

Psychological support for individuals historically infected with HIV and/or hepatitis C as a result of NHS-supplied blood transfusions and blood products, and for affected families

Final report

Eva Cyhlarova, Jessica Carlisle, Emily Warren,
Martin Knapp and Ellen Nolte

For further details, please contact:

Ellen Nolte

Deputy Director of PIRU

Department of Health Services Research & Policy
London School of Hygiene & Tropical Medicine
15–17 Tavistock Place
London WC1H 9SH

Email: ellen.nolte@lshtm.ac.uk

piru.lshtm.ac.uk

Psychological support for individuals historically infected with HIV and/or hepatitis C as a result of NHS-supplied blood transfusions and blood products, and for affected families

Final report

**Eva Cyhlarova^{1#}, Jessica Carlisle^{1#}, Emily Warren²,
Martin Knapp¹ and Ellen Nolte^{2*}**

1. Care Policy and Evaluation Centre, London School of Economics and Political
Science, London, UK

2. Department of Health Services Research and Policy, London School of Hygiene
& Tropical Medicine, London, UK

The authors contributed equally to this work.

* Corresponding author: ellen.nolte@lshtm.ac.uk

August 2023



ACKNOWLEDGMENTS

We would like to express our sincere gratitude to the 52 infected and affected people who participated in this study. Each of these participants generously shared their time and experiences with us, although this was often a very difficult experience for them. We have learnt a lot from participants and felt privileged to hear about the ways they have tried to cope with the consequences of having been infected as a result of NHS-supplied blood transfusions and blood products or being an affected partner, parent or child, despite limited formal support. In many cases, infection continues to be life-changing.

We would also like to thank the 14 mental health practitioners and experts who very generously made the time and shared with us their many insights and experiences of providing psychological support to this very vulnerable community.

We are grateful to the following organisations who have helped us shape the research presented in this report: the British Red Cross, the CJD Support Network, the Haemophilia Society, the Haemophilia & Bleeding Disorders Counselling Association, the Hepatitis B Positive Trust, the Hepatitis C Trust, and the Terrence Higgins Trust.

It was not possible, within the constraints of this report and its focus on psychological support, to fully account for the very rich stories that people shared with us. But we hope that we have captured the key issues to help shape the development of a psychological support service for infected and affected people that is available when required, effective and responsive to people's diverse needs and expectations.

This report was funded by the NIHR Policy Research Programme through its core support to the Policy Innovation Research Unit (Project No: PR-PRU-1217-20602). The views expressed are those of the authors and are not necessarily those of the NIHR or the Department of Health and Social Care.



Contents	Executive summary	1
	Introduction	3
	Study aims and objectives	5
	Methods	4
	Study design	6
	Participant recruitment	6
	<i>Infected and affected people</i>	6
	<i>Mental health practitioners and experts</i>	7
	Data collection	7
	<i>Infected and affected people</i>	7
	<i>Mental health practitioners and experts</i>	8
	Data analysis	8
	Ethics approval	8
	Findings	9
	Experiences of infected and affected people	10
	<i>Expressions of infected and affected people's psychological state</i>	10
	<i>Issues and barriers faced when trying to access psychological support</i>	18
	<i>Impact of the Infected Blood Inquiry on mental health and wellbeing</i>	28
	<i>What a better service delivery system could look like</i>	30
	<i>Expressions of an unmet, non-clinical need that may improve mental health</i>	35
	Views of mental health practitioners and experts	37
	<i>Current need for counselling and psychological support</i>	37
	<i>Issues and barriers faced by infected and affected people trying to access psychological support</i>	41
	<i>What psychological support for infected and affected people should look like</i>	45
	Summary and conclusion	55
	<i>Strengths and limitations</i>	55
	<i>Summary of key findings</i>	55
	References	59
	Appendix A	63



Executive summary

Background

Between 1970 and 1991, between 30,000 and 33,000 people in the UK were infected with HIV and/or hepatitis C as a result of treatment with NHS blood and blood products; 2,900 deaths during 1970-2019 are estimated to be attributable to these infections, and people are still dying.

The statutory Infected Blood Inquiry, launched in July 2018, has been investigating the circumstances that led to individuals becoming infected and the impacts this has had on them and their families. Among the many issues raised, the Inquiry emphasised the psychosocial impacts and the lack of access to dedicated psychological support for those infected and affected.

The England Infected Blood Support Scheme (EIBSS) provides access to a discretionary payment of up to £900 for privately arranged psychological support per year (with the option of ‘further treatment’ funding), which can be accessed upon application. However, uptake of the payment among EIBSS beneficiaries and their family members has been very low, and the reasons for this are unclear.

There is lack of robust evidence on the needs for psychological support among those infected and affected by infected blood and blood products. The need for this evidence has become more urgent with the Inquiry concluding in autumn 2023. This study was commissioned to help fill this evidence gap and to inform and consider options for improving the existing offer of psychological support services for infected and affected people.

Approach

We conducted in-depth interviews with 52 infected and affected people and 14 mental health practitioners and experts to understand these needs and explore possible service improvements. Interview participants came from a fairly broad age range and across regions in England, although there were a larger number of women and people identifying as White British than would reflect the UK population. Interviews were conducted between January and May 2023.

Principal findings

The infected blood scandal had, and continues to have, a profound impact on the mental health and wellbeing of infected and affected people. Study participants shared multiple accounts of grief and loss, anger, fear and anxiety, guilt, and facing stigma, isolation and discrimination because of infection.

About half of the people who participated in the study explicitly said they had experienced trauma, and most described incidents that have caused them significant distress. Additionally, many participants described further long-term ill health linked to the side-effects of their infection(s) and their treatments, which many described as having life-changing impacts on their wellbeing. Affected people also reported very significant impacts of their loved one’s infection on their own wellbeing, including profound emotional and financial consequences of bereavement.

Only some of those interviewed for this study had been able to access and use psychological support services for their mental health over the years, and only just over half of the study participants were aware of EIBSS payments for psychological support. Some participants only learnt about the availability of the EIBSS discretionary payment during the research interview.

Identified barriers that prevented people from accessing counselling and psychological support included social and personal issues, such as feeling unable to open up, stigma



and secrecy. But these personal barriers were frequently reinforced or exacerbated through encounters with the wider health system; study participants reported instances of discrimination in healthcare settings, which made it even more difficult for people to seek professional help.

Only a very small number of people found the EIBSS payment scheme for psychological support easy to work through. Most described this route as requiring substantial effort, and being physically and mentally unwell further exacerbated these experiences. Study participants described feeling burdened by the application process and reported that finding a competent and suitable practitioner was often difficult.

There is a substantial need for psychological support in the infected and affected communities, and this need is likely to increase once the Inquiry concludes. Practitioners working with infected and affected people cited instances where the Inquiry had already impeded the progress of clients working towards improving their mental health outcomes.

Conclusions

Existing psychological support services in England – whether accessed through the NHS or privately – do not currently meet the needs of infected and affected communities. Access to psychological support that is effective and experienced as tailored to an individual's needs is not common and finding the right match between client and therapist is often down to chance.

Accordingly, a future improved psychological support service should:

- involve infected and affected people with a range of experiences in the development and design of the psychological support service;
- address the substantial distrust in and legacy of EIBSS and the wider health system to provide an effective service;
- be offered as standard to all individuals known to be infected or affected, and not just upon application;
- be proactive, reaching out to and encouraging individuals to take up support;
- be accessible through various routes with self-referral important to empower people and reduce access barriers;
- be inclusive and broadened to a wider group of affected people than is currently the case;
- be flexible and agile, allowing infected and affected people to access the service when they need it and re-enter it without additional administrative burdens for them;
- be compassionate, respectful of its clients and non-judgemental.
- be set in a specialist setting, include assessment, and offer individual therapy as well as peer support;
- offer a range of therapeutic modalities and delivery modes (in-person, online, telephone);
- work with adequately qualified, accredited and registered practitioners who have experience of working with trauma-affected populations, understand long-term health conditions that impact mental health and vice versa, and, importantly, have sensitivity to, and knowledge about the infected blood scandal, and related conditions including but not limited to HIV and hepatitis C.

The service should be of high quality, with appropriate mechanisms for oversight and accountability. It should be embedded in a wider support system that is proactive, so that those who face the highest barriers or who are most vulnerable are still able to engage and benefit from this support service. This includes the creation of a single contact point or person (a navigator) who assists individuals to navigate the health and social care system more effectively.

A service that 'does the work' by proactively reaching out to infected and affected people was seen as an important way in which the government could begin to address the harm it caused.



Introduction

It has been estimated that between 30,000 and 33,000 people in the UK were infected with HIV and/or hepatitis C between 1970 and 1991 as a result of treatment with NHS blood and blood products.¹ This includes around 1,250 people, including 380 children,² with bleeding disorders who were infected with HIV, and between 2,400 and 5,000 people who were infected with hepatitis C. Around three-quarters of those with HIV and up to 35% of those with hepatitis C had died by 2020. Some 26,800 people were infected with hepatitis C following blood transfusion. Around 2,900 deaths during 1970-2019 are estimated to be attributable to infections from blood or blood products in the UK,³ and people are still dying.

The statutory Infected Blood Inquiry (hereafter, the Inquiry), launched in July 2018, has been investigating the circumstances that led to individuals becoming infected because of receiving NHS blood and blood products.⁴ In assessing the many impacts infection had on infected people and their families, as well as the authorities' (including government) response, the nature of any support provided to those infected, and whether there was a cover-up, the Inquiry specifically emphasised the psychosocial impacts and the lack of access to dedicated psychological support for those infected and their families in England.⁵⁻⁷

However, there is little systematic research on the psychological impacts of HIV and hepatitis C contamination of blood and blood products.^{6, 8} In its report to the Inquiry, the Expert Group Psychosocial Impact described a wide range of psychological and psychosocial issues that infected and affected people were facing and experiencing. It noted that:

"[t]he current expectation would be that all infected individuals, who had received infected blood or blood products, as well as their affected family members, would have received some form of counselling or psychological support, particularly in the context of additional diagnoses of HIV and hepatitis C infection. However, the evidence emerging from the witness statements is that counselling and psychological support was rarely offered, and many witnesses describe being offered no counselling or support."^{6, p. 27}

The Expert Group highlighted that a lack of adequate psychosocial support would have negative effects on a range of psychological outcomes, including adherence to treatment regimens, and noted that this was *"an ongoing theme in witness statements regardless of the age when diagnosis was received"*.^{6, p. 28}

Financial support for infected people and their dependents has been made available from 1988 (Box 1).⁹

1. Infected Blood Inquiry. Expert Report to the Infected Blood Inquiry: Statistics. 2022.
2. The Haemophilia Society. The contaminated blood scandal. 2023.
3. Infected Blood Inquiry. Expert Report to the Infected Blood Inquiry: Statistics Group (Supplementary). 2023.
4. Infected Blood Inquiry. Explore the Inquiry.
5. Infected Blood Inquiry. Sir Brian Langstaff calls on new sponsor Minister to cut through problems with psychological and financial support. 2020.
6. Infected Blood Inquiry. Expert Report to the Infected Blood Inquiry: Psychosocial Issues. 2020.
7. Infected Blood Inquiry. Expert Report to the Infected Blood Inquiry: Psychosocial Issues (Supplementary). 2020.
8. Riva S, Del Sordo S, Genovese U, et al. Medical decision making and risky choices: psychological and medicolegal consequences of HIV and HCV contamination of blood products. *HIV AIDS (Auckl)* 2017; 9: 161-165.
9. Department of Health. Infected blood: reform of financial and other support. 2016. London: Department of Health.



Box 1 Financial support schemes for infected people, bereaved family members and dependents

Since 1988, successive governments have set up different schemes to provide financial and other support to infected people and their dependents: the Macfarlane Trust (from 1988), Eileen Trust (1993) and MFET Ltd (2010) to support people who contracted HIV, and the Skipton Fund Ltd (2004) and Caxton Foundation (2011) to support those infected with hepatitis C. Payments by MFET Ltd (HIV) and Skipton Fund Ltd (hepatitis C stage 1, 2) were made in respect of infected persons, while the Macfarlane Trust (people with bleeding disorders infected with HIV including hepatitis C co-infection), Eileen Trust (people infected with HIV (including hepatitis C co-infection) through blood transfusion) and Caxton Foundation (hepatitis C) supported both infected persons and uninfected family members, including those who had been bereaved.⁹ In 2017, the various schemes were brought together in the 'Infected Blood Support Scheme' administered by the NHS Business Services Authority in England and similar governmental schemes in Northern Ireland (Infected Blood Payment Scheme), Scotland (Scotland Infected Blood Support Scheme) and Wales (Wales Infected Blood Support Scheme).

Payments initially did not cover access to counselling or psychological support. This was introduced after a 2010 review by the Department of Health of the support available to infected people and their dependents,¹⁰ leading to a decision to provide financial support to pay for counselling from 2011. In England, this currently includes a discretionary payment of up to £900 for privately paid psychological support per year (with the option of 'further treatment' funding), which can be accessed upon application through the England Infected Blood Support Scheme (EIBSS) (Box 2).¹¹

Box 2 England Infected Blood Support Scheme counselling and talking therapy funding

EIBSS provides funding towards counselling and talking therapy costs for private treatments. The funding covers the cost of an assessment with a registered therapist and the cost of talking therapy sessions. It is available to infected people and to bereaved individuals who are registered with the EIBSS, as well as family members of an infected person registered with the EIBSS or previous schemes.

Types of funding include initial funding, which involves up to £900 per year to fund the cost of talking therapy sessions with a counsellor or therapist. The payment is made to the beneficiary. From April 2023, further funding has been made available if beneficiaries and their counsellor or therapist agree that a further treatment plan is required. The additional funding is paid directly to the counsellor or therapist. The further funding option is available for a one-year evaluation period, after which a review will be undertaken to understand if the support will continue.

Source: NHS Business Services Authority¹²

10. Department of Health. Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants. 2011. London: Department of Health.

11. NHS Business Services Authority. England Infected Blood Support Scheme. 2023.

12. NHS Business Services Authority. Talking therapy support. 2023.



In April 2022, 3,200 people were registered for support through the EIBSS.¹³ The vast majority were people with hepatitis C (72%); those with HIV/hepatitis C co-infection accounted for 9%, and bereaved partners for 17%. The uptake of discretionary payment for counselling has been low however; in 2021/22, a total of 62 payments were made,¹⁴ which is just under 2% of beneficiaries. While there is understanding of some of the potential shortcomings of the current discretionary payment arrangements, such as the adequacy of the annual amount of £900 for those requiring longer-term support or the nature of the application process, there is a lack of in-depth research explaining the low uptake of payment for counselling and psychological support.¹⁵

There is awareness that the Inquiry might lead to greater need for (additional) access to psychological support as infected and affected individuals provide evidence to the Inquiry and/or upon publication of the final report, which is expected in autumn 2023.¹⁶ Contributing or listening to the Inquiry means that infected and affected individuals will have to revisit the distressing experiences of receiving infected blood and blood products and reflect on the long-term consequences this has had and continues to have on their lives. Further, the Inquiry's Second Interim Report released in April 2023 recommends *"that without delay steps be taken to provide a bespoke psychological service in England"*^{16, p. 92} likely creating greater demand for such services.

The Department of Health and Social Care (DHSC) has identified an urgent need for evidence on the needs for psychological support among those infected and affected by infected blood and blood products. This study was commissioned to help fill this evidence gap and to inform and consider options for improving the existing offer of services.

Study aims and objectives

The study aimed 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 and the requirements for psychological support to meet these needs.

Specifically, we sought to:

- assess the current need for psychological support for infected and affected people and how this need changes as the Inquiry concludes and the government responds to recommendations;
- determine the extent to which existing psychological support services can meet the needs of infected and affected people and explore the routes they are taking to access support;
- understand the experiences of infected and affected people of accessing psychological support services and the barriers or enablers they encountered in doing so;
- assess the experiences of practitioners providing psychological support services to infected and affected people and their understandings of how to meet the specific needs of this group; and
- explore what else would be required to meet the psychological support needs of infected and affected people.

13. NHS Business Services Authority. England Infected Blood Support Scheme. Annual Report 2021/22.

14. NHS Business Services Authority. Personal communication, 19 June 2023.

15. Infected Blood Inquiry. Eighth written statement of William Vineall. 2022.

16. Infected Blood Inquiry. Second Interim Report. 2023.



Methods

Study design

We conducted a qualitative descriptive study using in-depth interviews with (a) individuals historically infected with HIV and/or hepatitis C and/or family members of infected individuals, and (b) mental health practitioners and experts involved in the commissioning, oversight or delivery of psychological support services across the UK. We complemented the work with a rapid review of existing documents of psychological support services for infected and affected people in place in Northern Ireland, Scotland and Wales to understand the range of approaches taken by the devolved nations. The document review was primarily intended to inform the interviews with mental health practitioners and experts.

A key consideration of our work was the added burden that the planned interviews might place on participating infected and affected people as it would require them to reflect on their experiences as survivors and/or bereaved family members of infected individuals. We consulted with several organisations providing support to affected individuals during autumn 2022, namely the British Red Cross, the Haemophilia Society, the Haemophilia & Bleeding Disorders Counselling Association, the Hepatitis C Trust, and the Terrence Higgins Trust, to help us shape the work. These organisations have provided feedback on our research materials (information sheet, interview topic guide, see below), which we have incorporated. The organisations also acted as facilitators to engage infected and affected individuals to participate in the study.

Participant recruitment

Infected and affected people

We used two approaches to participant recruitment. We first consulted support organisations (Hepatitis C Trust, Terrence Higgins Trust, British Red Cross) who helped advertise our study among their newsletter subscribers, or by word of mouth, inviting them to contact the research team if interested in participating in the study (December 2022 to January 2023). Secondly, we drew on the 2022 Service Satisfaction Survey of England Infected Blood Support Scheme (EIBSS) beneficiaries, operated by the NHS Business Services Authority (NHSBSA), which was fielded between November 2022 and January 2023. The EIBSS survey included a set of questions on awareness of payment for and use of psychological support services among beneficiaries and an additional question inviting respondents to participate in the research presented in this report. Survey respondents interested in participating in the study were able to provide a telephone number or email address for the research team to contact them. For those providing contact details, NHSBSA shared the following data: name, age, gender, region and ethnic group as well as all answers to survey questions on psychological support.

We initially expected to use the data to create a subsample of survey respondents, aiming at recruiting approximately 15 to 20 in each of three broad interview 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 or charities); and (c) individuals who have not done either. However, by the time we received the survey data (February 2023), we already had expressions of interest from some 20 participants via the support organisation recruitment route; we therefore recruited a smaller sample of participants via the survey route. Within the latter, we sought to include people from a range of socio-demographic backgrounds (age, gender, region of residence, ethnic group).

Interview participants recruited through the support organisation route

A total of 36 infected individuals or family members expressed interest in the study via the support organisation route and 24 were interviewed between January and May 2023.



Interview participants recruited through the EIBSS survey route

A total of 366 EIBSS survey respondents had indicated their willingness to participate in further research; this represents 20% of respondents to the EIBSS survey (n=1,835 survey respondents out of 3,286 survey invites (56% response rate))¹⁴ (see also Appendix A). Of these, we contacted interested survey respondents in seven groups as shown in Table 1. Of 63 invited, 28 agreed to be interviewed during April and May 2023.

Table 1 Sampling of interview participants recruited through the EIBSS survey

	Invited	Interviewed
Has received discretionary payment and has had psychological treatment in the past	9	6
Aware of but has not received discretionary payment; has had psychological treatment in the past	7	4
Not aware of the discretionary payment; has had psychological treatment in the past	8	3
Has not had psychological treatment in the past and does not wish to access treatment*	7	4
Has not had psychological treatment in the past and does not know whether they wish to access treatment*	7	3
Has not had psychological treatment in the past and wishes to access treatment*	16	5
Did not wish to disclose survey responses to the research team	9	3
Total	63	28

Note: * Response to the question “Would you or a family member want to have access to any psychological treatment, support or counselling linked to your, or your partner’s, infection?” (No; Don’t know; Yes)

Mental health practitioners and experts

We purposively sampled mental health practitioners and experts across the UK. We invited individuals working with support organisations in England and the devolved nations as well as people with expertise in the wider mental health field. Potential participants were identified from relevant organisations’ websites, the authors’ professional networks, as well as recommendations from interviewed participants. We invited a total of 19 mental health practitioners and experts, of whom 16 expressed an interest in the study. We were unable to arrange interviews with two potential participants, leading to a final sample of 14 mental health practitioners and experts who were interviewed (in 13 interviews).

