benefitted ‘a lot’, 1 replied ‘quite a bit’ and 1 replied ‘somewhat’.

Indirect work

1.20 In addition to the clinical interventions described above, the clinical psychologists in SIBPS also gave a presentation at the British Psychological Society Health Psychology Conference in Bristol in June 2022 about the Scottish Infected Blood Service. They have continued to write regularly for the Hep C Trust, SIBSS, SIBF and Haemophilia Scotland newsletters to raise awareness of the service. In addition, they have developed a cognitive screening tool for psychologists to use if a patient reports problems with their cognitive functioning and this has been shared with the specialist infected blood services in Northern Ireland and Wales.

Summary

1.21 The data indicates that the SIBPS service is accessible to patients who live across Scotland, in different areas of deprivation, who had have been infected via blood transfusions as well as by blood products and by the relatives of those infected as well as those directly affected.

- 1.22 People have found the service easy to access and both patient and clinicians have reported that the clinical interventions have been effective in reducing the severity of the psychological symptoms people presented to the service with.

2 Please provide any updates arising from your previous statement to the Inquiry

2.1 People who have been infected or affected by the receipt of contaminated blood or blood products in Scotland currently have access to 2 distinct national psychology services: the Scottish Infected Blood Psychology Service (SIBPS) and the Psychological Support Service (PSS) for Inherited Bleeding Disorder Services. SIBPS can be accessed by those impacted by both contaminated blood and blood products while the PSS for Inherited Bleeding Disorders provides support for all individuals with inherited bleeding disorders including those who have received contaminated blood products.

2.2 These specialist services have an understanding of the history of contaminated blood, the ongoing national Inquiry and the specific needs of this population. Although all individuals impacted have some similar experiences, there are clear differences. The experiences of individuals with bleeding disorders, who were infected through blood products, and their families, are different to those people infected/ affected through blood transfusion. The bleeding disorder patients, especially those with Severe Haemophilia, will have spent much time in hospital receiving treatment of their bleeding disorder, alongside their peers and family members. Many of these peers and family members did not survive. Despite their anger and mistrust of the NHS, those with bleeding disorders often had to continue to attend the same setting where they had received the contaminated blood products. For many families this has led to multi-generational trauma, impacting upon their decision making in changing treatments etc. The embedding of a psychologist within the Haemophilia multi-disciplinary team allows the exploration of these complex emotions and the tailoring of psychological support around medical needs (and vice versa).

2.3 For some individuals with bleeding disorders, the mistrust they have can be a barrier to seeking and accepting psychological support from the haemophilia team. Access to SIBPS supports their preference to utilise specialist support elsewhere. It is important

that those who have received contaminated blood through transfusions have equitable access to specialist psychological support through SIBPS.

2.4 Currently, the Scottish Infected Blood Psychology Service (SIBPS) has agreed funding for 1.0wte Clinical Psychology post from Scottish Government until May 2023, which is the end of the initial 2-year pilot. Further discussions will be held with the Scottish Government to discuss ongoing plans regarding the funding and organisation of this service. The post-holders in this service continue to receive Line Management support from the senior Clinical Psychologist leading the PSS for Inherited Bleeding Psychology Service.

2.5 Funding for the Psychological Support Service (PSS) for inherited bleeding has been agreed for 2 further financial years, until April 2024. This funding continues to be split equally between the Scottish Government and NSD. An SBAR has been prepared in relation to the need for ongoing permanent funding of this service and has received provisional approval by Acute SMT, NHS Lothian. Funding is now being sourced to prioritise this service being continued on a recurring basis, with NHS Lothian preference being for the continuation of centralised funding for this national service. The psychologists working in these services will be able to train and support any new members of psychology staff who join, should staff leave these services.

Statement of Truth

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

Signed

GRO-C

Dated

10th October 2022