Contaminated Blood CAMPAIGN

submissions@ GRO-C

Sir Brian Langstaff
Chair of the Infected Blood Inquiry

16 June 2022

Dear Sir Brian

Further to your request for initial written submissions outlining any recommendations (beyond compensation) for you to consider; Contaminated Blood Campaign's initial submission is set out below.

1. To consider the need for future monitoring and testing for the infected community

From experience within our community, backed up by oral and written evidence provided to the Inquiry, it has become increasingly evident that those infected are not being monitored anywhere near closely enough (if at all) for their infections and associated health conditions, particularly those that have achieved an SVR as they are considered to be cured and are then discharged from any specialist care. It has effectively become a 'postcode lottery'. We believe those that have been infected should receive the best possible healthcare and monitoring for the rest of their life, moving forward.

Our concern is that future monitoring and testing for those infected through NHS contaminated blood and blood products is not compatible with the protocols currently applied by the NHS in terms of those that have achieved an SVR for Hepatitis C. It is for this reason that we now ask you to consider looking into the scheme currently set up in the Republic of Ireland in terms of their Health Amendment Act Cards (HAA). To further your knowledge of this specific scheme we would like to request that you ask Brian O'Mahony (Chief Executive of the Irish Haemophilia Society) to give oral evidence so that he can provide you with a broader understanding of the scheme.

If the NHS continues to fail to deliver proper monitoring and testing, the only option left would be to look at introducing private health care.

Anything less than proper monitoring and testing will increase the already horrific mortality rates on the infected community.

2. Changing Pattern of Mortality over Time

The government have consistently used arbitrary categories within the support schemes in order to limit their financial exposure to those they infected and their bereaved spouse/partners. Within EIBSS for example there are seven categories of those infected and four categories for bereaved spouse/partners. The payments vary hugely within these categories with some infected individuals receiving £19,498 while others receive £46,469; the support payments made to bereaved spouse/partners also vary hugely with payments ranging between £14,623 and £34,851.

The greatest difference in terms of regular support is between the mono-infected and co-infected individuals registered with the schemes. The reasoning given by the Department of Health and Social Care (DHSC) for the difference in levels of support payments is ***there is a greater level of mortality in the co-infected community and that the co-infected community suffer 'a greater disruption to life'***. However, recent data obtained by CBC following the submission of Freedom of Information Requests (FOI) to each of the schemes operating within the 4 UK nations proves that there is a far greater level of mortality within the mono-infected community (see FOI data on pages 7 & 8 below). This may sound 'counter intuitive' but it is a fact, the data does not lie.

In terms of 'disruption to life', including any differences in quality of life and personal suffering, this is very much down to the individual. It would be wrong to assume that every co-infected individual suffers more than any mono-infected individual, or indeed, vice versa.

CBC hope that the Inquiry does not simply accept without question, the Department of Health and Social Care's assertion that the co-infected suffer a greater level of mortality and a greater disruption to life without examining all the facts. We therefore request that in order to gain a complete understanding of the changing pattern of mortality within the schemes (including looking back to the inception of each of the entities operating out of Alliance House) the Inquiry fully examines how mortality has changed over time within each category used by each of the schemes, displaying the results in an easy to follow and user friendly format.

CBC believe that capturing and analysing this data is crucial if we are ever going to gain any understanding of how mortality has changed over time. There will never be another opportunity to gather this data and if we do not secure it now, it will be lost forever.

3. Anomalies within the schemes

Despite attempts to reduce levels of disparity in recent years, there are many anomalies that still exist within the current ex gratia schemes. Some examples include bereaved spouse/partners who are supported at four different levels and those infected are supported at seven different levels. This also includes some non-infected spouse and partners receiving greater levels of support than those that have been infected, even though the infected suffer physically as a direct result of their infection/treatment and they also suffer a far greater level of mortality.