Data collection

Infected and affected people

Individuals who had indicated their willingness to participate in the research were contacted by the researchers via the means indicated by the participant (telephone, email, text message). The researcher explained (verbally or in writing) the purpose of the research and what participation would involve. Upon agreement to take part, a date for the interview was set, seeking to identify mode of interview (telephone, video



conferencing, in person), dates and, in case of in-person preference, location that was most convenient for the participant. Those agreeing to take part in the interview were provided with a copy of the information sheet and the consent form by post or email in advance of the actual interview, depending on the participant's preferences.

Interviews used a semi-structured topic guide exploring participants' views on and experiences of counselling, psychological and other types of support; their knowledge of EIBSS and experience of accessing counselling and talking therapy funding through the scheme; and views on what a psychological support service should look like. We also collected broad demographic information (age, gender, region of residence, ethnic group). Most interviews were conducted using the video platforms Zoom or MS Teams (n=31), followed by in-person interviews (n=11); the remaining 9 interviews were conducted via telephone. One interview involved two participants (a couple). Interviews lasted an average of just under 60 minutes, with the majority ranging from 41 to 73 minutes. Written consent for participating, and having the interview recorded, was confirmed verbally at the beginning of the interview. Participation in interviews was entirely voluntary and participants were able to request the interview or interview recording to be stopped at any time; no such request was made. Participants were offered £35 in compensation for their time (in the form of a gift voucher or cash payment); travel costs were also reimbursed where relevant.

Mental health practitioners and experts

Potential participants were contacted by email; in this initial approach, they were also provided with the information sheet. Upon agreement to take part, a date for the interview was set, seeking to identify dates that were most convenient for the participant. At this point, participants were also provided with the topic guide and consent form prior to the interview. Written consent for participating, and having the interview recorded, was confirmed verbally at the beginning of the interview.

Interviews followed a semi-structured interview guide and explored perceptions of the psychological support offering to infected and affected people, including the availability and appropriateness of existing services offered through the NHS; access routes; service uptake; challenges involved in providing appropriate services including waiting times; and required practitioner competencies and training. The topic guide was adapted for participants in the devolved nations to reflect differences in the psychological support service offerings and routes into them. All interviews were conducted using the MS Teams platform and they lasted an average of 52 minutes (range of 48-78 minutes). One interview involved two participants.

Data analysis

Interview recordings were transcribed and anonymised. Interview transcripts were analysed following a thematic approach.¹⁷ This included the research team familiarising themselves with the interview data through reading and rereading transcripts and team discussions to identify relevant themes. This process of developing, synthesising and contrasting themes was ongoing as the team worked towards their final analysis.

Ethics approval

Ethical approval for this study was granted by the Observational/Interventions Research Ethics Committee at the London School of Hygiene & Tropical Medicine (LSHTM Ethics Ref: 28215).

17. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77-101.



Findings

We interviewed 52 infected and affected individuals in 51 interviews. Table 2 provides a summary overview of selected socio-demographic characteristics of those interviewed.

Table 2 Key characteristics of infected and affected people interviewed for this study

	N		N
Infected	41	Ethnicity	
Affected	11	Black/Black British, African	1
Bereaved	10	Asian/Asian British	4
Gender		Mixed: White and Asian	1
Male	20	Mixed: White Other	1
Female	32	White: British	37
Age group		White: Irish	1
21-30	1	White: European	2
31-40	3	White: Other	3
41-50	8	British	2
51-60	17	Region of residence (current)	
61-70	13	East of England	7
71+	10	London	7
Recruitment route		South East	12
EIBSS survey	28	South West	7
Other *	24	Midlands	8
		North West	4
		Yorkshire/Humber	5
		Wales	1
		Europe	1

Note: * People volunteering for interview after receiving information about the study (via other organisations or word of mouth) including n=3 recruited from the EIBSS Survey

We further interviewed 14 mental health practitioners and experts (in 13 interviews). The majority of interview participants were practising clinical psychologists or psychotherapists (n=10); the remainder were involved in service support roles for people with HIV or hepatitis C.

In the next section, we describe first the experiences of infected and affected people, followed by an analysis of our interviews with mental health practitioners and experts. To maintain confidentiality, study participants are only described by a study identification number; we will not disclose age, ethnicity, region of residence or, in case of mental health practitioners and experts, organisational affiliation. Identification



numbers starting with a '1' refer to infected people, those with a '2' to affected people and those with a '3' to mental health practitioners and experts.

Experiences of infected and affected people

Analysis of interviews with infected and affected people identified five major themes: (1) expressions of infected and affected people's psychological state; (2) issues and barriers faced when trying to access psychological support; (3) impact of the Inquiry on mental health and wellbeing; (4) what a better service delivery system could look like; and (5) what broader, non-health system approaches can be taken to improve mental health and wellbeing. We discuss each theme in turn.

Expressions of infected and affected people's psychological state

Participants were encouraged to talk freely about their current psychological and emotional states, resulting in rich, complex accounts from 52 infected and affected respondents. We invited participants to evaluate their current psychological and emotional states on a scale of 1 (worst) to 10 (optimal). Most (n=48) provided a response to this question, with some putting themselves on a sliding scale capturing day-to-day fluctuations in their sense of wellbeing (e.g., from 5 to 7, which would produce a median of 6 for that person). The mean 'score' for our respondents' current psychological and emotional states was 5.8, with individual responses ranging from 1.5 to 10. An equal number of participants (n=17) rated their current psychological and emotional states as either high (7 or higher) or low (5 or lower); some 30% (n=14) rated it as medium (5 to 7).

Most of the infected people we interviewed described living with long-term health conditions associated with their infection(s) (and their treatments) that had a life-changing impact on their wellbeing, with some people coping with further health complications unrelated to the infected blood. Affected people also reported very significant impacts of their loved one's infection on their own wellbeing.

The impacts on people's psychological and emotional states that were predominant across the interviews were: grief and loss; anger; fear and anxiety; guilt; and feeling stigmatised and/or isolated. In addition, although only about half of the study participants explicitly identified themselves as having experienced trauma, most described incidents that have caused them significant distress when discussing their current state of wellbeing. We describe the reported psychological and emotional states in turn before outlining three broad ways in which people have independently coped with the impacts of infection. Some people told the interviewers that they were pleased to have the opportunity to talk about their experiences and had found it beneficial.

Grief and loss

Almost all participants described feelings of profound loss as a consequence of infection by NHS-administered blood or blood products. These losses included the death of an infected loved one, decisions not to have children, failed marriages, the ending of professional or working lives, forced sale of homes, periods in people's lives in which they or a loved one 'self-medicated' with alcohol or drugs or 'opted out' of future-orientated activities (such as going to or completing university), and times when they felt unable to care for children the way they wanted (such as during interferon treatment for hepatitis C). People also talked about the stress, pain and discomfort of living with chronic health conditions associated with having been infected, including liver failure and cancer. Combinations of these experiences shaped feelings of grief and loss for a large majority of the people we interviewed. One respondent explained: *"I grieve for my life. I'd like to be able to tell somebody, "I used to do this, and I could have been, I should have been" [104].*



Experiences of bereavement were common among interviewed infected and affected people. Participants described their grief for spouses and partners, mothers and fathers, siblings, uncles and friends, and living with distressing memories of their ill health, treatment and the circumstances of their passing (including experiences of stigmatisation and isolation). Some of the lasting impacts of these bereavements have been guilt, feeling “robotic” [209], a frequent sense of the loved one’s absence, and vivid, painful recollections. A woman whose husband died as the result of infection with hepatitis C summed up a sense from everyone who talked about a loved one’s or a friend’s, death:

This money [compensation payment] doesn’t give me anything. I’ve lost something that I’m never going to get... I’m never going to get his love back. And I wouldn’t - I don’t know what my life would have been like without this because we’ve lived with it for such a long time. It [his illness and death] was totally unnecessary. [209]

People also talked about how infection had impeded their ability to parent their children due to their ill health or the treatment they were receiving, particularly courses of interferon and ribavirin to treat hepatitis C, and many described acute effects on their day-to-day lives:

Well, my average day, at the worst end of it was I would possibly wake up about 9 or 10 o’clock. Take me a little while to come round from feeling a bit groggy, so 11 o’clock, I’m feeling reasonably human. But by 1 o’clock, I was starting to feel tired again. So, anything I wanted to do during the day was in that very short space of time. I would then go back to bed, or back on the sofa; it was bed, sofa, bed, sofa. And then come teatime, I would get up to spend some time with the children. And then seven o’clock, eight o’clock, something like that, back to bed and that was it, that was Groundhog Day. No life, just existing. [103]

They described how chronic fatigue and mood swings, caused by interferon treatment, affected their relationships with their children, describing “the trouble, the upset, the trauma” [105] of illness and treatment severely impacting family life. They remembered uncharacteristically losing their temper at a “flick of a switch” [108], and children moving out, going into foster care or dropping out of school. Some parents have been left with lasting regrets.

I was the worst mother because I knew I had to sort of support them, really, I had limited energy, I felt ill all the time, and I had to get myself through – I left school with nothing, I was working all hours for peanuts and I suddenly realised that I needed to go to university, get some qualifications, and earn a decent amount of money, which is actually what I did with everything that I had. And like I didn’t even see that as – I just thought, well, it’s luck that I got through university, do you know what I mean. And I did that. And I wasn’t there for [my children]; I wasn’t there for them. And that is the one thing that I feel so guilty about. And they’re grown up now [...] and I never told them about what I had. So, all they saw was this woman who was like doing whatever she wanted to do and going to bed and not able to cope with them. [107]

Several parents also had concerns about the continuing impact of these difficult times on their children into adulthood. One mother described the importance of making “better memories that are more prominent than those early, unhappy ones” [103]. Other infected and affected parents talked about their concerns for their adult children’s mental health, including their children being prescribed medication for depression, not seeming to be doing well, and from whom they had become estranged.



Affected people whose parents were infected while they were children additionally spoke about the far-reaching implications of infection for family relationships. These included children not knowing or not being informed about the cause of their parents' ill health; parents seeming to withdraw from them (possibly on medical advice regarding infection risk); children witnessing their parents' deteriorating health and their responses to treatment (including mood swings, fatigue and suicide attempts); secrecy and stigma; and a parent's death. In some cases, adult children had not received any financial or other support from EIBSS at the time that we interviewed them.

Additionally, people talked about lost periods in their lives ("*We grieve for ourselves*" [120]). Some people felt that they lost years to illness or treatment. Some people lived with chronic ill health for years, some over three decades, unaware they had been infected. People infected with HIV described being told not to expect to live long and so not to aspire to careers or make long-term plans.

I wasn't going to have a career, because what's the point of having a career when you're going to be dead. [135]

There wasn't the data so the early assumption and this carried on for a long time, was that you were going to – it's fatal; there's no getting away from it: "this fatal disease, you will die." But before that, you were told "well, it might – in some people, it's characterised as nothing more than flu-like symptoms and other people will die." And you had no idea; this was about, kind of, the original situation: "you may have flu or you may die." But then, more and more people kept dying [laughs] and less people seemed to have flu so there was a shift, but you weren't really told; you had to learn this for yourself. [116]

Several people explained that the knowledge that they were infected had a profound effect on their life course. One man who was infected with hepatitis C said he "*blew*" his first compensation payment from the Skipton Fund in a "*purple haze*" and explained:

I was an angry young man, and I think that is off the back of that. Trust. Trust for like authority and doctors went completely out the window. Still is. Don't trust them anymore. [...] I think because I was only young when it first happened, so I think you can mix it in with teenage angst or whatever. I don't know, but you know what I mean. [117]

Some people talked about their sadness about not having been able to have children and the impact that this had on their relationships with partners. One woman felt pressured into going through termination of a pregnancy on medical advice. Another woman whose partner had been infected with HIV described not being offered sufficient support or advice as she and her partner thought about the implications for having children.

And actually, through the sort of lack of support, you know, lack of any – because we were isolated, we were thinking "Oh this is something that's happening to somebody else," and you know, we want to have children, you know. And you know, "It's not a good idea but if you want to go ahead, we'll monitor you." And that was it and then I became [HIV] positive. It was sheer utter, you know, brutal negligence really. Instead of kind of like sitting and talking and saying, "Well you know, what support do you need? Are you actually fertile? Do you know what you do?" Do you know when you're supposed to have sex, you know. You know, it's like that, you know, just the basics, so it was awful. [101]



Anger

Most people described experiencing feelings of anger; anger in response to government and NHS involvement in the administration of infected blood and blood products, as well as institutional and individual, particularly some medical practitioners', responses to infected and affected people, including the withholding of information and denial of responsibility.

Anger towards the authorities, the NHS and medical professionals increased in response to revelations about policy and practice during the Infected Blood Inquiry. Many people described long personal and collective struggles for transparency about the infected blood scandal and to have their situations recognised. One person described feeling “*gaslighted*” by government and “*made to feel like a beggar*” [111], while another referred to a “*cover up*” [104]. People we spoke to had heard evidence or read submissions from doctors that they were sure – from personal experience of being treated by them – contained falsehoods.

Most people described successive failings in NHS responses, including not being informed about their or their loved one's infection(s) for many years, being informed inappropriately about infection(s), and the withholding of information about the circumstances in which they or their loved one were infected. These feelings were often intensified by the difficulty accessing medical records or finding that records were missing around the time of infection and diagnosis. One woman who reported continuing physical health problems and sporadic mental health challenges (including periods in residential psychiatric care) throughout most of her adulthood told us that she was only informed at the start of the COVID pandemic that she had been infected. It was found that infection was through blood transfusion in the 1970s, which itself had become necessary because of problems during labour that had not been acted on in time, ultimately requiring surgery.

I try not to get angry, because they didn't do it maliciously. They didn't go out to say we are going to do this, maybe they did but I don't know. I thought it was a mistake. They were just trying to help. The only thing that upsets me a little bit is when they found out why didn't they call us, instead of destroying all the evidence? [136]

People we spoke with were also often angry about medical staff who subjected them to intrusive questions or judgements about their lifestyles by assuming their infection was the result of intravenous drug use or involvement in sex work. Several people have felt stigmatised during medical treatment, such as through overly cautious ‘infection control’ practices, which was sometimes accompanied by hostility from individual medical practitioners, and of not having had concerns taken seriously about their or their loved ones' ill health.

I went in and said to him how extremely tired that I'd been feeling; that it was beyond normal tiredness, and I'd had two blood transfusions before the bloods were screened and was worried about hepatitis. And he basically said to me, “Look, of course you're tired, you've got four young children. And don't be silly, you won't have that,” and ushered me out of the room. So, no test was offered. [120]

Several people told us about specific incidents in which they felt that they or their loved ones had received inadequate medical care. One man, whose wife was infected with hepatitis C, described years of struggling to ensure she had care, including complaining when she was housed with patients who were inebriated on the ward:

She lasted about three years after the transplant, but most of that three years, she was in hospital. [...] And in the end, I'm certain – they wouldn't tell me – but they was running out of antibiotics to treat her, because she had been on so many different antibiotics. The pharmacy were making them – their own. In the end,



she had an infection that they couldn't cure, and I'm pretty certain it was either [Clostridium difficile] or the MRSA or something like that. And no matter how much I questioned them, they wouldn't – but she just had so many things go wrong. [214]

Participants reported that their infection(s) resulted in devastating outcomes, including losing livelihoods and homes, damage to their marriages, family relationships and social networks, and derailing their ambitions, including their decision to have children, as noted above. Many people also had a strong sense of the wider damage caused to other infected and affected people:

I've always said if you can imagine the infected person standing in the middle and there's a ring around them, and then another ring layer would go to their spouses or partners, and then the next ring out would be their children and then their family, friends, work colleagues etc. Suddenly you've got this big ripple effect of the effects on the person. And for those people that lost more than one person, it's ... [120]

Participants talked about various ways in which they experienced anger and responded to feeling angry in different ways. Some described how anger followed on from debilitating emotional responses and enabled them to take action. One woman described the process of becoming angry after her request for a blood test for hepatitis C had been refused by her GP in the mid-1990s and she was found to be infected in the mid-2010s:

[M]y world come crashing down; it was like a bulldozer had hit me. [...] And I went through various stages of emotions, which started with me becoming very withdrawn, which is not me. [...] And I didn't want to go out, I didn't want to speak to my kids. [...] I then went through the emotions of feeling dirty, where [I sat] in the bath, scrubbing, knowing that I'd got something in me that was potentially life-threatening. And then I got angry, and I mean I got really, really angry. [120]

However, people also described how they have worked to prevent their anger from impacting on their daily lives and relationships.

I've managed to stabilise myself, so much so that I don't get angry anymore because the anger is so destructive. [102]

Occasionally, something will happen, and I'll have one of these anger flare-ups. [...] It's not something I see coming or feel coming. It's just very much bang and it's on me, and then five minutes later it's over. But then I'm left with a very low feeling afterwards for quite some time. But I think what I take away is that those episodes are much fewer and further between. And I do put that down to generally being able to deal with and process things much better. And there's still – I am a bit of the opinion that there's always stuff to do. There's always stuff to do. I certainly am not thinking, "Woohoo, I've dealt with everything. I'm absolutely fine." Because I'm not. [109]

Fear and anxiety

Most people we spoke with experienced fear or anxiety related to a range of uncertainties in their lives linked to infection and its impacts. Many worried about being financially dependent on EIBSS without a guarantee of continued income from the scheme. People were also frequently anxious about the effect that infection has had on their parents, children, or other close relatives. In addition, people raised fears or anxieties about their health in the future, the risk of infection of loved ones, and the end of life.

One participant, who, due to a rare medical condition had received large quantities of blood during his treatments, told us about suffering a massive haemorrhage on his way home from the hospital:



I was there at the edge of this field vomiting blood and my mum was holding me, and I just looked at her and I said, "I can't do this anymore." I says, "I know what they're going to do, and I can't, I can't." I says, "Please just sit with me and just let nature take its course here." And I remember the look on my mum's face. [132]

Despite this trauma and having to undergo major invasive surgery immediately after, he reflected that being told he had been infected with hepatitis C was a worse experience because of the "relentless" uncertainty around the infection:

There's no end zone. There's no, "Well, this is the starting point. This is the finishing point" [a cure]. The finishing point, I don't know and that's [the uncertainty] the killer that you have to live with on a day-to-day basis. [132]

Anxiety can also pervade people's daily lives. Study participants spoke about their fear about "people finding out some way or other" [134], having caused anxiety and stress in others ("[My son is] a mess of anxiety and stuff, and that's my fault" [111]), or feeling unable to engage outside their families. People often mentioned fears or anxieties about their future health as the result of infection. Many people who spoke to us had personal experience of severe illness or were aware of poor health outcomes for infected people. They explained that living with hepatitis C and HIV infection was a constant worry, even if effectively treated.

And we'd been in [country] for my son's wedding and I'd got to the point where I'd just finished a 12-month course of treatment for hepatitis, it was the same time I'd gone through treatment. And I remember being in the hotel just me and [name], and I just broke down, and it came from nowhere. And I just broke down and I was sobbing like a baby. And [name] was like, "What the hell is going on?" And I said it was just the pressure of finishing that treatment and then not knowing whether it's going to come back. [108]

Several people experienced anxiety about the risk that their infection might spread to others. Many of those infected with hepatitis C told us that they had been given very strong warnings about taking precautions when they were informed about infection in the 1980s and 1990s, and which had created "a sort of deep-seated restraint on getting involved with other people" [137] that pervaded people's lives ("I mean even making love with [my wife] was worrying at the time, and nothing seemed to [have] happened, so we seemed to be all right." [137]). We heard instances of fear and anxiety worsening other mental health problems, including through the constant worry of infecting others ("I have a fear of going too near the grandchildren." [134]). One man explained that his obsessive-compulsive disorder (OCD) was hugely aggravated by living with hepatitis C infection.

They locked me up in [psychiatric care] because the OCD was so bad, but the OCD was saying, "Well, if you don't do this, your hepatitis will come back. If you don't do this, someone in your family will die." [134]

Several people referred to healthcare settings as a cause of anxiety because of past encounters and feelings of (continuously) being stigmatised ("And "How did you get [infection]?" Every bloody time. "How did you get it?". [107]) or feeling the need to protect healthcare staff.

Knowing full well, actually, why I didn't want to go to the dentist. [...] I felt morally responsible not to infect people [...] But what do you do? You go to the dentist, "Don't put your finger in my mouth, because I've got hepatitis C. Or if you do put your finger in my mouth, please protect yourself. Can you wear two lots of gloves?" [104]



A few people expressed concerns about growing old and the need to rely on healthcare, given the experiences they have had in the past.

As I get older, I'm fearful for my life, I'm fearful of what I'd be in this country and the way we treat, let alone someone who is HIV positive, but how we treat the elderly [...] I have no children. I have no one. I'm fearful of that vulnerability that I know because I've experienced it and I've been there. I've been down to six stone, I've been dying, I've been emaciated. I've been – and I know what it's like to be in a social, in a healthcare system with no one. [101]

Coping

Our interviews did not specifically focus on coping mechanisms, and it was clear that people were only able to give us limited insights into the complex and dynamic ways in which they had dealt with significant challenges to their psychological and emotional wellbeing. Study participants gave us some indications about how they had coped with the health, financial, professional, social and personal implications of infected blood and the impact that this has had on their current psychological and emotional states.

Three broad types of coping strategies were identifiable in what they told us: getting on with life; activism and solidarity; and managing. Many people described moving between these different forms of coping or using more than one type simultaneously.

Getting on with life

Most people we spoke with said that they were 'getting on with life' at the time that we interviewed them, although it is important to note that 'getting on' was often experienced as a struggle, with the negative effects resulting from infection remaining ever present. Participants described the various factors that they felt had helped them to get on, including having supportive partners, family and/or friends, a purpose (including religious faith) and meaningful activities, sufficient income and manageable health conditions.

I'm very conscious of the balance that I've got, which is a very fine one between being OK and not being OK. [109]

Many people explained that getting on with life required effort. This included people reframing their own experiences compared to others, as it could have been worse: they could have died.

I realised, actually, maybe my situation's not too bad. And it really made me feel – it was like a bit of a, almost a shot in the arm. It was, well, you're – things are not as bad as you think. When you see people from the haemophiliac group that – there was six or eight of them at the front, and now there's only four, and where's the other two gone? Well, they've died. And so, I don't – there's no self-pity. I think that's what I'm really trying to explain; there's no – absolutely no self-pity on my part whatsoever. What's happened has happened. What I do about the future is what's really important to me and getting through the next sort of 20 years and hopefully stretching it to that will be great. [104]

Many mentioned the difficulty of "opening up" [108] about their emotions after putting them "in a box" [117, 203], focusing on "pulling yourself together like a pair of curtains" [208].

I'm quite strong minded, but at the same time I'm quite weak. From being a youngster I've always put up a front there, but behind that front there's demons, skeletons and it's fear of the unknown at the moment. That's the main problem I face on a daily basis. I try and keep busy. [119]



One woman remembered how her own distress which she had “powered through” caught her by surprise while on a holiday:

Some counselling at that point would have been so useful to help me find my way through. But I found myself, I went down and laid on a sunbed one day and I'm reading my book and I put my book down and I just burst into tears. Wow. That's not right, is it? This is so out of character for me [...] it was just a moment of recognition. I think stepping out of the busy, day-to-day employment of being somebody's wife, somebody's mum, somebody's employee, all the jobs you have to do at a weekend, the laundry, the stuff and the shopping, blah, blah, blah. It's like just shove all that noise to one side and listen. And I just fell apart. [103]

Dealing with the additional stresses and strains of daily life can heighten the feelings associated with the psychological and emotional impacts with which people have otherwise been able to cope.

So, I've had to deal with this on my own, and this is when it's hard. When you lose a partner, you think when he dies that that's it, you know. People they worry about you when they die, but they don't think about the years to go on and what implications it has, and that's where I think it'd be incredibly important to help support – you know, like with me having to go to look after and help my daughter with the baby and no husband to share it with. It's really hard. [202]

Activism and solidarity

Several study participants were involved in forms of solidarity and activism as a coping strategy, of being concerned for other infected and affected people and engaging in meaningful activity developing supportive networks. They spoke about how this strategy had felt beneficial to their wellbeing.

I thought, “I've got to put this negative into something positive. Otherwise, I'm going to end up doing something silly.” And I don't mean silly to myself at that stage but maybe outside, outwardly and end up, I don't know, maybe even in prison; the anger was that bad. [120]

Also, activism was experienced as something that might bring about change.

I mean I guess a lot of my adult life has been studying healing and being a warrior and trying to support others in my situation, being an advocate. I mean it gives life meaning. It's not what I necessarily would have chosen to have done with my life. [111]

Solidarity included a spectrum of activities including attendance at the Infected Blood Inquiry, membership of self-organised support groups, maintaining contact with individual infected and affected people, and involvement in consultations. These activities are orientated towards helping communities of infected and affected people, but they can also be experienced by individuals as empowering: “I thought, “This is because I'm fighting.” I didn't hide away.” [120]

People involved in solidarity and activism often expressed an interest in hearing or supporting the voices of infected and affected people who they felt were not always heard.

I am the listener, that's what I do; I listen and I talk to victims affected or infected. That group gave me back my purpose in life because I've always been a doe-y sort of person and I'm a giver, as well. [121]



Managing

Most people talked about going through very difficult periods since they had learnt about the infection, during which they had just about managed to cope with its psychological and emotional impacts. Several noted times in the past in which they had experienced severe “breakdowns” [116], had not wanted to live, or had suffered from depression. Some people also talked about currently or recently trying to manage with debilitating psychological and emotional states including “flashbacks” [206], feelings of being “worthless” [141] and intrusive thoughts.

I tried to deal with everything on my own. A year ago, well last year, I was just like, “I really need – the inquiry’s not finishing. I’m not coping. It’s affecting me still. I’m still getting flashbacks. I’m still getting the ... you know, I need help with this. I’m having endless – more diagnoses linked to that. I’m being treated differently or badly by medical people who treated me before they’d found out the diagnosis and then wouldn’t see me until after treatment, and their attitudes have changed to me.” So, I needed help. [104]

One woman talked about the complicated painful feelings she had as an adolescent while her father was undergoing interferon treatment towards the end of his life. She explained the difficulties of trying to find support to cope with the psychological and emotional legacy of her father’s prolonged illness and death as an adult, describing successive periods of feeling overwhelmed and slightly more able to cope.

The annoying thing about the doctor is that whenever I was in a crisis, I didn’t feel capable of going to the doctor at that point, when I was at my worst. It was more of a, like, I’m trying to get through every day and to get to a point where I’m basically not – where I would feel like I’m going a bit bonkers, kind of thing. So, then you try and work yourself through it. I got to a point where I was feeling a bit more able to manage the situation. [212]

Some people in this situation told us about successfully taking remedial action to address their extreme distress, including trying to find a suitable therapist or visiting their GP. However, several people had not yet found any external source of help to cope, while others were doubtful that anything would be helpful. One woman who said that her husband’s death had “destroyed [her] whole family” and that she had “to learn to let go” first although even if that was ‘successful, she was not certain “if talking [therapy] would help” [209].

Of those who said that they had had contact with mental health services or therapeutic practitioners, several felt that they had been misdiagnosed or treated without full understanding of their experiences.

My sons have tried to kill themselves over this. They were under [Child and Adolescent Mental Health Services, CAMHS] at the time, but CAMHS did not understand it. They couldn’t grasp it and, of course, they outgrew CAMHS and were transferred to the adult service. The adult services didn’t take notice of what was actually being said and they were just like, “Come on, why don’t you go to a youth club?” and it’s like, “Boom, you haven’t listened”. [105]

Issues and barriers faced when trying to access psychological support

Study participants described a wide number of issues and barriers that they faced when trying to access psychological support. These can be grouped under three main headings: social and personal barriers; structural barriers; and issues and barriers relating specifically to the England Infected Blood Support Scheme (EIBSS).



Social and personal barriers

Social and personal barriers related to a range of observations including family responsibilities; difficulty acknowledging or recognising the need for help; stigma, shame and secrecy; perceptions of social roles; and feeling too overwhelmed or unwell to seek help. Some of these mirror the expressions of psychological states described in the preceding section.

Family responsibilities

Some study participants said they prioritised bringing up children or holding their families together over seeking support. This was sometimes because they believed that opening up the sadness would stop them from being able to function. There was also mention of having (had) no spare capacity to look after their own mental health.

And I still didn't know anything about Hep C, didn't have any friends, but there was a local meeting going on and I went to it, and I like everybody seemed to know each other, everybody knew what was going on, they were active, and I just collapsed in a heap. I think I had a breakdown then. [...] and I'd never thought about how I was feeling or whatever, I just got on with it, had to, I had three young kids. [107]

Difficulty recognising or acknowledging the need for help

Not recognising a need for help also posed a considerable barrier to accessing support. Participants expressed feelings of being alone and isolated, that they had to 'get on with life' and did not pay attention to their mental health needs.

I probably skirted round it quite a lot. And I haven't actually spoken to [Name] about it but since the Inquiry's been going [...] I have been thinking to myself about whether I should actually put myself forward for the counselling. Do I really need it? [...] But then moments like this, where you've brought it to the fore and it's made me emotional, makes me think that perhaps it might be a good thing to do. [Pauses] Yes, instead of just storming through. But it's quite difficult to recognise in yourself that you would benefit from it. [103]

Getting on with life was often referred to by participants living with haemophilia, who described how they had developed some form of resilience, which may have deterred them from reaching out for support.

And particularly those of us who've got severe bleeding disorders: we've always had to cope with that. So, we've developed a coping mechanism, which is usually just "I'll just get on with it. I'll just push through, because, you know, that's fine. I'm a survivor. I can do that." But not acknowledging all the pain and all the feelings and everything else. [109]

This form of coping often also affected partners, who might then feel equally unable to seek help, as noted by one participant describing her husband's coping strategy:

Of course, because he felt "no, I'll deal with this myself", because that's what he was like, he felt sure that I would be able to as well. I feel as though I have been quite a strong person all my life because we had to be but there were some things it's just too much. [208]

Several participants also thought that psychological support or treatment could uncover issues that they were not prepared to face.

But I think it's something that my mum should have had and probably would benefit from. But she finds it incredibly difficult to talk about her feelings. I think she would probably just not manage it. [...] I think part of it is for her, like, having to go through everything from the beginning, I think it's more traumatising than beneficial to start that process off. And I think she's so fearful of that.... [212]



In several cases, various external events acted as a 'trigger' to eventually "open the box and look in and deal with stuff" [145], for example when the Inquiry invited them to give evidence, requiring people to "stop and think about their mental health needs, because nobody had asked about how they were feeling" [208].

... that I realised that I might suffer with mental health issues. I don't think I do; I think I suffer with some guilt issues and some stress issues and some anxiety issues. It wasn't until someone says, "These are significant mental health challenges that you're facing." [...] I never thought about it in that way. [108]

Again others said that they were not certain whether therapy or counselling could help them, while also stating that speaking to the interviewer for this project had been helpful. This suggested that some talking therapy might be beneficial for them.

Stigma, shame and secrecy

Perceived stigma, shame or not wanting to burden others were commonly mentioned reasons for not sharing their diagnosis or discussing the infected blood scandal with anyone.

[A]t that time, it was pretty horrific. We never told anyone, so we just lived in this little bubble of secrecy. And to be honest that's what's done the damage, that's what's done the most damage is not being able to tell family, friends, for them to understand why you're behaving the way that you are and why the situation is what it is with you, why, you know. I mean family and friends it was awful because I just couldn't be myself, so I just got lost in the whole screen of secrecy, you know. [102]

Even where people were able to share with their partner or close family, the infection and its impacts were often either not discussed at all or discussed in a way that respondents would have found helpful ("It's like we say, 'It's been on the news,' and that's all we say. We say no more." [117]). This could create additional burden for infected people, and reluctance to open up about their mental health or seek support.

My family have just recognised that that's a closed chapter and [Name], dad or grandad doesn't want to talk about it, so don't even mention it. It's up to me to mention it. Nobody else would say, "Let's sit down and tell us how you feel about all this stuff." We don't even talk about the Inquiry in general conversation except when it's been on the news. [...] But that's a general conversation, not a specific one, you know, the one that gets to, "How do you feel about stuff?" that's a very specific – that's about me conversation. And that's the bit that's closed off, or the bit that I have closed off. It's not anybody else's fault other than mine. [108]

Stigma was a recurring theme, reinforcing the perceived or indeed real inability of people to open up about their experiences and seeking support. This was mentioned as a specific challenge in minoritised communities.

I still think that people from ethnic minorities are not coming forward [...] I think it would be due to the stigma attached to it. I think there is a big [lack of] understanding, how do you get Hepatitis C. Most of them think it is through sexual contact, but they don't think it could be through blood transfusion. [143]

Participants talked about experiences of stigma and discrimination in the health care setting as a frequent occurrence that could, ultimately, deter them from seeking formal help from professionals.

I can't tell people, only immediate family like my husband and my two children, and my mother knew before she died. My other sister knows, and that's it. The stigma with it is horrendous. Because I went in to have a gallbladder removed 10 years ago



and as part of the Hepatitis C issues that you get, and while I was in the hospital, I got wheeled into day surgery and they put a big red cross across me. She's contaminated, stay away from her. [...] And they put me in a different theatre, and they really made a big hoo-ha and I said "Look I'm cured, I haven't got it now" but that upset me, and then I went back into the day ward, and everybody was looking at me like I was a leper basically. It was horrible. But I'm quite a strong character actually so I'm able to rise above it, the ignorance of it. [139]

Perceptions of social roles

There was a strong sense among some of the men we spoke with that perceptions of their social role as a man and provider prevented them from seeking support. These challenges and experiences were expressed by approximately half the men in this study. Several acknowledged that they did not want, or felt unable, to talk about their experiences with family or friends.

And that was in a time when A) you didn't talk about mental health and B) you definitely didn't talk about mental health as a man, especially in a macho working environment like that. [123]

Sharing information was at times perceived to be 'dangerous', because of what might follow as a result of disclosing that information, and it was felt to be easier to compartmentalise or 'park' feelings and emotions as they related to their infection, while acknowledging that this may not be the best way of coping. Participants also spoke of entrenched behaviours that acted as a barrier to seeking help even where their families were supportive.

But I keep telling [my son] he needs to see somebody. He's very macho about it and sort of – he's very stigmatised by it. [...] And my youngest son won't talk to me about it, so ... he just doesn't even want to go there. He remembers things that happened, but he – he remembers that I was ill, but he doesn't have the details... [126]

I actually wrote ... – that I didn't think I needed [psychological support], because I go fishing. Actually – I think that's an excuse. I think that if I'm really truthful about it ... and just like I was keen to come and sit and talk with you ... is it about I don't want to do it? Or is it that I'm too embarrassed to talk about it? Or – and I'm not sure. But do I think it would do some good? Definitely. I do. [104]

One participant chose to share his written statement for the Inquiry with his close family because he found it hard to open up. He felt that it was his "job to make sure everybody else is OK" and that feelings of guilt prevented him from talking about it. He found it easier to speak to people with the same experience rather than his family:

And when I started talking to these guys a bit more openly, not to my wife, because I think it was easier to speak to someone that's gone through it than [Name], my wife, who's living with me and living with it. And I spoke to these guys, and I was like, "How do you get around talking about it and doing stuff?" and they said, "There's no support mechanism, it's just us. We're just here and we'll message each other and do all that kind of stuff." But I asked them if they felt guilty and they said massively, and that's why they don't talk about it because the guilt is so bad. [108]

Feeling too overwhelmed or unwell

Being physically unwell and feeling overwhelmed was, for some people, a barrier to engaging with their mental health and getting support. Even if there was awareness of the potential benefits, the process of organising mental health support was frequently seen as too daunting to pursue and resorting to 'just getting on with it' seemed easier.



If I wanted to talk to someone and arrange counselling, I would have to find somebody, make the appointments, make myself go, and I don't think I want to do that [...] I'm sure it would be beneficial for me, but I don't want to do it. [129]

It's almost like there needs to be some sort of pack for people who are diagnosed with – like a little card for the Hepatitis C Trust and their helpline, and just various other pieces of information. Yes, it felt like we had to go looking for stuff and we were both working full-time and just trying to cope with it all. It was kind of like, "Well, that's just, yes, a step too far. Let's just try and get on with this in our own way". [206]

Structural barriers

Structural barriers to accessing psychological support included lack of appropriate support; long waiting times; professionals' lack of knowledge about the infected blood scandal; difficulty finding an appropriate therapist or counsellor; and limits on the number of sessions offered. These barriers often occurred in combination.

Lack of appropriate support

Most participants reported that they were never offered any psychological support and were merely left to "get on with stuff" [108]. Some reported being offered 'counselling' in the form of a leaflet, generally about HIV or hepatitis C, but not psychological support:

Now, if you look at technical or dictionary meanings of counsel, I think it is fair to say they informed me. So that in itself comes into one form of counsel. They counselled, they informed, but it's not our understanding of counselling [...] at all. Because in that interview, basically I had the blood test, I came back to a gentleman in a white coat, who I'd never met before, but very pleasant and "Please sit down. Sorry to inform you, it's come back as positive. Here's a leaflet". [114]

Some participants reported being let down by the people and institutions that were meant to help them. Even when they experienced especially difficult life events, people reported instances of health professionals simply dismissing their emotional distress rather than offering support.

[B]ecause of this and all the stress I was put under – well, I tried to commit suicide. I took overdose. [...] And, yes, no, I didn't get counselling for that. [...] No, they just said it was my mood. I was trying to get attention. [121]

Sometimes support was offered but not in a way that the person could use or understand. One participant remembered a doctor mentioning the possibility of seeing a psychiatrist, which they felt not appropriate, while another participant was referred to a sexual health clinic.

They didn't support me, and they knew what the situation was. So, because I wasn't a haemophiliac, like I had to go to a bloody sexual health clinic when I ... I didn't want to be in there and I don't want to be talking about homosexual behaviour. It's nothing to do with me, it's nothing to do with my life and I found it really offensive. [102]

Several participants described their experiences of trying to access mental health support through their GP, who were frequently reported to being ignorant about their situation and specific needs. When support was offered, it was not always suitable.

I went back to the GP and said, "I'm really struggling. I need some support," and was told, "Oh, you need to go online and fill out some questions, and then you can access it that way". So I did that, and I was told I could join a group therapy



programme. And it was in [town], which was about an hour away, at 9 o'clock in the mornings on a Tuesday once a month. And admittedly I wasn't working, but I also was having really bad chronic fatigue. So, there was absolutely no way I would have been able to go there. And that was the option, and when I said, "I'm not able to do this," that was the option. That was all there was. So that wasn't helpful. [109]

One participant described how her husband's consultant wrote to his GP asking for a referral to counselling, but that was not followed up.

And he was diagnosed kind of by mistake like I think a lot of people are. So, he was being assessed at [hospital] for a lung transplant. And they tested him, and found that he had hep C. And they wrote to his GP to say, "Could you tell [name] that he has been diagnosed and offer him – refer him on, and to get him some counselling?" [But] the GP didn't tell him, so [he was never offered counselling]. [210]

In the context of a general lack of appropriate support, some participants resorted to setting up their own support groups or tried to access support through routes outside the NHS.

[H]e was desperate to go to some [support] group when he was with Hep C, and the only group he could find was in [town] prison. So, he went into [town] prison. [130]

Long waiting times and fragmented referral system

The challenges of finding suitable psychological support were often compounded by long waiting times, described by one person as "horrendously difficult" [105].

I tried for my daughter, and I tried a little bit for me back at that point when we were doing the witness statement for the Inquiry, whenever it was. 2020, something like that? But it was – you were just coming up against brick walls or waiting times of six months. [210]

When psychological support eventually became available it was often experienced as being too late, or no longer appropriate to the specific situation and needs of individuals.

Not so good because [counselling] didn't start until actually [my husband] had died, so it was more bereavement counselling. [...] I think partially [because of] the waiting list [...] but it definitely didn't start until [after his death], and whether they just didn't have the people to deal with that sort of thing, I don't know, but as I say it was a bereavement counsellor that was OK but not really that useful. [208]

Several participants described that the long wait meant that their condition had deteriorated to such an extent that their marriage or relationship broke down.

My wife's saying "maybe you should move out?" You know, that's how bad things had got, and she wasn't wrong; these were the options we were facing. And there was no point going back to the GP because I was on a waiting list that seemed to be endless, psychological support from the GP. And there was no point going – I'd been to A&E with, you know, a breakdown, taken in by ambulance and that didn't really get far. [116]

Referral pathways were experienced as long and convoluted.

A couple of times I have [had mental health support] [...] I had to fight to get it. [...] Also, once I'd had it, I had to go through the process of, one, waiting ages, two, having to go and see one service who then referred me to another service



who referred me to a third service, to the point I'd got to, "OK, I've not got to see somebody who I think is going to listen to me, ask my full problems and history", and she actually turned around to me and said, "Oh my gosh, I'm getting stressed listening to it. I don't know how you cope". [105]

Professionals' lack of knowledge about infected blood

A main barrier to accessing care for many participants was the need to repeat the story about infected blood to multiple people because professionals did not have knowledge about the infected blood scandal and what this meant for those affected by it. We heard many accounts from participants describing encounters with health care professionals, which they recounted as ignorant at best and damaging at worst.