There are other anomalies between the schemes that operate across the 4 UK nations. One example of this is that support payments are made to dependent children within the EIBISS scheme but they are not paid to dependent children under the WIBSS scheme.

The CBC position is that payments within the schemes to the infected should be uplifted to the highest payment level which is currently £46,469 per annum and payments to the bereaved spouse/partners should be lifted to their highest payment level which is £34,851.

If these schemes are to continue, which the majority of people within the community certainly want as proved by the recent survey carried out by the Haemophilia Society, then the scheme anomalies that still exist within the 4 UK Nations must be rectified.

The survey results also confirmed that the majority of people want the support schemes to be guaranteed for life and that they must be kept completely separate from any award of compensation. We would therefore like the inquiry to recommend the continuation of the ex gratia schemes, any payments made through the schemes be kept separate from any award of compensation and that these schemes are guaranteed for life.

4. To consider the need for further research for the infected community

We do not believe there has been enough research undertaken into the long-term impact of the treatments that people have received for their infections, including interferons and ribavirin.

We also do not believe there has been any research undertaken into the long-term impact of living with the viruses as we get older.

There has been a great deal of anecdotal evidence that people within the infected community have developed several forms of cancers. We would like you to consider recommending that research is carried out to better understand if there are any links between cancers and being infected with the viruses, including their associated treatments/medications.

We also know that the Hepatitis C virus can cross the 'blood/brain' barrier; there is evidence that the HCV virus and/or its treatments can cause damage within the brain and the nervous system including brain haemorrhage, cerebral dysfunction/syndrome and peripheral neuropathy. Medical conditions relating to cancers and brain disorders represent a real threat to life and therefore these medical conditions are of particular concern. However, minimal research has been conducted into these conditions, which fails to properly identify specific areas of concern within our community. Other conditions with a link to Hepatitis C include autoimmune illnesses such as Systemic Lupus, Sjogrens syndrome, Rheumatoid Arthritis and Scleroderma.

We would therefore like the inquiry to recommend research looking into any available evidence linking these medical conditions to the long-term effects of Hepatitis C and/or its treatments including interferons and ribavirin.

5. To consider the need for DWP passporting/light-touch approach

These infections have devastated the health of our community and as a consequence, many are unable to work full time, if at all.

The majority of those infected within our community were infected when the benefits system was part of the Department of Health. Between 1968 and 1988, social security came under a government department called Department of Health and Social Security (DHSS). This is ironic as the DHSS was the same department that was responsible for infecting us back in the 1970s and 1980s and now the social security element of the DHSS (now the DWP) refuse to even consider any form of passporting or light-touch approach for those they infected.

Anyone who has applied for benefits will know how incredibly time consuming, stressful and traumatic it can be; the benefits process in itself causes unnecessary levels of anxiety and stress for those that need to apply for them. CBC alongside others, have previously engaged with the DWP as part of a working group to try and make the benefits process less stressful and fairer, but this has proved of little benefit.

There is a culture within Government and the DWP to remove people from the benefits system no matter how serious their conditions might be. We believe those that have been damaged by the state should now be protected by the state in terms of the benefits system and throughout the application process. We also believe the advice provided by Neil Bateman in his second written statement dated 20 January 2021 should be explored further and that the suggestions made by Neil at paragraphs 81 - 89 are of particular relevance. https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/WITN3487002%20Second%20Written%20Statement%20of%20Neil%20Bateman.pdf As yet, there has been no exploration of the benefits system by the inquiry and we believe that this is crucial.

6. Pensions

Many of those that have been infected have been unable work and as a consequence have been unable to invest in a work based pension and in many cases this has continued for many decades; this has had a huge impact on their financial future and security. Also, carers that have had to give up work to look after an infected individual have also faced the same financial impact in terms of pensions.

CBC would like the inquiry to examine this huge financial impact/loss on our community which has been caused by the inability to invest in work-based pensions with its associated tax advantages.