So, I remember going to hospital appointments with [name]. One of them might have been a dermatology appointment, and the doctor would kind of look at his notes and go, "Oh, you've got hepatitis C. So, are you still an intravenous drug user?" And I remember just practically levitating off the chair with anger. [Name] was always very calm and would just say, "No, it's through a contaminated blood transfusion," and then you'd get the response of, "Well, is that proven?" [206]

Within a therapeutic context, lack of understanding of the infected blood scandal was described as causing frustration because it was felt as a waste of highly limited counselling time required to educate counsellors about it.

[having only recently learned about the availability of EIBSS discretionary payment for counselling] ...one of the downsides to that is that actually, yes, you can get the support, but you won't necessarily know how to find somebody that knows about the infected blood. [131]

Participants described repeat cycles of beginning counselling, using up their available sessions, waiting for a new referral, and then beginning again with another repetition of 'the story', which was experienced as disruptive to improving their mental health. One participant commented that they had to repeat their story to over 20 different professionals and that by the time of taking part in the research interview they still had not found an appropriate practitioner.

[Y]ou waste a lot of time because you start all over again. So, it's all that get to know you, develop some trust, understand your past and you waste a lot of time saying the same things. [116]

So, they need a background understanding of the issues, without a shadow of a doubt, because you waste at least one or two sessions updating people. So that's over £100 wasted just teaching someone else. [111]

Some participants found the burden of having to explain the infected blood scandal so exhausting that they gave up seeking any support.

Difficulty finding an appropriate therapist or counsellor

Finding and engaging an appropriate therapist or counsellor was described as a challenge by many participants. We heard accounts of people not knowing "who to go to" [145] or "where to start" [141].

I keep being told [counselling] might be a good idea, but I haven't – I suppose in some ways, I would like to if I knew it was the right person and they had that understanding and that knowledge. Without that, you'd go to – I have friends who are therapists and counsellors. I wouldn't go to them, but they could recommend somebody and that's fine. [210]



Part of the reason for not knowing where to start that participants mentioned was a lack of understanding of the types of treatment that may be beneficial to them.

And also, this may sound obvious, but it's something that I didn't realise, I think as a patient or a client of a therapist you need enough prior knowledge yourself to be able to get the most out of it. I didn't realise that I needed a trauma-based counsellor until last year. I was just thinking – because there's so many different strands of therapy, unless you know what you actually need it's hard to access it, but you don't know what you need unless you're told what you need. So, you're kind of trapped in this loop. [111]

One participant reported finding a good therapist through their haemophilia centre, but when the person retired, the practitioner was not replaced. Several participants mentioned an 'excellent' social worker, who was also not replaced when he left his job.

Several participants described encounters with therapists or counsellors who viewed their cases as too complex, traumatic or so overwhelming that professionals rejected them. One participant described how "impossible" it felt to find a therapist to work with, recounting how they had approached eight counsellors from the list provided by EIBSS and "not one of them would or could take me on" [105]. They found the process so stressful, they felt they "wanted to throw [themselves] in front of a truck because everybody was saying no" [105].

Participants described instances of therapists being overwhelmed by individuals' stories, with one reporting that once they found a therapist, "[the therapist] actually burst into tears [...], because [they] couldn't handle what was being said to [them]. So that was my first experience of getting help" [111]. The same person described finding another counsellor years later, still without success:

I've tried other people. Another woman who just sat there looking so absolutely appalled and out of her depth. I was worried about her, which kind of is like a theme really. Well-meaning, nice, middle-class ladies that don't believe in state sanctioned cover-ups and it's too much for them to cope with [...] So I don't blame them, but it's been an utter waste of my time and money and just made me feel worse. [111]

Another participant described seeking counselling with their partner:

And at the end of an hour which I was paying for, [the counsellor] said "well, that's all very, very complicated and I don't think I'm in a position to help you." And [they] wouldn't see me but I still had to pay for that consultation; £150 it cost me for somebody who said my problems were too complicated, too whatever for [them] to deal with. [116]

Such experiences were not only seen as a waste of money and time but, importantly, made people feel worse, exacerbating feelings of frustration and anger with 'the system' that repeatedly let them down.

Limits on the number of sessions offered

Several study participants commented on the limited number of counselling or therapy sessions that they were offered, which they experienced as too few to really address the issues that they were facing. One participant who was offered six sessions said that it "didn't feel like we even remotely scratched the surface of what was going on. It was not very helpful" [109]. This was in large part because a significant amount of therapeutic time was often spent explaining the background of the infected blood scandal (as noted above). The limit on the number of sessions was often described as compounding stress, and participants reported feeling pressured to rush through their trauma-processing.



But there's always this thing where it's always going to end and when you're in the session, they're always telling you how many sessions you've got left and I find that really difficult and almost offensive because I know when they say "right, that's it. It's over," well, it's not over [laughs]. Come on, we're just where I was when we started, and I still need somebody to share my situation with. That's how I feel about it." But they think it's over because you've had ten sessions [...] it doesn't fit in with how the NHS structures its treatment plans. You don't get open-ended emotional support and to me, that's just a travesty and it's Orwellian in terms of the situation that I'm supposed to be getting support for. [116]

Issues and barriers relating specifically to the England Infected Blood Support Scheme

Study participants welcomed that funding was principally made available to access psychological support via the England Infected Blood Support Scheme (EIBSS). However, only just over half of those interviewed for this study were aware of the payment, and there was a strong sense that there was a lack of information about it; the process of accessing it was perceived as laborious and the payment was too small to allow meaningful treatment. The application system was experienced as traumatising and there was a lack of trust. Participants found advocating for themselves difficult and some experienced feelings of abuse, especially when their applications were rejected by EIBSS.

Lack of information about support and funding

Almost half of participants were not aware that financial support for counselling was available. In some cases, people learnt that specific grants for psychological support were available through participating in the interview for this study, even though they were registered with EIBSS. In other cases, people described finding out about support from an "off the cuff remark" [117, 118] made by medical staff, or by chance through a Facebook group.

I really wish, back then, I would have known about the Hepatitis C Trust and that kind of thing, because then I could have spoken to them or – you know, and I know like the EIBSS thing now you can get counselling. I've only found out about that in the last two months. ... So, a lot of my life I've just been dealing with this the best I can. Yes, it's not been easy. [203]

Participants commented on a lack of clarity about eligibility, with affected people saying that they were not aware of the possibility of getting support for themselves. One participant thought they could not apply because someone else from their family was already in receipt of support. Several felt they had been misinformed.

Burdensome application process

Among those who had applied for payment for counselling through EIBSS, only a small minority reported this as having been a positive experience. They described the application process as "easy" [117, 212], "quite efficient" [142] or they did not have any problems accessing the payment [130]. However, many more participants had negative experiences, describing the process as "awful" [104] and "traumatising" [105], while others reported that they felt ill-equipped to cope with the requirements needed to secure help. Even those who described the application process as efficient or easy said that they could not have completed the required paperwork without help or they only found out about the availability of payment through the Inquiry. Some participants said that the EIBSS website was difficult to navigate or that they did not know what to do to get the payment for support.

Not that I know a lot about websites, but it's not the easiest to follow and it's like you know they – I know they do like one-off grants for things, but there again it's filling out more forms and again explaining why you think you need X for this to do whatever, and it's just [...] It's not easy. [131]



Participants cited instances of unnecessary and redundant paperwork and having to complete the same paperwork repeatedly, making accessing services difficult. Several participants described the knock-on effects of accessing funding and support, which often involved having to go through repeated cycles of justifying, asking for referral, waiting, and explaining the infected blood 'story'.

I think, deep inside of me, there is an element of deep unhappiness that I don't let come to the fore, I suppress it, but I recognise it needs to come out. But I don't want to put all of that feeling and angst into an application form and nor should I have to. I should be able to go to them and say, "Look, you know, I'm receiving something from EIBSS already, I think I need counselling". [103]

Some participants also mentioned an element of chance when going through the application process, the outcome depending on "how good you are at putting words together" and whether their medical practitioner "put down the right words" [103].

There was a sense that the application process was overly complicated and could be putting people off applying for funding altogether.

[A]nd if you trial and trial around their complicated website, which is complicated for someone who's looking for the first time, who's not sure what anything means, we are offered £900 but then you've got to find the person and you don't want all that, you're tired, your body has had enough. [120]

There was expressed frustration about having to make the case and carry the 'burden of proof' to demonstrate eligibility for support, especially for those already registered in the system.

Lack of guidance on finding the right counsellor or treatment

A few people reported that the payment from EIBSS helped them access psychological support, such as Eye Movement Desensitisation and Reprocessing (EMDR) or counselling. However, more participants said that they did not know how to go about identifying the most appropriate type of counselling or therapy. EIBSS was regarded as not being very helpful, and participants commented on a lack of guidance or what to expect from it on the website or from the team: "So you would never really get anything, or it's all done by email" [110].

I phoned the local Talking Therapies for the NHS and was told that obviously I can't do anything through the NHS, that I would have to go to a private therapist, and it was them that sent me the details of all the local people. But, as I said, there's so many on there, I just wouldn't know who to pick or which way to go with it. So, to be honest, [the EIBSS form] is still sitting here, so I, and also my family, have not pursued that in any way because it just seems such a barrier to go through. [213]

Participants said that a more proactive approach on part of EIBSS was desirable to encourage people to take up the offer of financial help for psychological support.

So, you'd have thought somebody would go, "Right, OK. Here you are. These are the people [who are registered with EIBSS]. Let's see if they need anything or not". [117]

Need to make the case for support

There was expressed frustration about having to make the case and carry the burden of proof to demonstrate eligibility for support, with several people reporting that their claim for psychological support had been rejected. People felt that they should not have to keep proving their case.



Having to justify a claim was experienced as burdensome, especially where medical records were missing. In cases where medical records were available, it was difficult to get them, and it fell on the infected people to obtain them, which was often challenging, sometimes requiring payment.

So, I contacted them and after I applied then for some compensation money, and it was refused because I hadn't got any proof. So, with difficulty [...] I got my medical records. They were not overly keen, because I wasn't a solicitor, to give me copies of my maternity records, for which I had to pay I should add. [129]

Where errors were made, the burden of proof was felt to be on the claimants to correct, leading to a further breakdown in trust. Some people had difficulty providing evidence because their doctor or therapist did not want to be involved in their claim. We also heard reports of psychological support being rejected for loved ones who had been profoundly affected by their situation.

My mother has been there every step of the way; she's had to deal with haemophilia, AIDS, Hep C, CJD; she was there when I was told I was going to die a very horrible death and end up a vegetable on life support. And at the moment, my mum's not even recognised as somebody [who is affected]. I tried to get counselling for my mum, and they said there was no funding. [110]

Others described situations where they had to “sort out the money, the grants, because they said EIBSS want to know how many sessions” [105] and were then rejected. There were expressed feelings of mistreatment by the system. Some reported being denied funding for approved psychological interventions, such as EMDR, and multiple respondents reported feelings of desperation about needing but not being able to access care because of EIBSS. These rejections further compounded the trauma of being infected or affected.

Where people were awarded money for mental health support, this was often described as being inadequate and dehumanising. Participants reported that the £900 annual award was not sufficient to pay for the support they needed, with one person describing that they were making good progress with their counsellor but at £160 per hour they had used up their allocated funds quickly and were unable to afford continuing working with their counsellor much longer without “hurting financially”; they stopped counselling [103].

Overall, these experiences contributed to general feelings of abuse and distrust in medical professionals, especially doctors, the NHS and government bodies generally, and the EIBSS specifically.

Impact of the Infected Blood Inquiry on mental health and wellbeing

Attending the Inquiry in person, giving evidence or following it online had both positive and negative impacts on participants. Many felt they finally met others with the same or similar experiences, which was seen as beneficial for their wellbeing. At the same time, thinking back to the times they or their loved ones were infected was very difficult, as they relived their trauma, it ‘reopened the wounds’ and brought back distressing issues. Participants were generally pleased with the way the Inquiry was conducted but were very concerned about the outcomes and any follow-up action by the government.

Community

There were generally positive feelings about the Inquiry. Most people felt it enabled them to be finally heard and that was perceived as helpful. Most participants said that the Inquiry had been helpful in the sense that it brought people together who had been feeling isolated before. Many felt for the first time that there was a community of people who could relate to their experiences.



... I went to the tribunal because – because I'd always been alone in this, really, and I never had anybody to help. [...] So, I went to the tribunal and, of course, it was – I spent the entire day crying and upset and everybody was wonderful. But they got the counselling service there as well. [107]

I think we have healed some divisions within the community, and inevitably you'll never cure all those, but I think the Inquiry and we, and many other groups, have brought the community together, and that's helped as part of the healing process, I think. [123]

People felt validated when they met others with similar experiences. They felt understood without having to explain anything and saw this peer support as beneficial. One participant described how she finally realised that the impact of treatment on her husband's mental health was experienced by many others.

So, I think the Inquiry has helped with that, in that you're suddenly thinking, "OK, so everybody has that reaction to interferon and ribavirin." Which we didn't know. And it's normal for them to be completely loony, and you come back from work and he's trying to commit suicide in the other room. But it's normal. Well, not normal, but you know what I mean? It's not an unusual occurrence. So, I think in that way, it's been really helpful, because you don't feel so on your own with it. [210]

Bringing issues out

At the same time, the Inquiry was also seen as having negative impacts on people participating. Several interview participants explained that they found it difficult giving evidence, as it opened up feelings that they had previously "buried" or "put in a box" [135]. Others said hearing or reading stories of other families had triggered distressing memories and "everything being brought back again" [202].

The stuff in the media; sometimes it can be quite like "Ah, I wasn't ready for that," you know. And then something will come on the TV and all of a sudden, I'll be in floods of tears, like "Oh, no. This is actually me. This is me." And you always think about things on the TV, you think "Oh that's really sad, but it's happened to someone else," and then all of a sudden, you're like, "Actually, no, I'm in this group of people that have, you know, been affected by this." And then sometimes for a few days afterwards it really stops me in my tracks with like doing work and all sorts of things, because you can't stop thinking about it. [203]

Several people commented on their difficulties when they realised that some infected people had died during the period of the Inquiry. Several said that they had not known about the large numbers of people who had been infected and affected, as for many years they had not heard of anyone else with the same issues and felt very isolated.

I had no idea on the scale of it at all. Nothing at all, which opens your eyes. Yes, you know, still makes you feel isolated because I've had nothing, but there's – yes, I didn't realise how many people were affected and stuff like that, or sadly gone and stuff like that. [117]

Anticipating the final Inquiry report

Participants were very positive about how the Inquiry was conducted. They commended the process and also the Inquiry staff and others supporting it.

[T]he Inquiry team, the Red Cross, the civil servants, the legal team and the chair, etc. have been phenomenal, and to have done what they have done with a deeply damaged and mistrustful community has been exceptional. [123]



However, there were mixed views about the anticipated outcomes of the Inquiry. Many people were concerned about the final report, about the government's response and "*whether or not it changes anything and how quickly that happens*" [116]. Some were worried that nothing would change, and that often "*recommendations don't actually happen*" [119].

It's like any Inquiry, they say, "Oh, well, we'll learn lessons from this, and it won't happen again." So I think I've already resigned myself that there's going to be no real closure to that. They've done it, it's gone, that's it. [129]

Need for psychological support because of the Inquiry

Several participants mentioned that they thought they needed support after attending the Inquiry or giving evidence.

And I was doing OK right up until the Inquiry, and I was at the Inquiry for the last week – the closing bit. And I had to come home a day early. It was getting to me. I just couldn't handle it anymore. [214]

I was very keen to speak to someone because it was quite hard to give evidence, and it opened a lot of things up. I'm glad that that's been put in place and I'm sure a lot of people have benefited from that kind of thing. [135]

Others mentioned that there may be an increased need for psychological support after the final report of the Inquiry, mainly because people have focused on the Inquiry for so many years and have expectations that may be unfulfilled as indicated above.

I know that I will need some more support as the Inquiry ends, particularly because we haven't had [husband's] inquest yet. Nobody, and I suppose nobody would, but nobody told us that people with Hepatitis C have to have an inquest. [206]

Some participants stressed the urgency for psychological support, asking for relevant services to put in place now, as people had suffered for many years often without help. One participant explained that even waiting for the Inquiry to report was difficult for some people.

Yes, people are really at the end of their tether with all of this. I think one, because it's gone on for four and a half years, I understand that. That Inquiry had to be as thorough as it could possibly be. But now, we're in this situation where I think people's mental wellbeing and people's you know, anxieties and stress levels are probably at a point where it's really difficult at the moment. I think people are very frustrated about this time now, this time when Sir Brian has put out a second recommendation and, you know, nothing happening now till maybe September, October. I just think people are just really frustrated and angry and that showed within that meeting in Bristol the other day, when we were there. Because there was, it was even, it was quite – I can't really explain how it was. The emotion in the room was really high, you know, and as I say, there was ... [Cries] sorry. [213]

What a better service delivery system could look like

Participants offered a range of suggestions about what they would like from a better psychological support service. Some study participants had been able to access support while others had never spoken to a professional about their experience. Most agreed that they would like to see a network of professionals with knowledge about both the infected blood and blood products scandal, as well as the common infections, diseases, conditions and treatments affecting this community. In many ways, proposals for a better service mirror the experienced barriers to psychological support described in the preceding section. Here we discuss four broad areas: knowing the back story of infected blood; therapeutic modalities; nature and scope of psychological support services; and going beyond signposting.



Knowing the back story

Having professionals who have knowledge about the infected blood scandal, HIV, hepatitis C, haemophilia and transfusions, as well as common ailments and treatment side effects, was seen as a pathway through which each individual's needs could be met more directly.

So, I really wish there was a psychological service there, things like they've got in the other countries that would just go, "Yes, we know what you're going through, we know all the history you're going through. We just deal with you and how it's affecting you." It's horrible [trying to get mental health support]. [105]

Study participants also reported that not only was knowledge of the disease and conditions important, but understanding the way in which the infected blood scandal had permeated all aspects of their lives in ways that are detrimental to infected and affected people. One affected person reported:

...it's [the infected blood scandal has] affected people in so many different ways, like the stigmatisation, the pressure on finances, just living with illness in the family, the specific types of treatment that used to be given that made people go a bit bonkers, the psychological effect of lack of consent of treatments, of testing – and then you've got all of the other stuff like the effect that that has on couples who wanted further children but perhaps couldn't. Like, the way that it changed the perception of the family and friends who maybe didn't understand the condition and thought it might have meant that they'd taken drugs or were having gay sex or all of this kind of stuff. [212]

This background knowledge was seen as vital, especially in the context of the very few resources being available for mental health support.

Treatment modalities

Many participants considered talking therapies to be necessary. Some, especially those who had reservations about more public, group-based approaches, expressed interest in individual talking therapies, partially because the therapist or counsellor was seen as an independent third party. This independence was described as crucial, particularly for participants who felt guilt or shame, and who felt that speaking to family or friends was placing a burden on them.

The privacy of one-to-one therapy was described as especially important for infected and affected men, who felt unable to participate in group-based approaches. One man described attending a group meeting about the Inquiry and reported:

They have the chats; I think it's every month or so. And I've done one of those. But I burst into tears, so I thought, "This is useless, [his own name redacted]. Get a grip." So [I'm taking a] break [from participating in therapy] until I can do it sensibly. [210]

Needing to talk, "get stuff off your chest", process the 'what-ifs', understand their thoughts and feelings, and process grief and trauma, were described as important for making sense of what happened, and consequently improving mental health.

Some respondents thought that bereavement and trauma-based support were necessary. This was especially the case for respondents who had been discharged from generalist mental health support teams or who were deemed 'too much' from generalist care providers as described in earlier sections of this report.

Group and peer-based approaches were also frequently mentioned, with perceived benefits ranging from providing an important source of community with those who have shared experiences to helping to normalise their feelings and provide a source of support and guidance from knowledgeable people. The idea of a community



was seen to provide a baseline level of comfort, especially in the context of having conditions for which others may subject them to stigmatisation and shame.

I mean a place where you could hang your hat and go and say, "Right, this is happening and, you know, this is the impact." I don't think it's just a psychological thing, it is like, how you live your day, how you cope with things. [102]

I think maybe groups that like, which I suppose are already there, grieving groups or... abuse groups, or illness groups, are something that I think we need because nobody really understands how traumatic it is, mentally...to have an illness that, A, you had to keep secret, which we had to do. [107]

While many infected and affected people expressed interest in group and peer-based approaches, there were certain communities for whom peer-based approaches had been or were predicted to be particularly beneficial. These included people infected through blood transfusions, who said that they had less of a community compared to people with haemophilia, who have specific hospital units and charities advocating for their interests and bringing them together.

...the haemophiliacs in this story had a terrible time, but they... [have a] discreet route, just by the definition of their medical condition. Whereas for us with transfusions, we were spread across the nation, different times, different reasons, no obvious connection, no obvious network. So, unless – well, I mean I just was never aware of anybody else going through that. [114]

As mentioned above, some men felt unable to participate in group-based approaches, but others found them to be a vital conduit through which they could break through their isolation.

A guy in his 60s in [town], he just blurted out for about 25, 30 minutes during the coffee break, he never stopped talking. He said, "You're the first person I've spoken to about it." I said, "What, your wife, your family, your doctor?" He said, "No. You've asked me a question and I've just told you how I feel. But I wonder, if you've ever been in the same situation as me, I probably wouldn't have said anything solid, just said 'I'm fine, thank you for asking.'" [Laughter] So that was good. [108]

Some suggested that that they would benefit from a listening service or helpline, or someone to simply chat with.

Even if you just need to go, "I'm having a really bad time. I just want to talk to somebody who understands. I don't want to offload on my family," just someone who's going to listen. [105]

People felt that a good service would include professionals who can offer a range of modalities, including access to psychiatrists who can prescribe antidepressants and other medications as well as EMDR therapy, and would be able to advise on alternative therapies such as yoga, reiki and social prescribing for time outdoors and positive social interactions.

Nature and scope of psychological support services

Notwithstanding the precise treatment modality that interview participants had considered, two features were commonly described as vital. First, there should be no limits on the number of sessions that individuals seeking support are eligible to receive. Second, the service should provide the option for people to drop in and out of the service as they required. People wanted greater acknowledgment by the system that individuals' needs change over time and that there should be a mechanism allowing people to re-access care and support when required. Several



study participants noted that they did not foresee themselves needing counselling all the time; instead, they expected that there would be phases in their life in which they needed therapy options to remain available to them. One participant summarised the need to be able to drop in and out as follows:

That's [being able to drop in and out is] probably a good idea because if something happens and then it may bring back things and it – yes, I think that probably sounds like a good idea, because at different times things – you know, I cannot think about it for months and months, but then something happens, and it brings it back and you just think [therapy would be useful]. [131]

This was seen as especially important as some triggers for feeling upset or retraumatised were unpredictable. For example, one woman who had been infected as a result of a blood transfusion following a post-partum haemorrhage, expressed being retraumatised when she was a support person for her daughter while she was in labour.

I had the equivalent of post-natal depression again, even though it was my grandchild.... I was surprised at how quickly I was back into the, "This is me 30, whatever it was, years ago. This is how it happened," and thinking – and I just couldn't be involved. I just had to sit at the opposite end of the room and just think, "No, I'm just not thinking about what they're doing and what's happening." But, yes, it did, and then I just wanted to go home, even though it should have been all very lovely and been a lovely delivery and all the rest of it. But, yes, just sitting there thinking, "No, that's it. I want to go home now. Can't cope with this". [129]

About a quarter of participants explicitly advocated for both infected and affected people to have access to the range of services, even for those who are currently not recognised by EIBSS. There was also a sense that affected people should be able to continue accessing services, even after the infected person connected to them has deceased.

The need for assistance to access physical health care was described as an essential component of mental wellbeing, with the illnesses described as very stressful in themselves. There was thus an expressed desire by some that support should go beyond mental health support.

So yeah, I mean it's not a case where I'm going to sit down with somebody, I'm going to go through what I've been through and talk about it and, "This is what happened to me, oh my God, what can we do?" But no, it's getting on, getting on with your life and, you know, if you've got worries about the fact that, you know, in ten years' time you might think, you know, maybe a health issue, a comorbidity with HIV, there's a lot of dementia and stuff, you know, I'm worried about this, where can I go? You know, can I make sure that my support would be paid to ... [102]

Regardless of which therapeutic modalities were chosen and whether the person accessing support was infected or affected, it was clear from the interviews that some people preferred in-person face-to-face, while others preferred online telehealth options. Preferences were shaped by many factors, including level of comfort with technology, whether they were well enough to physically get to appointments, distance from nearest city where an appropriate provider might be located, and whether they could see themselves developing a therapeutic bond with someone online.

There was no clear consensus among study participants regarding who should provide or manage the psychological support service. There was a clearer agreement that those working in the system must be compassionate and sensitive. People described that a kinder service would work with staff that tried to help claimants, rather than treat people in a way that was described as abusive and traumatising.



I think if it a proper support scheme was to be set up, it needs to be a completely new system but the scheme that's set up has to come from a complete 180; it hasn't got to be them and us and it's not right "you have to prove yourself to us," it should be "right. What can we do for you? How can we help you? You have a problem; right, let us take this out of your hands. Let us deal with this now. You; support you," not "fight you all the way". [110]

While some people felt that, in England, the NHS was a sensible place to house the service, this suggestion, as well as it being run by any other current stakeholder, was seen by some respondents as unacceptable. However, as indicated in the preceding section, the organisation spoken about with the most vehement distrust was EIBSS. Any new system would need to address the substantial distrust in and legacy of EIBSS to provide an effective service. There was a strong sense that applications for support through EIBSS would need to be simplified, for example, by not requiring those already registered in the system to apply for each element of support separately; psychological support should be offered as standard and not upon application.

Going beyond signposting

Overall, there was a strong feeling among many study participants that an improved system should move from largely reactive to a proactive one which approaches beneficiaries to offer help and relieve the administrative and cognitive burdens currently placed on them. It was also felt that the system 'doing the work' was an important way in which the government could begin to address the harm it caused.

...in a perfect world...EIBSS or whatever it becomes would live in this hub and actually be a support service as opposed to some kind of, I don't know [...] And they [EIBSS] need to get away from that and make it like "how can we help you?" – [...]– like, see if you qualify for some; let's help you apply for them." As opposed to "go away and do it – work out, yourself, what support you might be able to get from us, go away and apply for it all on your own and then wait for us to tell us if it's any good, your application after you've spent three months doing it when you're not well [laughs]. [116]

I think ... the best way to approach it in my mind's eye would be, anybody that's registered with the EIBSS, Skipton Fund, whatever, they should have been contacted and said, "We are here for you." [...] "Is there anything that we can do for you to help? We can offer you help with X, Y and Z." That's never happened. [132]

Participants noted that a better support service would include a contact point or person ('system support worker' or navigator) who could help them navigate the health and social care system more effectively. Navigators' roles were envisaged to include the following:

- Signposting infected and affected people to relevant services, including suggesting therapeutic modalities most appropriate to individuals' needs and financial advice.
- Assisting with applications for EIBSS benefits and serving as a general liaison and advocate.
- Reaching out to beneficiaries to help them cope with the consequences of their infection(s), including organising screening, testing and future planning.

As noted above, the current system was described as laborious and traumatising, with the 'system support worker' envisaged as someone who can relieve the burden of need to cope with the perceived EIBSS bureaucracy.

It's probably an idea to have maybe a point of contact and then, yes – because I found, with the talking therapies, I had to apply all online and you had to write this huge spiel about why you thought you needed it. And that in itself is quite traumatic... [131]



Another area where system support workers were felt necessary was in translating, explaining, and facilitating better access to EIBSS-based support and resources.

EIBSS, sometimes they will write letters and tell you this is how much you get every month; you can apply for this. But you don't understand what they're saying. [136]

This need for assisted communication appeared to be especially important for people who also described themselves as having learning difficulties or cognitive side-effects of their infection and/or treatment.

Others proposed the introduction of a form of care-passport or similar mechanism to help beneficiaries access physical healthcare associated with their infection or conditions related to receiving infected blood or blood products.

People have talked about a passport, do you know, that you have a card, and it says – and you should be treated – we got infected through no fault of our own, so we're not – I don't think anybody's asking for special treatment, but at least some ease of treatment, I think it's a better way to describe it. You should be able to go and ask and say, "Look, my fibromyalgia that I'm suffering from is really giving me gyp this month; please help me this month. I don't need it every month." You should be able to have easy access to that medical help". [104]

Finally, there were a number of issues that respondents felt were important for an improved support service to be inclusive and sensitive. These included being more inclusive of affected people, same-sex and non-married partners, and people having English as an additional language. Particular sensitivity was felt important for those with pre-existing or complex mental health needs and those with learning difficulties or cognitive decline, and to the experiences of women who were infected secondarily by their partners and who either had birth-related traumas or who were told or chose not to have children as a consequence of either their or their partner's infection.

Expressions of an unmet, non-clinical need that may improve mental health

There was a strong sense among study participants that, while improved access to psychological support services would be welcome and needed, there was an equal need for action going beyond psychological support services, which can be summarised as: need for acknowledgment of the harm suffered; accountability and apology; and justice.

Acknowledgment of the harm suffered

Many study participants expressed a need to have their suffering acknowledged. One woman who was both affected by her husband's HIV infection and was later infected herself explained how she was coerced by NHS staff into having a termination at 7-months gestation, being unable to speak about their diagnosis, suffering through her husband's complex mental health challenges, having to leave the home she had paid for, and the dissolution of her marriage. Despite the myriad ways the infected blood crisis has impacted her life, she said,

...this whole tsunami of crap that we've got now, isn't recognised, you know. It isn't recognised what I did, but yet a widow is recognised, you know, but I'm not recognised for what I did, you know. [102]

Others expressed that, if at the end of the Inquiry, their suffering remains unrecognised by the government, "I will be hurt, I'll be emotionally wounded if Sir Brian Langstaff doesn't make the recommendation for me, I have to be honest about that" [113]

Part of being acknowledged was being heard. One woman who has been denied care and support by EIBSS on technical grounds reported that



[being heard] that's so important ... You know, I've felt, over the years of the Inquiry, and with Lead A offering to support me, and the judicial review, even though I haven't won, I feel heard. And that's what people need ... That's why this community is so damaged because not only have they been, had their lives blighted by HIV or Hep C, or whatever, they haven't been heard. [113]

Part of the feelings of betrayal from the government and EIBSS relate to the perceived inadequacies of the English system compared to the devolved nations. In relation to needing to be acknowledged, an apology was felt to be vital, but which has, as yet, been absent.

It's like with the whole Scottish government in the whole trial they've gone, "Yes, sorry. We've made a mistake." Where the English just went, "No comment". [117]

Study participants also asked for greater public awareness about the infected blood scandal. This was proposed as being a travelling education programme across the country, a national monument, a memorial service, or acknowledgment in the King's Christmas Speech.

Haemophilia is the Royal disease. Queen Victoria was a carrier of it, and yet here we are and there's not a single member of the Royal Family that's ever acknowledged it. The Queen never mentioned it in her Christmas speech for example, and we'll wait to see if Charles does at all, but – and for so many people, we can never change the past and we can't really change the future for them, but we can just acknowledge what they've been through. And just someone of that stature saying "Sorry," or, "I acknowledge your plight," or, "Commend your courage" – all those sorts of things. That's all they've got left. And being denied that, which is something so simple and so easy, adds to the frustration, and it adds to the feeling of stigma and otherness, that we are in some way different to other tragedies. More people have died as a result of this than died in 9/11, but who knows about it? And that's part of the frustration, and people just want acknowledgement and recognition. [123]

Accountability and apology

Accountability from the government was viewed by many respondents as an important mechanism to improving their wellbeing. The experience that many shared with missing medical records contributed to the sense that there had been a cover up and increased the need for accountability.

Particular anger and incredulity were directed at the UK government and its failure to apologise and for not clarifying what precisely the government had apologised for at the start of the Inquiry in 2018, even when asked by the Inquiry Chair (with reference to the closing submission by Eleanor Grey KC on behalf of the Department of Health and Social Care, 18 January 2023¹⁸). This appeared to confirm to some respondents that the government was *"disingenuous and totally insincere"* [116].

Justice

After decades of feeling alone and stigmatised, one respondent reported feeling like the government was taking a *"divide and conquer"* strategy and explained,

If you have somebody in isolation who's experiencing something, they're a very quiet, lone voice, which is, the voice is just going to disappear on the wind. But then if you have people who come together who then realise they all have the same kind of event, it becomes a louder voice. And I think it is growing and growing and growing. And I will be very surprised, if the report that comes out, if it's not damning, I think it will be incredible damning. I just hope that it will ... Yes, there's been calls to have all of the documentation sent onwards to the police afterwards. [103]

18. Infected Blood Inquiry. Transcript – London – Wednesday 18 January 2023 (Eleanor Grey KC, instructed by Government Legal Department, on behalf of the DHSC, and Barbara Scott).



Study participants said that they wanted justice for the harm done to them and to other infected and affected people. There was a strong emphasis on the legacy of the scandal and that the injustice carries on intergenerationally.

The parents of children that have died or the children of parents that have died. Do you know, one poor girl, her and her brother – they were twins – she was seven when her mum and dad died in the same month, in August, and they were separated, and they were sent to different homes for the rest of their lives. Doesn't that make you feel sad? It certainly made me feel sad, and yet people seemed to think that it was not important. And they still, to this day, that girl, sits in the room, and she's had not a penny of compensation. [104]

[The infected blood scandal has] damaged us physically and mentally, and it's ruined our lives, and not just my life, my kids' lives. They might not have caught or was – I didn't catch it; I was given it. But they have felt the aftermath of it ... Because I asked my kids would they write about them what it was for them, and how it was, because it totally messed my son and daughter up. [141]

Views of mental health practitioners and experts

Our analysis of interviews with 14 mental health practitioners and experts across the UK focused on perceptions around three main topic areas: (i) current need for counselling and psychological support for infected and affected people; (ii) issues and barriers faced by infected and affected people trying to access psychological support; and (iii) what psychological support for infected and affected people should look like. We describe each of these in turn.

Current need for counselling and psychological support

Mental health practitioners and experts who were interviewed felt that 'need' for counselling and psychological support was difficult to define, highlighting diverse communities and diverse needs as well as wide variation in expressed need. Participants cited various layers or dimensions of need, including unaddressed trauma, intergenerational trauma, as well as the psychological impacts of feelings of anger and being wronged. There was strong agreement that the Infected Blood Inquiry will likely intensify the need for counselling and psychological support.

Diverse communities and variation in expressed need

There was a strong perception that 'need' (however defined) did not follow a linear or predictable pattern, that 'it goes in waves', with some people interested in talking therapy or counselling but 'not right now'; some 'dip in and dip out'; some "just don't want to talk about it" [301].

I think it's very difficult to quantify what the community as a whole needs because having spoken to people, everybody is at different levels really. [303]

[T]hey may come in and just need to tell their story to start with and then step away. But then it might be that it becomes more a time for them to work on it or it becomes more of a problem for them that then they feel they have to work on it. [314]

It was noted that some communities have known about and lived with the consequences of infection since the 1980s or 1990s, while others have not ("the blood transfusion group came much later" [302]) with some diagnosed very recently and who are facing "many of the same problems and difficulties, but they haven't had that length of time" [302].



Blood transfusion is very different that they, hopefully, didn't have that experience of witnessing people around them also dying. But they also are very isolated and, for many of them, they didn't find out until much further down the line, after, sometimes decades. [310]

There was a general sense among mental health practitioners who have been working with infected and affected people that, while the need for psychological support changes over time, for some the psychological difficulties linked to infected blood are very entrenched and 'deep-rooted', requiring ongoing support long-term.

Some people have long-term therapy in their life for these difficulties. So, in terms of the demand, it feels like there could be just a steady need for psychological work. I can't see, for some people, when that would stop. [311]

Multiple layers of need

Practitioners spoke of multiple dimensions or 'layers' of need among infected people and their families linked to encounters with health care providers and the wider system, feelings of shame, uncertainty and secrecy in day-to-day life, and their impacts on mental wellbeing and 'functioning'. Practitioners spoke about 'multiple layers of trauma' that people were experiencing.

So, you have the infected blood situation, then you have how it was handled, and then you have years of having to fight to be heard and to have your experience heard, and for somebody to take account of that. So, there'll be layer upon layer upon layer of trauma, and what I know is that sometimes it's not the actual original trauma that distresses people, it's how they're treated afterwards that becomes the trauma. [306]

Particularly for this cohort [people with bleeding disorders] ... being told you can't do the same things as your peers, maybe being told you'll never have a job, that if you go and do something and then you have a bleed, that you have to stay in bed for a week. There are lots of traumas often and messages from families about having to not do things or you being a burden or ... So, there are often lots of multiple traumas even before you get to the stage of the trauma of what's happened with their infected blood. [313]

Practitioners working with people with bleeding disorders highlighted the difficulties and challenges that infected and affected people have been facing because of their condition, and in many instances are still facing when deciding on treatment.

This is a persistent, for many, attachment-based trauma, multiple hospital visits where there was fear and uncertainty, the sword of Damocles hanging over them about each treatment, "I need the treatment, but is it going to infect me?" The anger and the mistrust of NHS England, doctors, who knows, but somewhere. And then all the "I can't tell anyone this because they'll think things about me and look what the news is saying about ..." [314]

Others spoke about unaddressed trauma, creating a need for long-term specialist support to help breakdown behaviours that people have developed as a consequence.

It's going to be part – it's very hard to get rid of behaviour that you've been living with for six months never mind six years, or it could be 40 years, 50 years for some people. ... So, they're really entrenched, and I don't think a few counselling sessions is really going to help with that. I don't even know if two years of psychotherapy is going to help with that either, but it feels to me that it should be more weighty. [302]



Participants cited secrecy as a recurring theme among infected people and how this has impacted their ability to form relationships and consequent isolation experienced by many, exacerbating the trauma of infection in the first place.

First of all, secrecy. A lot of them basically will live in complete secrecy – completely. Even with regards to partners. So, they don't actually really have support. It really limits some of their social interactions with others. [...] And it's also important to say that a lot of them, it's coming from an older generation and part of being affected by the scandal, they don't even share their haemophilia status because it's known among the groups, the link between the haemophilia and HIV. [312]

Some participants spoke about new challenges that people are encountering,

...there's a theme around ageing and their physical health is declining through ageing, but that's bringing up all the stuff around when you're told when you're 20 that you're not going to live for very long, never plan to be ... there's a whole load of other stuff that's feeding into that that's really unique to the infected blood community. [314]

Other challenges are linked to the Inquiry which we discuss below.

Intergenerational trauma

Several practitioners who work with people with bleeding disorders highlighted intergenerational trauma as a need that has, in their view, become more prominent in recent years, requiring due attention.

But actually, that's not going to be the end when the last person who was directly infected by contaminated blood dies, because their family and their family's family carry the legacy of that sense of mistrust of health professionals, of that sense of being made to feel less valuable as a human being as a result of their treatment. Those messages, they travel down generations. [313]

Participants emphasised the need for recognition of the “whole family unit” [312], of “those remaining” [308], because it “affects decisions and relationships and how the whole family think about things” [314] as they relate to haemophilia and treatment options.

Being wronged, being ignored

Study participants repeatedly highlighted the anger, the notion of being wronged, of feeling of “being hard done to” [301] that people they have been working with expressed.

There's so much anger, I'm sure you must have heard that, why has this been done to me. Why didn't anybody tell me. Why didn't anybody find me straight away. Why didn't anybody test me. Why doesn't the public know about this. Why haven't the government done something about this. [302]

Practitioners noted that the ‘bleeding disorder’ and ‘transfusion’ communities were facing very specific challenges that resulted in expressions of anger. One example is that of having received non-life-saving treatment, which was the case for many people with haemophilia.

They went [to the hospital] and they were having a tooth pulled out, so their mum said yes, give him factor. And then 10 years later, they found out actually, you now have AIDS and it's because of that injection you had which was not probably that necessary, but we did it to prevent you bleeding. [310]



Several participants highlighted the difficulties faced by those more recently diagnosed with hepatitis C resulting from historical infection through blood transfusion, citing feelings among those affected of being ignored, creating a further layer of need for support.

I think there's still this sort of perception with the public that the haemophilia community and not people with transfusions, so the people with transfusions do feel completely lost, angry, frustrated. There's many of them, well we don't know how many are still out there undiagnosed ... [302]

Impacts of the Infected Blood Inquiry

There was agreement that there would likely be increased need for support following the conclusion of the Inquiry. Study participants who are or have been working with infected and affected people noted that the Inquiry required people to go back to and revisit memories and experiences, causing distress and renewed trauma.

[T]he people who survived buried their stories for many, many years. The trauma of a parent who in effect feels they've killed a child can sometimes only be dealt with by saying, "I'm not going to talk or think about it," and then the Inquiry has come along, and it's raised all these issues. And telling that story again and again is triggering and retraumatizing. [305]

But, as with evaluating the current need for counselling and psychological support among infected and affected people, participants found it difficult to quantify the expected increase in need. Some practitioners noted that there are people ("an awful lot" [310]) who have not wanted to 'do trauma work' as the Inquiry was ongoing, for reasons of self-preservation, but who would be able to engage in therapy after the Inquiry has closed. However, whether they would indeed come forward for treatment would be difficult to predict.

There was agreement among participants that the nature of need for psychological support would be strongly shaped by what people were experiencing as they followed the Inquiry, such as finding out new information about the infected blood scandal.

There are people who have learnt new information about their own treatment, or their family's treatment. There are people who have listened every day to the inquiry and have heard the most horrific, heart-breaking stories. There are people who've lost friends, lost family members during this inquiry and they've just had to shut it down to get through and to survive. [310]

They witnessed anger having (re)surfaced among infected and affected people as the Inquiry progressed, when they learned about different perspectives, as well as anger and "frustration at the length of time this has gone on" [303]. Some practitioners reflected on how this had already impacted their work with infected and affected people.

I definitely had sessions with people where I was moving toward discharge and suddenly, it was like no. I've a lot of people on my caseload that we were doing really good work, in my opinion, before the Inquiry started. [...] And suddenly they were signing up as core participants [of the Inquiry] and they were recalling their medical notes and instead of facing forward they were told, encouraged, to face to the past. [...] And they were going through medical notes from 20 years ago with a fine-toothed comb and reactivating a lot of anger, a lot of that grief, a lot of things they'd [buried], things they'd missed. [310]

In addition, new issues have been brought up by the Inquiry that would require support. One is related to the specific difficulties of those were only recently diagnosed, and who are still in the process of understanding what has happened to them.



So, you can imagine to find out today that you've got Hep C and then realise you caught it back then, and to be coming in on the end of the Inquiry and everything, so there's a lot of distress there. [303]

There was general agreement among practitioners and experts that the level of need for support would be shaped by the government's response to the Inquiry, in particular around compensation.

So, there's a real lack of trust with any officialdom and we don't know what this is going to be like. This could be a lot worse in a year or two's time depending on how the government act around compensation. And how they react around the recommendations for this. There could be a huge amount more to unpack than we even know depending on what happens in the next year to 18 months. [301]

One practitioner pointed to the challenges related to the interim compensation payment that was made available in 2022, which “comes with a lot of pain and a lot of suffering and a bitter taste and a lot of uncertainty about what to do with it, whether it might get taken away at some point because it was that interim payment, like, “Might this go away?”” [314].

Finally, there was an expectation that the recommendation of the Inquiry's Second Interim Report to provide a bespoke psychological support service in England will likely create demand for support.

I think that some of my clients, through the Inquiry, through things being occasionally mentioned and on the radio, are hearing that this is happening, and that for example there is support available. So I think if there – if this makes headlines, then there'll be more people who think, “Oh hey, like, there's – there is support available.” And so in that respect, the need for it might grow. [308]

Closure

Practitioners whom we interviewed recognised that the Inquiry provided a ‘lifeline’ for some, a “helpful focus” [311], but that there was also significant potential for the Inquiry to cause and exacerbate emotional distress where the Inquiry's findings and recommendations did not align with people's expectations of, or hopes for, resolution or closure.

I would say with some probability people will be quite angry, people would not feel that they've obtained the resolution that they were hoping for. And they would not feel that their grievances have been either addressed correctly or actually provided any sense – you can even have people talking about the compensation. “I got the compensation and what?” It wouldn't bring the kind of closure that perhaps they're hoping to achieve, because the closure would not come – I cannot see how a closure would derive from that. [312]

There was an expectation among some participants that there would be “a significant group of people” likely finding it difficult to move on from “whatever the Inquiry says” [301]. They raised the question about how psychological support will help these groups to do so, which was felt would need to be addressed before the Inquiry closes.

I think we've been trying to be realistic with clients in terms of that work in terms of, OK, what will this [Inquiry] actually do for you. Because it's definitely not a full answer, is it, and it definitely isn't going to be a solution to anything, as such. So, in some ways, the psychological concerns or the patterns that we've been dealing with, I don't think, would be ended when the Inquiry outcome is produced. [311]



Issues and barriers faced by infected and affected people trying to access psychological support

Mental health practitioners and experts described a wide range of factors and issues that they saw as preventing infected and affected people from accessing psychological support or counselling. These ranged from issues around self-preservation, a legacy of distrust in institutions and difficulties in accessing services, lack of knowledge of the types of support that are available to experiences of inappropriate support and understanding of what therapy can and cannot do. We address each point in turn.

Self-preservation

Practitioners highlighted a real fear among their clients of psychological treatment or counselling reopening wounds, not wanting to face the trauma or 'go through all of this again'.

Clients saying, "How can a series of eight therapy sessions or even 20 therapy sessions possibly help me through 30 years of hurt and pain". There's a fear of re-traumatisation, of having to relive everything again. Of exposing themselves again to emotions that they've locked up, even if some people feel that it may do good, they're scared, understandably, of reopening again, after having perhaps reopened it for the Inquiry, again going through that. [303]

One practitioner commented that some infected people "are so desperately broken that they just can't get breath sometimes", noting that they "just don't want to engage at all". They described deeply-rooted trauma from losing a loved one, having been told at a young age of having to expect to die within the near future, "they just want to listen to what's gone on in the Inquiry, and once that's over and done with I think they'll go back to, or try and make their way back to the lives that they had prior to this happening" [301].

Legacy of distrust in institutions and difficulties in accessing services

Similar to what we heard from infected and affected people (described in the preceding sections), practitioners talked about clients who have had poor experiences trying to access support in the past ("It [referring to the Skipton Fund] was like hard work all the time, it was just putting barriers in people's way" [302]) and had little trust in the system as a consequence of that.

I was talking to a gentleman who is effectively stuck in the anger stage, and because of his mistrust of the Trusts, originally the Skipton Trust, and also through EIBSS, the feedback was "I have absolutely no confidence whatsoever, they'll just refuse me because I've been refused grants in the past". And even though myself and I know at least one other person has tried to convince him that that probably wasn't the case, and that they can move forward, and they can apply for the help that they need, and I know that EIBSS have tried to reduce the burden to be able to get access to that there is a case of "I don't believe it. I have no trust. It's not something I'm going to even bother to fill the form in for because why should I bother". [303]

There was a strong sense among practitioners currently working with infected and affected people that the high levels of distrust within the community would require considerable work from the authorities, the NHS and the wider system to earn that trust back.

They don't know that they can [access psychological support] and they don't feel that they can trust it. And also, they've been let down so many times, they don't believe that anything will change. [307]



Lack of knowledge of the types of support that are available

Lack of understanding of the types of support that are available can present a significant barrier to accessing services. However, practitioners noted that even the eligibility criteria that people have to meet to receive payment for psychological support or counselling are not necessarily well understood.

[A]nd then there's the people where actually they have no access at all to anything through EIBSS because they have no connection. They're a sibling, they're a carer, they're a child of. They're not connected to the support scheme. They don't get the notifications. If they're not members of [organisation] they don't even know that they can access that, and that's been quite recent as well. [303]

This situation is further compounded by the need to prove eligibility, which may prevent people from seeking to access support altogether, as we heard from accounts from infected and affected people (noted earlier in this report).

I think the criteria for accessing support perhaps excludes some of the people who have been affected. And there's the ongoing issue which is coming up [...] quite a lot, that people who didn't even know or who have found it hard to get proof. You know, the whole issue of testing and getting hold of medical records, and I think for some people the barriers are just so great that they just think it's just not worth it. [305]

Participants further highlighted that even if people were able to access funding from EIBSS for psychological support, there are additional barriers preventing them from going through with it, because of the difficulty of finding someone who may be able to provide support. This may have been experienced as random and requires some understanding of what support is appropriate to their specific situation (“*You don't know whether it's anxiety, whether it's generalised anxiety, whether it is depression*” [303]), which people are unlikely to possess.

So, there's lots of, I think, issues with giving people a payment to seek therapy, but that's one of the biggest things for me, is that they don't know who they're going to get. [311]

Practitioners generally welcomed the principal availability of funding for psychological support through EIBSS while also noting the limitations of the funding, warning that it would only allow for short-term support work and could be seen as “*tokenistic, because what's twelve sessions, really? I think there needs to be something ongoing*” [308].

There was also a perception among practitioners that the range of treatment modalities available was perhaps too restricted to address the varied needs.

For some people therapy might be absolutely brilliant. I'll give you an example, I had someone recently who rang [organisation] to seek our guidance on finding a therapist, but she was very clear she didn't want psychotherapy. She did not want counselling. But what she would personally find really helpful would be some sort of life coaching. Motivating to kind of get back in the world. She's been hidden away for ages. [302]

Understanding of what therapy can and cannot do

Practitioners further noted that there may be a more general lack of understanding of and misconceptions about what psychological support or counselling can (or cannot) do for them.



Given what has happened to people, the idea that talking to somebody would make any difference is very alien to many people. How could it make a difference? You know, we're not going to make things better. We don't have a magic wand, all those things. And yet I think we all know that the experience of talking to somebody and being listened to in the right way does make a difference, even if you can't change any of the facts. [305]

At the same time, for those coming forward and wanting to access support, treatment options accessible through EIBSS were considered to be 'limited' and 'narrow'.

[W]e're finding that people want something that's maybe a little bit broader than just what we might see traditional psychoanalysis, analytic help, so we are having people who want hypnotherapy and other things like that that are maybe more broad in terms of the therapeutic offering. [301]

Lack of appropriate support

Similar to what we heard from infected and affected people, practitioners highlighted the negative impacts of having received inappropriate psychological support in the past. This was not only seen to be potentially harmful in terms of mental health and wellbeing. It may also affect people's understanding of and willingness to engage in further treatment.

I think one of the long-term effects of the lack of appropriate support means that people will possibly think, "What's the point? It didn't help before." So, their previous experience obviously affects their decision about asking for more support. [305]

All of the interviewed practitioners voiced concern about offering generic support to infected and affected people, which, on the whole, they described as not appropriate for this community, because it lacked understanding of their specific circumstances. There were concerns that people "were kind of like bounced around between [services]" because "the NHS basically did not really know what to do with them" [312].

And for me, it is a crying shame that people might think – that [generic support] might be their experience of therapy, because clearly, they're needing something that is much more tailored, long term, in depth and very knowledgeable about their specific pain. [308]

There were many comments on Improving Access to Psychological Therapies (IAPT; now called NHS Talking Therapies) currently signposted by EIBSS as one route into counselling and psychological support for infected and affected people,¹² and practitioners and experts were clear that, from their perspective, IAPT would not be suitable to meet the needs of most infected and affected people.

Well, there's absolutely not a cat in hell's chance of these people, who've already been stigmatised literally to within an inch of their life, going and sitting in a group and saying, "I've got Hep C" or, "I've got HIV, and I've had this. You get people doing this." You know, it's just – it needs to be a very specific service. I don't think making provision within the NHS business as usual would be helpful at all. [306]

While most participants viewed IAPT as a useful approach for working with "early mental health issues" [305] and addressing "unhelpful thinking styles" [308], they were concerned that IAPT would not deliver the high-intensity work needed for the infected blood community.

IAPT is an excellent service for very specific and focussed pieces of low-level psychological work around anxiety, depression, even some simple traumas, as well, absolutely. But the population that we're working with have not experienced simple trauma. [314]

12. NHS Business Services Authority. Talking therapy support. 2023.



Practitioners expressed concern that the structured approach employed by IAPT could ultimately be harmful as people are “not going to feel heard and if they don’t feel heard, you’ve lost them” [307].

And that’s not to disrespect IAPT services – they do an incredible job – but I think there are very specific needs around somebody’s lived experience and the trauma that they’ve experienced that is probably beyond low-intensity IAPT work. And also, I guess, you don’t really want people to have that same experience of being let down again by health professionals, which is just replicating some really difficult stuff, really. Especially if they’re voicing a lot of distressing things and then get told, “Oh, we can’t help you,” or, “It’s beyond us,” or whatever it might be, then actually that does, it just replicates that experience, really, of having a difficult time with and not being able to trust people. [313]

What psychological support for infected and affected people should look like

When discussing what a (future) psychological support service for infected and affected people should look like, practitioners and experts considered a range of options that can be broadly summarised under the following headings: who should provide the service; practitioners’ competencies and skills; key features of a psychological support service. There were suggestions of existing service models that might provide suitable examples for a psychological support service across England. We discuss these in turn.

Who should provide the service?

Interview participants found it challenging to identify a single ‘best option’ for a service provider. Views varied depending on participants’ backgrounds and experiences, although there was consensus that it should probably be a mix of different options.

There was a preference among most participants that the service should be provided through the NHS rather than by professionals in private practice. However, there was recognition of the significant distrust in the NHS given its involvement in the infected blood scandal.

But I do think if it [the psychological support service] came with an NHS title, people wouldn’t want to go near it. They’d be like, NHS? It’s still the NHS, it’s still medical. [307]

There were also mixed views on the role of haemophilia services. There was some agreement that these should be involved, although trust could be and, as those working with people with bleeding disorders confirmed, remains an important issue.

For example, if you are a severe haemophiliac who has been through all this you still have a very significant connection with your centre, because you have to. You go in every six months and there is trust being rebuilt over the years with the nurses and the doctors, not in all cases, but in many cases, there is certainly significant trust links with them. [303]

However, while haemophilia services could provide an important location for psychological support, on its own, this route will miss an unknown number of people who do not (regularly) use haemophilia services, including affected communities and those infected through other routes, such as blood transfusion.

[W]ouldn’t want to do is to set up a service that, yet again, makes [people infected via blood transfusion] feel different and quite isolated ... , it’s a very different journey. Very different traumas, very different experiences, but it is really important that they’re not, yet again, made to feel different or poorer. [310]



There was some suggestion that there could be a provider separate from the NHS but commissioned by government.

[I]f we want something that's quite specific then it is about probably having a preferred supplier that the government use that specialises in this. [301]

Some participants mentioned that charities could take on this role, although there was recognition that such a model might not reach those who do not identify with the given charity's cause.

And so, I think it shouldn't have the label of any of the charities that currently exist, nor have a name that suggests that it's really just for people with haemophilia or really just for people who have hepatitis, or for somebody who was close to somebody who died of one thing and not another. [305]

One participant felt very strongly that whoever provides the support service, it should be separate from any organisation that was directly or indirectly involved in the scandal.

[A]nd it has to be someone independent who is a voice for that community and an advocate for that community, not part of whatever system perpetrated the pain that they're – it has to be separated out ... It can't be too connected to those institutions that caused the harm in the first place ... and that people can simply refer themselves. [308]

But whatever the 'best' service provider option looks like, practitioners and experts interviewed for this study were unanimous in their view that infected and affected people should be involved in the development and design of the psychological support service if it is to be effective in supporting the diverse communities.

One of the things that has always been an issue has been that people feel like things have been done to them. So, I think whatever service you come up with it needs to be communicated that you have spoken to many people. How this has come around is not just something that's just been created, it's been done in consultation with people. [303]

There was also a very strong sense that there should be mechanisms in place to ensure that the service is of high quality and there is a system of oversight and accountability (*"Is there going to be a board? Is there going to be a safety and safeguarding committee? All those other things that go with providing a service."* [305]) as otherwise there is the risk that *"people are throwing really important money for them at something that nobody is actually taking clinical governance over that"* [310]. A strong oversight mechanism was seen to be of key importance given the many vulnerabilities of the infected and affected communities as described in earlier sections of this report.

Practitioners' competencies and skills

Mirroring the discussion around practitioners' and experts' views on generalist psychological support described above, there was a strong sense that practitioners providing the service should be adequately qualified, accredited and registered, with a good understanding of the history of infected blood and the challenges people were facing. As indicated earlier, the requirements of the service would have to go beyond primary care mental health services, given the complexity of needs among the infected and affected community.

Because it is very niche and it's not something that generic services – not that they wouldn't know how to deal with it, but they don't see it. So, it's like asking somebody with a very rare form of cancer to be seen in a diabetes service. Like



it just doesn't map on. Not to say that there aren't people across the board who would have the skills to work with this group. Absolutely. [311]

There was agreement that the type of practitioner is perhaps less important (“So, whether that is counselling psychologist, health psychologist, clinical psychologist” [310]) as long as they have the necessary clinical skills.

[I]t's really important to have someone on the support side who actually thoroughly understands that situation and so these should be people who are not let loose on any affected people until they have really been trained and talked to lots of people and understand really what the issues are. [...] everybody's issues are going to be different and it's very important not to anticipate what people are going to need until they actually start to talk about their own situation, and then you can explore with them what they think might be helpful. [304]

Practitioners working with infected and affected people further emphasised the importance that psychological support services should take account of the physical health problems that infected people were experiencing, given the impact that this can have on mental wellbeing and overall functioning.

[A] lot of psychological support is based around people's behaviours, and how they are as people. [...] But on the top of that, you know, what people and especially infected people, they are still dealing with a very, very chronic in a lot of cases medical conditions. [301]

Participants considered a range of competencies and skills that they felt an ‘ideal’ provider of psychological support for infected and affected people should possess. There was wide agreement that “it needs to be someone who has the capacity for to [do] complex trauma work” [314]. The desired ‘profile’ of practitioners working with the community are perhaps best summarised in the (paraphrased) words of one participant [310]. Thus, practitioners should have:

- an interest in and experience of working with trauma;
- experience of working with people who have physical health issues that impact mental health and vice versa;
- be self-motivated and proactive in terms of willing to reach out and making themselves available;
- be flexible in the way they are working (i.e., providing face-to-face, online, or telephone sessions);
- and, most importantly, have the sensitivity and knowledge about the infected blood scandal.

The last point was seen as essential for anyone working with infected and affected people, and very much mirrors what infected and affected people themselves have told us (as described in earlier sections), and which again may be best summarised in the words of one practitioner:

[T]here's an expectation because a lot of these people have lived this. It's been such an integral part of their lives for so long that this is an expectation that if they go to a professional that professional will understand everything about the contaminated blood Inquiry. [...] because if people come across and walk in blank to somebody who has perhaps never worked in this area before, has very scant knowledge, again that may produce anger of like how can this have happened to all these people, the biggest disaster, the biggest killing of people, and you don't know. How can you not know. Because there's an expectation that everybody knows, even lay public, they get angry if even the lay public don't know anything about this because it's such a priority and been such a part of their lives. [303]



Key features of a psychological support service

In discussing the key features of a psychological support service for infected and affected people, participants described a range of characteristics they considered to be important. These included that the service should be responsive and pro-active; flexible and agile; compassionate; and visible and trustworthy. Practitioners and experts also suggested some potential service models, including some form of triage or assessment.

A responsive and proactive service

There was a strong sense among study participants that the psychological support service should respond to the diverse communities' needs for support, which they would expect to change over time.

[[It would have to be a programme that would have to constantly evolve because the people's needs are evolving all the time. The affected people, the children that are coming through, you know, we are dealing with an infected person. [301]

Given the history of the infected blood scandal, and the ensuing distrust among infected and affected people in the organisations involved, there was agreement that the support service should proactively reach out and encourage engagement.

You know, when you've got a lot of mistrust, people-to-people is much more impactful than it is on a website or a letter or, you know, a phone call. I think the more human contact they have, the better; when they can look you in the eye. Because they've been so dismissed that actually, you know, they need to be able to hear it from somebody themselves, don't they? [307]

It was also argued strongly that solely providing information on a website, such as EIBSS, will not be sufficient if the government was serious about providing psychological support.

[[It's about alerting people about what might – how these services might help them, and encouragement to take up the services, rather than hope – you know, put it out there and then hope they don't take them up because it'll save money. [306]

[Infected and affected people] should be supported, encouraged, given information, given different options to do that. [302]

A flexible and agile service

Linked to the above is the need for the service to be flexible and agile, as participants have described it, offering the ability for infected and affected people to access the service when they need it and re-enter it without having to reapply for funding.

And the flexibility that's needed in that service [...] that ability to step in, step out, not to have to go to the back of a long waiting list queue and wait your turn again, that it's flexible and agile. And it needs to be well-resourced in order to do that. [314]

There was concern about what was felt to be an arbitrary cut-off on the number of sessions that can currently be accessed through EIBSS funding.

[W]e have to move away from this is amount of money you've got to spend to what do you need ... it isn't the right approach. I think it's about what people need that is going to allow them to move forward with their lives in a way that they happy to go on, and are happy with in the future, and that's what it should be based around rather than just presenting people with a number that they can have forever. [301]



There was agreement among practitioners working with infected and affected people that people should be able to self-refer to the service and give them the flexibility to do so. The option for self-referral was seen to be important for several reasons. First, it reduces the reliance on a GP or consultant to issue a referral.

Not everybody is going to feel able to do [therapy] [...] That they don't have to, as it were, go and say to somebody, "I think I need this," and for somebody else to make the judgement about whether or not they do. Because even if the person they're talking to says yes, there's still the sense of, "Do I deserve it? Do I really need it? Is it for me?" So, I think a self-referral route is an important part of it. [305]

Second, self-referral can be empowering, "because you're not then incumbent on somebody else doing something to – for you to get that help. Which in this community, matters" [308]. There was wide agreement that people who self-refer are "cognitively ... ready" [308] for therapy. Third, self-referral was widely seen to remove barriers to accessing services felt to be particularly pertinent in this community for historical reasons.

Even going into a hospital sometimes for people is very difficult. Or having to have a standard routine blood test or whatever that might look like, or receiving medications and they're a bit suspicious of what they are or who's provided them [...] to just remove some of the barriers. [311]

A compassionate service

Many practitioners and experts interviewed for this study referred to the way the Inquiry approached infected and affected people, and how the Inquiry Chair had shown real empathy and compassion, treating those giving a statement in a respectful and non-judgemental manner. Study participants felt that these should form core elements of a psychological support service, as indeed of all mental health services.

So, listening to some of the stories, the neglect, the anger, the despair, the having to fight to be heard I think has been a huge issue. And I think that's part of what I think people will – they will need to be heard, and listening to Sir Brian and his team, listening to the way in which they're spoken to in those arenas, in the most sensitive, respectful way, I think was healing in itself for some people. The way in which it was conducted and the care with which the teams around the affected and infected people there has been a huge help. [306]

There was a strong sense that the whatever the psychological support service would look like, there should be a key point that people can get in contact with and discuss options.

[P]eople like having somewhere they can come back to, somewhere they can phone back, and they will speak to the same person and that person will know about them and the situation. I mean that makes a huge difference. That personal contact. Governments always try to save money and not employ people but actually people are a hugely valuable resource, especially in this sort of situation. There's nothing as good as having a person you can talk to really and you know who that person is, and where to find them. [304]

A visible and trustworthy service

A recurring theme in practitioners' descriptions of what an optimal psychological support service for infected and affected people should look like was that of the fundamental distrust in health services among many members of that community. Practitioners working with the community recounted how much of their work was dedicated to (re)building trust.



I think it certainly has been a longer process than in my other clinical settings. [...] And if we said we would do something, then we really did have to do that to build that trust and build that kind of rapport, I guess. So, it was very slow work to begin with, before you then get into the kind of deeper work. I'd say that a good chunk of the first part of the work was about building that relationship. [311]

A key component of building that trust was for the practitioner to have a good understanding of the infected blood scandal and what this meant for people affected, as mentioned earlier in this report. It was felt crucial that an effective support service should reduce the need for infected and affected people having to retell their story.

Because it's very demeaning and quite belittling when you have this person who's supposed to be in a position of supporting you just having no notion of what you've actually been through. [308]

Some practitioners spoke of the need for validation of their clients' experiences as an important component of the therapeutic relationship.

I think it's so important to be able to acknowledge and validate what people have experienced [...] to fully acknowledge what people have experienced [...] and I try to acknowledge that I now work as part of the NHS. But in no way do I not understand that actually, as an organisation, that was partly responsible for what happened to people. [311]

There was a general sense that the fundamental distrust in the NHS and related services was affecting use of psychological support services that are offered.

You'd be talking to people that want to be heard but don't want to come to you. So it's that sort of, you'd have to build your reputation and have the integrity that these services have lacked. [307]

Practitioners working with the infected and affected community thus highlighted the need to be proactive, reach out, build 'authenticity', embed themselves and "becoming visible to the community before necessarily people would accept a referral, or would self-refer to [the] service." [310]

Assessment and triage

Participants suggested that there should be some form of high-level triage or initial assessment to understand people's needs and identify the 'right' or tailored support, which may also include services other than psychological support.

You're going to need a team that can actually assess people and say, alright does this person just need someone to talk to or do they have a condition that actually needs evidence-based treatment. You need a pretty well qualified person to do that initial assessment and think about what direction to send this person in, what their needs are going to be. [304]

However, there were concerns that triage should not be seen as a way to evaluate whether someone can have access to a given service or not. It should not be seen as a 'gatekeeping' service but instead an initial assessment in discussion with infected and affected people to direct them to support services that are most appropriate to their needs.

So, they can have like almost an upfront conversation which isn't therapy, but which identifies what they need, and also to explain that for somebody to have benefit from psychological services that the therapist themselves doesn't need to have a massive understanding of what went on because the way that people react to things is – it need to be done in a gentle way. [303]



Participants highlighted that such an “assessment framework” would need to be set in a specialist setting to understand the nature of the need and identify the most appropriate support [311]. There was agreement that there should be a team of practitioners working together to provide the service. The team approach was seen to be important as it would enable the development and strengthening of expertise of working with the infected and affected community.

... rather than have a pot of money that people can go and then access anyone, because everyone's going to access someone different, and that knowledge doesn't build up and develop and grow. Whereas it would if you've got a team of psychological practitioners working together because, although they may not have that knowledge to start with, it would develop and grow and deepen as the work continues. [314]

Service models

Participants referenced a small number of existing services that could serve as a model for psychological support for infected and affected people in England. These are: the Choice and Partnership Approach (CAPA) in child and adolescent mental health; NHS staff mental health and wellbeing hubs; and the psychological support services offered as part of the Infected Blood Support Schemes in Northern Ireland, Scotland and Wales. We briefly describe these in turn.

Choice and Partnership Approach (CAPA)

The Choice and Partnership Approach (CAPA) has been implemented in (some) children's mental health services in a range of sites in England and Scotland.¹⁹ It has been described as an “accessible, child-centred and family-centred model of child and adolescent mental health service ... that better matches care to needs”, emphasising a collaborative approach to mental health care where young people and clinicians jointly develop treatment goals.²⁰ The first contact is the ‘Choice appointment’ which seeks to define the problem from the patient's perspective and to help them consider treatment options; it may include a brief therapeutic intervention and the patient might decide that this has met their needs, or that further treatment is needed.²¹ A further Choice appointment may need to be offered if no agreement is reached. The ‘Partnership’ element begins with the second appointment; the model distinguishes Core Partnership, that is, evidence-based first line treatment, such as cognitive behaviour therapy (CBT) for anxiety, and Specific Partnership involving a second clinician to deliver specialist intervention.

[S]o they come for the Choice appointment which is about an hour, it used to be about an hour and a half, of really good talk about things. You probably wouldn't need that with adults. A good hour's sort of assessment of what they might need. And then that person might explain, “I wonder if it would be helpful for you to have – you could have a person-centred approach, and this is what that's like, or you could have a trauma approach, and that's what this is like.” [306]

Staff mental health and wellbeing hubs

The NHS staff mental health and wellbeing hubs were launched in January 2021 in response to the psychological and emotional pressures that NHS staff experienced during the Covid-19 pandemic.²² The 40 Hubs were modelled on the Greater Manchester Resilience Hub that was set up to treat those affected by the Manchester Arena attack in 2017, including NHS staff. The Hubs were set up to facilitate “rapid access to assessment and local evidence-based mental health services and support where needed.”^{23, website}

There was an expectation that the hubs “offer proactive outreach, by identifying at-risk groups and making contact with individuals to offer assessment and support should they need it.”^{24, p. 3} The hubs provide rapid clinical assessment (accessed

19. The Choice and Partnership Approach. The Choice and Partnership Approach. 2022.
20. Campbell L, Clark S, Chorney J, et al. Choice and Partnership Approach to community mental health and addiction services: a realist-informed scoping review. *BMJ Open* 2022; 12: e064436.
21. Pajer K, Pastrana C, Gardner W, et al. A scoping review of the Choice and Partnership Approach in child and adolescent mental health services. *J Child Health Care* 2022; 14: 13674935221076215.
22. NHS England. NHS expands mental health support for staff after toughest year in health service history. 2021.
23. NHS England. Staff mental health and wellbeing hubs.
24. NHS England. Guidance for Mental Health and Wellbeing Hubs for Health and Social Care Staff. 2021).



through self-referrals and referrals from other sources) and onwards referral and care co-ordination to deliver rapid access to mental health services and support.

Government funding for the hubs ended in March 2023²⁵ and it was suggested that the hubs could provide a principal infrastructure for specialist psychological support for infected and affected people.

And when that came to a stop there was no funding for these hubs to continue so there will be loads of people in the job market who have had experience of working in these hubs and could do a similar kind of job, you know, if they were suitably trained in the issues, but they could do a similar thing here. [304]

Psychological support for infected and affected people in Northern Ireland

Northern Ireland introduced a dedicated regional specialist psychological service for infected and affected people following the recommendations of a working group that was set up in 2018 “upon receipt of original correspondence from the [Infected Blood] Inquiry’s solicitor.”^{26, p. 78} The working group made the business case to the Department of Health in Northern Ireland and secured funding for a clinical psychologist, who set up the service in January 2019. The service is delivered within the Belfast Health and Social Care Trust for people aged 18 years and older, although there is also potential to see children.²⁷ It is available to infected and affected people and accessible through direct referral and self-referral; there is no need to apply for funding to access the service.²⁶

Support is through a specialist clinical psychologist, who provides an assessment of an individual’s psychological needs, followed by therapy and longer-term support where required. Therapy modality is tailored to an individual’s needs and delivered in-person face-to-face, or online, depending on an individual’s preferences. There is no set number of sessions and almost all referrals are seen within six weeks.²⁶ By early November 2022, 38 people had used the service.

The funding of the service was initially set to end in March 2021 but the Northern Ireland government has now committed to psychological support continuing after the end of the Inquiry.²⁸

Psychological support for infected and affected people in Scotland

Scotland operates two distinct psychological support services for infected and affected people.

The Psychological Support Service (PSS) for people with inherited bleeding disorders was introduced after the 2015 Penrose Inquiry into hepatitis C and/or HIV acquired infection from NHS treatment in Scotland with blood and blood products.^{29, 30} It was initially funded as a two-year pilot at Edinburgh Comprehensive Care Centre.³¹ Funding included a full-time clinical psychologist and a liaison psychiatrist (0.1 FTE). In 2018, the PSS was extended into a national service, with referrals invited from all haemophilia centres across Scotland.³² The PSS is accessible through self-referral and referral-in from clinical teams, other mental health services or the third sector. It provides consultation, joint working and training, and clinical treatment, offering different treatment modalities. There is no set number of sessions offered, “we will do whatever is appropriate for that person at that time.”^{26, p. 93} Treatment is offered flexibly, including in-person face-to-face, online, by telephone; the delivery mode is negotiated with the client individually. By November 2022, the PSS had received 255 referrals to the service, of which just under half (47%) were from people infected or affected by contaminated blood.

The Scottish Infected Blood Psychology Service (SIBPS) was set up in 2021. It is a national service, accessible to “anyone who was infected, or affected, by contaminated

25. The British Psychological Society. Protect the future of NHS staff mental health and wellbeing hubs. 2023.
26. Infected Blood Inquiry. Transcript – London – Friday 11 November 2022 (Keith Carter and Specialist Psychological Support).
27. Belfast Health and Social Care Trust. Clinical Psychology Service for Individuals and their Families Infected/Affected by receiving Contaminated Blood. 2021.
28. Infected Blood Inquiry. Closing submission on behalf of the Belfast Health and Social Care Trust. 2023.
29. The Penrose Inquiry. 2015.
30. Infected Blood: Scottish Financial Support Review Group. Contaminated Blood: Financial Support: Conclusions and Recommendations. 2015.
31. NHS Lothian. Haemophilia centres: psychological support pilot. Edinburgh Service Interim Report. 2017.
32. Infected Blood Inquiry. WITN4063001 – First written statement of Belinda Hacking on behalf of the Scottish Health Boards – 26 Jan 2020.



blood and/or blood products received from NHS treatments in Scotland.^{33, website}

It is hosted by NHS Lothian and based within the Astley Ainslie Hospital in Edinburgh.³⁴

The SIBPS was also funded as a two-year pilot initially, within the Scottish Infected Blood Support Scheme (SIBSS). The service is delivered by a clinical psychologist. Access to the SIBPS is through in-referral and self-referral (currently paper-based, work on online self-referral is underway): *“it’s trying to be as easy as possible for people.”*^{26, p. 99} People will be seen in-person face-to-face, online or by telephone. By November 2022, SIBPS had received 28 referrals.

People who do not wish to use NHS services can also access private counselling fund that can be applied for through the SIBSS. The latter is available under the ‘Support and Assistance Grants’, with up to £1,000 made available to any SIBSS beneficiary as well as dependent children who have a parent who was a beneficiary and has died, to help with education or training courses.³⁵ Accessing the grant for counselling or psychotherapy does not require an estimate of the full cost, but beneficiaries are asked *“if possible”* to *“include a cost per session or per hour of any counsellor or psychotherapist.”*³⁵ People can either choose to find a counsellor themselves or ask the SIBSS for help to find someone who is accredited with Scotland’s professional body for counselling and psychotherapy (COSCA).³⁶

It is difficult to estimate the proportion of SIBSS beneficiaries who have accessed either PSS or SIBPS. From the above, it can be estimated that some 150 infected and/or affected people have accessed either one. The number of SIBSS beneficiaries in 2020 was 540.³⁷ This would give a proportion of just under 30%. However, as both PSS and SIBPS are offered to a broader group of the infected and affected communities beyond SIBSS beneficiaries, the proportion will be lower. According to the 2020 SIBSS customer satisfaction survey, some 25% of survey respondents had received psychological, counselling or other mental health support, although it is not clear whether this was through the PSS, wider NHS mental health services or was privately paid for.³⁷

Wales Infected Blood Support Scheme Psychology & Wellbeing Service

The Wales Infected Blood Support Scheme (WIBSS) Psychology & Wellbeing Service was established during 2019-2020,³⁸ following an announcement by the Welsh government in 2019 to provide enhanced support under the WIBSS.³⁹

The introduction of the Psychology & Wellbeing Service was prompted by an acknowledgment and acceptance *“that beneficiaries of [...] the Welsh Infected Blood Support Scheme (WIBSS) will have experienced significant mental health, well-being and post- traumatic stress (PTS) associated with their experience of infection.”*^{39, website}

Based in the Velindre Cancer Centre in Cardiff, the service employs a clinical psychologist and a counsellor.²⁶ Support is offered to people registered with WIBSS and their family members and bereaved family members.³⁸ The support involves psychological assessment and treatment, which is offered in-person face-to-face, online and per telephone, and also includes couple and family therapy.²⁶ The service is open-ended, with no set number of sessions offered. People can access the service through self-referral or by being referred in. The service is described as flexible, seeking to *“reach the needs of what people come with as much as possible”*.^{26, p. 85} There is currently no reported waiting list for people wishing to access the service.

According to the 2020/2021 annual report, there were approximately 60 clients currently accessing the WIBSS psychological support service.³⁸ That year a total of 213 beneficiaries were registered with WIBSS, including bereaved spouses and partners. This would equate to just under 30% of beneficiaries accessing psychological support, but as the service is also provided to wider family members of WIBSS beneficiaries, the proportion of ‘actual’ beneficiaries using the service will be lower, possibly at around 20%.

33. Scottish Infected Blood Psychology Service. Who we support. 2023.
34. Infected Blood Inquiry. WITN4063002 – Written Statement of Dr Belinda Hacking; 10 October 2022.
35. NHS National Services Scotland. SIBSS Guidance and Forms for Support and Assistance Grants. 2021.
36. Counselling & Psychotherapy in Scotland. Scotland’s professional body for counselling and psychotherapy. 2018.
37. NHS National Services Scotland. Scottish Infected Blood Support Scheme 2020 Customer Satisfaction Survey and 3-year Review of Service.
38. Wales Infected Blood Support Scheme. Annual report 2020/2021.
39. Welsh Government. Written Statement: Welsh Infected Blood Support Scheme (WIBSS) Enhanced support. 2019.



There are plans to broaden the service to the group and community level. This is based on the experience of those providing the support, where “[t]hemes of isolation, separation and difference from others” are frequently discussed.^{38, p. 17} Relevant modes are currently explored through focus groups with clients and other feedback, with the beginnings of a “buddy scheme in place, where people ... can be joined-up”.^{26, p. 89}

All three devolved nations have proactively sought to inform IBSS beneficiaries about the psychological support available through producing patient information leaflets (Northern Ireland,²⁷ Scotland⁴⁰), including detailed information on the relevant scheme’s website (Wales⁴¹), sending the beneficiaries on their databases newsletters,⁴²⁻⁴⁴ as well as engaging with relevant support organisations and charities.²⁶

40. NHS Scotland. The Scottish Infected Blood Psychology Service (SIBPS). Information for individuals accessing the service and their family members. 2021.

41. Wales Infected Blood Support Scheme. The Psychology & Wellbeing Service. 2023.

42. Department of Health HBSO. Infected Blood Payment Scheme (NI) Newsletter. 2023.

43. Wales Infected Blood Support Scheme. WIBSS Newsletter December 2022.

44. NHS Scotland. Welcome to issue 10 of the Scottish Infected Blood Support Scheme (SIBSS). 2022.



Summary and conclusion

The study sought to understand the need for psychological support among individuals and their families affected by NHS-supplied infected blood and blood products and to explore what the offer of support to meet these needs might be in England. We spoke with 52 infected and affected people and 14 mental health practitioners and experts to understand these needs and suggested service improvements.

This section briefly summarises the key findings from this work. We acknowledge that it is not possible, in the context of a summary, to do justice to the many moving, and often heart-breaking and very personal accounts that our interview participants shared with us.

Strengths and limitations

We sought to recruit a wide range of participants in terms of socio-demographic characteristics, and we were able to include people from a fairly broad age range and across regions in England. There were a larger number of women and people identifying as White British than would reflect the UK population. The former is reflective of the evidence that men are more difficult to recruit to health studies than women, especially in qualitative research.⁴⁵ The latter is probably reflective of the infected and affected community more widely (see also Appendix A) although we do not have data about the total population that has been infected and affected. However, our sample included individuals with a broad range of experiences: some had accessed psychological support using the EIBSS funding, some accessed support through other routes, while others have not had any support. We note that, among those who had responded to the EIBSS Service Satisfaction Survey and who agreed to be contacted for our research and for their survey responses to be shared with the research team (n=333), only 72 respondents (22%) reported being aware of the EIBSS discretionary payment for psychological support or counselling and of these, only about half (n=35) said that they had received a discretionary payment to pay for the cost of psychological support. Of those 35 individuals, 20 reported that the EIBSS funding had met their needs for psychological support (see Appendix Table A2). We cannot ascertain whether the sample of people who agreed to be contacted for the PIRU research is representative of the wider group of EIBSS beneficiaries. Finally, we were only able to recruit participants from January 2023, with a limited timeframe available for the conduct and analysis of interviews. This meant that we were unable to conduct some interviews, including with mental health practitioners and experts, as it was not possible to arrange a time that was convenient for participants within the timeframe.

Summary of key findings

We found that the infected blood scandal had, and continues to have, a profound impact on the mental health and wellbeing of infected and affected people. We heard multiple accounts of grief and loss, anger, fear and anxiety, guilt, and facing stigma, isolation and discrimination because of infection. About half of those we spoke with explicitly said they had experienced trauma, and most described incidents that have caused them significant distress. Additionally, many participants described further long-term ill health linked to the side-effects of their infection(s) and their treatment, which many described as having life-changing impacts on their wellbeing. Affected people also reported very significant impacts of their loved one's infection on their own wellbeing, including profound emotional and financial consequences of bereavement.

Our findings mirror the accounts of many infected and affected people who provided oral or written evidence to the Infected Blood Inquiry⁶ or as told to the Inquiry's Intermediaries.^{46, 47} Our study adds to this evidence by expanding the understanding

45. Affleck W, Glass K and Macdonald M. The limitations of language: male participants, stoicism, and the qualitative research interview. *Am J Mens Health* 2013; 7: 155-162.

46. Infected Blood Inquiry. Intermediaries' Report 2019.

47. Infected Blood Inquiry. Intermediaries' Report: Supplementary. 2023.



of the current mental health support needs of infected and affected people, and by describing their experiences of trying to access and use various psychological support services. We found that only some of those interviewed for this study had been able to find any support for their mental health over the years, and only just over half of our participants were aware of EIBSS payments for psychological support. Some of our participants only learnt about the availability of the EIBSS discretionary payment during the research interview.

Our interviews with infected and affected people, as well as those with mental health practitioners and experts, identified a wide range of barriers that have prevented people from accessing support. These included what we have described as ‘social and personal barriers’, such as feeling unable to open up, stigma and secrecy. However, it is important to note that these personal barriers were often reinforced or exacerbated through encounters with the wider system, such as reported instances of discrimination in healthcare settings, which made (and in some instances continues to make) it even more difficult for people to seek professional support.

Aside from not knowing what support options were available, even where people succeeded in accessing psychological support, this was in many cases experienced as inadequate or ineffective. Only a very small number of people we spoke with found the EIBSS payment scheme for psychological support easy to work through. More often than not, this route was experienced as requiring substantial effort from applicants, from the need to prove eligibility to then having to find a psychologist or counsellor by themselves with very little guidance, leading some people deciding not to pursue this route altogether. Being physically and mentally unwell further exacerbated these experiences, which is worrying given the particular vulnerabilities of these individuals. It was evident from most of our interviews that people felt burdened by the process of initiating and evidencing a claim for support funding, and that going through this process and securing funding did not guarantee finding a competent and suitable practitioner.

Our study suggests that there is a substantial need for psychological support in the infected and affected communities, and that this need is likely to increase once the Inquiry concludes. Practitioners working with infected and affected people cited instances where the Inquiry had already impeded the progress of clients working towards improving their mental health outcomes.

Existing psychological support services in England – whether accessed through the NHS or privately – do not currently meet the needs of infected and affected communities. Indeed, our findings suggest that access to psychological support that is effective and experienced as tailored to an individual’s needs is not common and often due to chance. Based on our analysis, we conclude that a future improved psychological support service should include the following features:

- Infected and affected people with a range of experiences should be involved in the development and design of the psychological support service if it is to be effective in supporting these diverse communities.
- The service would need to address the substantial distrust in and legacy of EIBSS and the wider health system to provide an effective service.
- Psychological support should be offered by the scheme as standard to all individuals known to infected or affected, and not just upon application.
- The service should be proactive, reaching out to and encouraging individuals to take up support. This will be particularly important for people who are less able to engage with services, including people with pre-existing mental health problems, learning difficulties or cognitive decline.



- The service should be accessible through various routes. A self-referral route will be important to empower people and reduce access barriers.
- The service should be inclusive and broadened to a wider group of affected people beyond family members of an infected person registered with the EIBSS, including same-sex, civil and non-married partners, and others who have not been able to access psychological support. It should be sensitive to the needs of specific groups including those having English as an additional language or women who were infected secondarily by their partners, or who either had birth-related traumas or who were told or chose not to have children as a consequence of either their or their partner's infection.
- The service should be flexible and agile, offering the ability for infected and affected people to access the service when they need it and re-enter it without having to reapply for funding or wait for a new referral.
- The service should be compassionate, respectful of its clients, and non-judgemental.
- The service should be set in a specialist setting, include assessment, and offer a range of support, including individual therapy and other types of support, such as peer support. Peer support (or similar) could be provided in partnership with existing support organisations.
- The service should offer a range of therapeutic modalities (such as trauma-focused talking therapies, EMDR etc.) and modes (in-person, online, telephone). It should enable access to psychiatrists where appropriate. It should be able to advise on alternative therapies such as yoga, reiki, and social prescribing for time outdoors and positive social interactions.
- Practitioners providing the service should be adequately qualified, accredited and registered, and have:
 - an interest in and experience of working with trauma-affected populations;
 - experience of working with people who have long-term health conditions that impact mental health and vice versa;
 - be self-motivated and proactive in terms of willingness to reach out and making themselves available;
 - be flexible in the way they are working;
 - and, most importantly, have sensitivity to, and knowledge about the infected blood scandal, and related conditions including but not limited to HIV and hepatitis C.
- Mechanisms should be put in place to ensure that the service is of high quality and there is a system of oversight and accountability.

This would ideally be embedded in a wider support system that is proactive and reduces many of the barriers that infected and affected people have told us they were and are continuing to face in accessing support beyond psychological services. This includes the creation of a single contact point or person (a navigator) who assists individuals to navigate the health and social care system more effectively. A navigator's role could include:

- Signposting infected and affected people to relevant services, including suggesting therapeutic modalities most appropriate to individuals' needs, other types of support such as peer support, and financial advice.
- Assisting with applications for EIBSS benefits and serving as a general liaison and advocate.
- Reaching out to beneficiaries to assist them to cope with the consequences of their infection(s), including organising screening, testing and future planning.



A service that 'does the work' by proactively reaching out to infected and affected people was seen as an important way in which the government could begin to address the harm it caused.

There is an opportunity for the relevant agencies to learn about infected and affected people's current psychological support needs, engage with mental health experts who have been providing support to these communities, including existing support organisations, and to learn from existing support service models in England and the devolved nations.



References

1. Infected Blood Inquiry. Expert Report to the Infected Blood Inquiry: Statistics. https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/Expert_Report_to_the_Infected_Blood_Inquiry_-_Statistics.pdf (2022, accessed 25 June 2023).
2. The Haemophilia Society. The contaminated blood scandal. <https://haemophilia.org.uk/public-inquiry/the-infected-blood-inquiry/the-contaminated-blood-scandal> (2023, accessed 25 June 2023).
3. Infected Blood Inquiry. Expert Report to the Infected Blood Inquiry: Statistics Group (Supplementary). https://www.infectedbloodinquiry.org.uk/sites/default/files/2023-07/Statistics_Supplementary_Report.pdf (2023, accessed 31 July 2023).
4. Infected Blood Inquiry. Explore the Inquiry. <https://www.infectedbloodinquiry.org.uk> (no date, accessed 23 June 2023).
5. Infected Blood Inquiry. Sir Brian Langstaff calls on new sponsor Minister to cut through problems with psychological and financial support. https://www.infectedbloodinquiry.org.uk/news?tag=492&field_date_value=2020-06 (2020, accessed 12 April 2022).
6. Infected Blood Inquiry. Expert Report to the Infected Blood Inquiry: Psychosocial Issues. https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/Psychosocial_Group_Report.pdf (2020, accessed 12 April 2022).
7. Infected Blood Inquiry. Expert Report to the Infected Blood Inquiry: Psychosocial Issues (Supplementary). https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/2020-09-16_Psychosocial_Supplementary_Report.pdf (2020, accessed 12 April 2022).
8. Riva S, Del Sordo S, Genovese U, et al. Medical decision making and risky choices: psychological and medicolegal consequences of HIV and HCV contamination of blood products. *HIV AIDS (Auckl)* 2017; 9: 161-165.
9. Department of Health. Infected blood: reform of financial and other support. 2016. London: Department of Health.
10. Department of Health. Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants. 2011. London: Department of Health.
11. NHS Business Services Authority. England Infected Blood Support Scheme. <https://www.nhsbsa.nhs.uk/england-infected-blood-support-scheme> (no date, accessed 12 June 2023).
12. NHS Business Services Authority. Talking therapy support. <https://www.nhsbsa.nhs.uk/talking-therapy-support> (no date, accessed 25 June 2023).
13. NHS Business Services Authority. England Infected Blood Support Scheme. Annual Report 2021/22. https://www.nhsbsa.nhs.uk/sites/default/files/2022-09/EIBSS_Annual_Report_2021-22_final_0.pdf (accessed 20 June 2023).
14. NHS Business Services Authority. Personal communication, 19 June 2023. 2023.
15. Infected Blood Inquiry. Eighth written statement of William Vineall. https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/WITN4688076- Eighth_written_statement_of_William_Vineall_%3B_14_December_2022.pdf (2022, accessed 23 June 2023).



16. Infected Blood Inquiry. Second Interim Report. [https://www.infectedbloodinquiry.org.uk/sites/default/files/2023-04/Infected Blood Inquiry Second Interim Report.pdf](https://www.infectedbloodinquiry.org.uk/sites/default/files/2023-04/Infected%20Blood%20Inquiry%20Second%20Interim%20Report.pdf) (2023, accessed 18 June 2023).
17. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77-101.
18. Infected Blood Inquiry. Transcript – London – Wednesday 18 January 2023 (Eleanor Grey KC, instructed by Government Legal Department, on behalf of the DHSC, and Barbara Scott). [https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/Transcript – London – Wednesday 18 January 2023 \(DHSC and Barbara Scott\).pdf](https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/Transcript%20-%20London%20-%20Wednesday%2018%20January%202023%20(DHSC%20and%20Barbara%20Scott).pdf) (2023, accessed 29 June 2023).
19. The Choice and Partnership Approach. The Choice and Partnership Approach. <https://www.capa.co.uk> (2022, accessed 25 June 2022).
20. Campbell L, Clark S, Chorney J, et al. Choice and Partnership Approach to community mental health and addiction services: a realist-informed scoping review. *BMJ Open* 2022; 12: e064436.
21. Pajer K, Pastrana C, Gardner W, et al. A scoping review of the Choice and Partnership Approach in child and adolescent mental health services. *J Child Health Care* 2022; 14: 13674935221076215.
22. NHS England. NHS expands mental health support for staff after toughest year in health service history. <https://www.england.nhs.uk/2021/02/nhs-expands-mental-health-support-for-staff-after-toughest-year-in-health-service-history> (2021, accessed 29 June 2023).
23. NHS England. Staff mental health and wellbeing hubs. <https://www.england.nhs.uk/supporting-our-nhs-people/support-now/staff-mental-health-and-wellbeing-hubs> (no date, accessed 29 June 2023).
24. NHS England. Guidance for Mental Health and Wellbeing Hubs for Health and Social Care Staff. <https://www.transformationpartnersinhealthandcare.nhs.uk/wp-content/uploads/2021/01/Mental-Health-and-Wellbeing-Hubs-Guidance-Final.pdf> (2021, accessed 29 June 2023).
25. The British Psychological Society. Protect the future of NHS staff mental health and wellbeing hubs. <https://www.bps.org.uk/protect-future-nhs-staff-mental-health-and-wellbeing-hubs> (2023, accessed 29 June 2023).
26. Infected Blood Inquiry. Transcript – London – Friday 11 November 2022 (Keith Carter and Specialist Psychological Support). <https://www.infectedbloodinquiry.org.uk/evidence/transcript-london-friday-11-november-2022-keith-carter-and-specialist-psychological> (2022, accessed 8 June 2023).
27. Belfast Health and Social Care Trust. Clinical Psychology Service for Individuals and their Families Infected/Affected by receiving Contaminated Blood. [https://www.infectedbloodinquiry.org.uk/sites/default/files/2021-11/Information Leaflet.pdf](https://www.infectedbloodinquiry.org.uk/sites/default/files/2021-11/Information%20Leaflet.pdf) (2021, accessed 26 June 2023).
28. Infected Blood Inquiry. Closing submission on behalf of the Belfast Health and Social Care Trust. [https://www.infectedbloodinquiry.org.uk/sites/default/files/Final Written Submissions for Publication copy/Final Written Submissions for Publication copy/SUBS0000052 - Written submission of Belfast Health and Social Care Trust - 16 Dec 2022.pdf](https://www.infectedbloodinquiry.org.uk/sites/default/files/Final%20Written%20Submissions%20for%20Publication%20copy/Final%20Written%20Submissions%20for%20Publication%20copy/SUBS0000052%20-%20Written%20submission%20of%20Belfast%20Health%20and%20Social%20Care%20Trust%20-%2016%20Dec%202022.pdf) (2023, accessed 26 June 2023).
29. The Penrose Inquiry. Home. <https://www.penroseinquiry.org.uk> (2015, accessed 8 June 2023).



30. Infected Blood: Scottish Financial Support Review Group. Contaminated Blood: Financial Support: Conclusions and Recommendations. <https://haemophiliascotland.files.wordpress.com/2015/11/contaminated-blood-financial-support-conclusions-and-recommendations.pdf> (2015, accessed 5 June 2023).
31. NHS Lothian. Haemophilia centres: psychological support pilot. Edinburgh Service Interim Report. <https://www.sibdn.scot.nhs.uk/wp-content/uploads/2017/05/Interim-Psychological-Support-Services-.pdf> (2017, accessed 8 June 2023).
32. Infected Blood Inquiry. WITN4063001 – First written statement of Belinda Hacking on behalf of the Scottish Health Boards – 26 Jan 2020. <https://www.infectedbloodinquiry.org.uk/evidence/witn4063001-first-written-statement-belinda-hacking-behalf-scottish-health-boards-26-jan> (2020, accessed 6 June 2023).
33. Scottish Infected Blood Psychology Service. Who we support. <https://www.sibps.scot.nhs.uk/who-we-support> (2023, accessed 8 June 2023).
34. Infected Blood Inquiry. WITN4063002 – Written Statement of Dr Belinda Hacking; 10 October 2022. <https://www.infectedbloodinquiry.org.uk/evidence/witn4063002-written-statement-dr-belinda-hacking-10-october-2022> (2022, accessed 29 June 2023).
35. NHS National Services Scotland. SIBSS Guidance and Forms for Support and Assistance Grants. <https://www.nss.nhs.scot/publications/sibss-guidance-and-forms-for-support-and-assistance-grants> (2021, accessed 8 June 2023).
36. Counselling & Psychotherapy in Scotland. Scotland's professional body for counselling and psychotherapy. <https://www.cosca.org.uk> (2018, accessed 8 June 2023).
37. NHS National Services Scotland. Scottish Infected Blood Support Scheme 2020 Customer Satisfaction Survey and 3-year Review of Service. <https://www.nss.nhs.scot/media/1325/2020-sibss-survey-report-final.pdf> (2020, accessed 29 June 2023).
38. Wales Infected Blood Support Scheme. Annual report 2020/2021. <https://wibss.wales.nhs.uk/wp-content/uploads/2022/01/WALES-INFECTED-BLOOD-SUPPORT-SCHEME-WIBSS-ANNUAL-REPORT-20202021.pdf> (2021, accessed 29 June 2023).
39. Welsh Government. Written Statement: Welsh Infected Blood Support Scheme (WIBSS) Enhanced support. <https://www.gov.wales/written-statement-welsh-infected-blood-support-scheme-wibss-enhanced-support> (2019, accessed 26 June 2023).
40. NHS Scotland. The Scottish Infected Blood Psychology Service (SIBPS). Information for individuals accessing the service and their family members. <https://www.nss.nhs.scot/media/2186/scottish-infected-blood-psychology-service-sibps-patient-information-leaflet.pdf> (2021, accessed 19 June 2023).
41. Wales Infected Blood Support Scheme. The Psychology & Wellbeing Service. <https://wibss.wales.nhs.uk/the-psychology-wellbeing-service> (2023, accessed 26 June 2023).
42. Department of Health HBSO. Infected Blood Payment Scheme (NI) Newsletter. [https://hscbusiness.hscni.net/pdf/Infected Blood Inquiry Scheme Newsletter - March 2023 - FINAL.pdf](https://hscbusiness.hscni.net/pdf/Infected%20Blood%20Inquiry%20Scheme%20Newsletter%20-%20March%202023%20-%20FINAL.pdf) (2023, accessed 26 June 2023).



-
43. Wales Infected Blood Support Scheme. WIBSS Newsletter December 2022. <https://wibss.wales.nhs.uk/wp-content/uploads/2023/04/WIBSS-newsletter-Dec-2022.pdf> (2022, accessed 26 June 2023).
 44. NHS Scotland. Welcome to issue 10 of the Scottish Infected Blood Support Scheme (SIBSS). <https://www.nss.nhs.scot/media/3380/sibss-newletter-issue-10.pdf> (2022, accessed 26 June 2023).
 45. Affleck W, Glass K and Macdonald M. The limitations of language: male participants, stoicism, and the qualitative research interview. *Am J Mens Health* 2013; 7: 155-162.
 46. Infected Blood Inquiry. Intermediaries' Report 2019. <https://www.infectedbloodinquiry.org.uk/sites/default/files/2020-01/WITN4000001 - Intermediaries' Report 2019.pdf> (2019, accessed 7 September 2022).
 47. Infected Blood Inquiry. Intermediaries' Report: Supplementary. <https://www.infectedbloodinquiry.org.uk/sites/default/files/2023-06/Intermediaries Report - Supplementary.pdf> (2023, accessed 29 June 2023).



Appendix A

Table A1 Selected socio-demographic of EIBSS survey respondents (n=333)

Selected characteristics of EIBSS Service Satisfaction Survey Respondents indicating willingness of be interviewed for the study (n=366).

Of these, 33 (9%) did not wish their survey answers to be shared with the research team.

	N	%
Gender		
Female	161	48.3
Male	170	51.1
Prefer not to say	2	0.6
Age group		
16-24	1	0.3
25-44	22	6.6
45-64	202	60.7
65-74	80	24.0
75+	25	7.5
Prefer not to say	3	0.9
Region of residence (current)		
East of England	39	11.7
London	42	12.6
Midlands	48	14.4
North East & Yorkshire	29	8.7
North West	40	12.0
South East	57	17.1
South West	42	12.6
Northern Ireland	2	0.6
Scotland	3	0.9
Wales	10	3.0
Other	14	4.2
<i>England</i>	2	
<i>Outside UK</i>	12	
Prefer not to say	7	2.1
Ethnic group		
White: English, Scottish, Welsh, Northern Irish, British	289	86.8
White: Irish	4	1.2
White: Other	11	3.3
Black/Black British: Caribbean	1	0.3
Asian/Asian British: Indian	3	0.9
Asian/Asian British: Pakistani	3	0.9
Asian/Asian British: Chinese	1	0.3
Asian/Asian British: Other	1	0.3
Mixed: White and Black African	1	0.3
Mixed: White and Asian	3	0.9
Mixed: Other	2	0.6
Any other ethnic group	3	0.9
Prefer not to say	8	2.4
No answer	3	0.9



Table A2 Receipt of psychological treatment/support

	N	%
Ever received any psychological treatment or support (including counselling)		
Yes, within the last 12 months	45	13.5
Yes, more than 12 months ago	60	18.0
No	227	68.2
Don't know/Can't remember	1	0.3
Provider of support among those reporting to having received treatment (n=105)		
NHS	38	11.4
Private	46	13.8
A mix of NHS and Private	19	5.7
Don't know/Can't remember	2	0.6
Aware that a discretionary payment is available to pay for the cost of psychological treatment, support or counselling through EIBSS		
No	33	9.9
Yes	72	21.6
No answer	228	68.5
Among those aware (n=72): received a discretionary payment to pay for the cost of psychological treatment, support or counselling		
No	38	52.8
Yes	35	48.6
Among those receiving treatment using EIBSS payment (n=35): the discretionary payment met support needs		
No	14	40.0
Yes	20	57.1
No answer	1	2.9



Table A3 Satisfaction with psychological treatment or support

	N	%
Respondents ever receiving psychological treatment/support (n=105)		
Not at all satisfied (1)	6	5.7
2	3	2.9
3	7	6.7
4	4	3.8
5	13	12.4
6	8	7.6
7	13	12.4
8	16	15.2
9	8	7.6
Completely satisfied (10)	25	23.8
No answer	2	1.9
Respondents ever receiving psychological treatment/support using EIBSS payment (n=35)		
Not at all satisfied (1)	1	2.9
2	2	5.7
3	0	0.0
4	1	2.9
5	5	14.3
6	2	5.7
7	7	20.0
8	5	14.3
9	4	11.4
Completely satisfied (10)	8	22.9

The Policy Innovation and Evaluation Research Unit (PIRU) brings together leading health and social care expertise to improve evidence-based policy-making and its implementation across the National Health Service, social care and public health.

We strengthen early policy development by exploiting the best routine data and by subjecting initiatives to speedy, thorough evaluation. We also help to optimise policy implementation across the Department of Health and Social Care's responsibilities.

Our partners

PIRU is a collaboration between the London School of Hygiene & Tropical Medicine (LSHTM), the Care Policy & Evaluation Centre (CPEC, formerly PSSRU) at the London School of Economics and Political Science (LSE), and Imperial College London Business School.

The Unit is funded by the National Institute for Health Research (NIHR) Policy Research Programme.



Policy Innovation and Evaluation Research Unit

Department of Health Services Research & Policy
London School of Hygiene & Tropical Medicine
15–17 Tavistock Place, London WC1H 9SH

Tel: +44 (0)20 7927 2784
piru.lshtm.ac.uk