7. Insurances

Those that have been infected find that travel and holiday insurance is either unobtainable or heavily loaded as a direct result of viral infection and the damage caused by these infections. Those infected can also find that life insurance is simply unobtainable because of

the infections and its associated viral/treatment damage. The government have consistently ignored this issue for over thirty years. We would now like the Inquiry to consider if the government should cover any premiums over and above the standard premium for each infected individual and to provide cover for those that have been made uninsurable as a direct result of damage caused to them by the state (again Brian O'Mahony can be of assistance here).

8. Mortgages

Access to mortgages has proved hugely difficult and often impossible. This has been particularly difficult for those that have been infected due to limited health and life expectancy. Those that have not been able to work because of their infections are at a particular disadvantage due to a lack of earned income. Further complications of the increasing age of our community has also added to the difficulties in obtaining mortgages.

We would therefore like the inquiry to recommend a government backed mortgage scheme.

9. Advocacy/Support Services

CBC believes there should be ongoing advocacy services for those registered with the schemes. This advocacy/support should cover two areas. 1. Medical Advocacy Support - the last thing we need when we are ill is having to fight the system in order to receive the best and prompt medical care, including physical and psychological care. There is a particular need here for those that have been infected as they are at greater risk of severe ill-health and early mortality; 2. Financial Advocacy Support including Pensions, Mortgages and Insurances. Again, Brian O'Mahony's knowledge and experience of the scheme operating in the Republic of Ireland would be of huge assistance here.

10. Final Report

CBC would like the Inquiry's final report to be written in a concise and user friendly form as much as possible. It would be disappointing after approximately six years of work for the inquiry's final report to be written in such a way that it is indecipherable to the very people it will be written for.

We have two examples of final Inquiry reports written on behalf of our community including the Penrose Inquiry report which amounted to five 'telephone directories' worth of material (plus interim report) that hardly anybody read and the Archer Inquiry report which amounted to one 'telephone directory' which far more people read. Legal and medical jargon must be kept to a minimum if members of our community are ever going to stand any chance of reading and understanding the report.

We thank you for taking the time to read and consider our submission.

Yours sincerely

Glenn Wilkinson
for and on behalf of Contaminated Blood Campaign

(please see mortality data below – pages 7 & 8)

NUMBERS REGISTERED INCLUDING MORTALITY DATA RECEIVED UNDER FOI FROM THE FOUR UK INFECTED BLOOD SUPPORT SCHEMES

England Infected Blood Support Scheme (EIBSS)

The total number of individuals registered and the total number of individuals that have died between 1/11/2017 and 1/11/2021

Category	Registered	Died
HCV Stage 1	1,191	91
HCV SCM	564	22
HCV Stage 2	562	125
HIV	63	*
HIV & HCV Stage 1	85	5
HIV & HCV SCM	86	*
HIV & HCV Stage 2	57	10
Bereaved	513	24

Please note, where deaths are less than 5 this is marked with an asterisk

Scotland Infected Blood Support Scheme (SIBSS)

The total number of individuals registered and the total number of individuals that have died between 1/4/2017 and 17/11/2021

Category	Registered	Died
Chronic HCV (Stage 1)	75	24
Chronic HCV (Stage 1) – Moderately Affected	91	6
Chronic HCV (Stage 1) – Severely Affected	168	6
Advanced HCV (Stage 2)	99	40
Coinfected HIV	24	*
Widow/Widower/Civil Partner	89	6

Please note, where deaths are less than 5 this is marked with an asterisk

Wales Infected Blood Support Scheme (WIBSS)

The total number of individuals registered and the total number of individuals that have died between 31/10/2017 and 1/11/2021

Category	Registered	Died
HCV Stage 1	39	2
Enhanced Stage 1 +	78	2
HCV Stage 2	41	6
HIV	1	1
HIV & HCV Stage 1	3	0
HIV & HCV Stage 1+	11	0
HIV & HCV Stage 2	2	0
Bereaved Partners/Spouses	39	3

Northern Ireland Blood Support Scheme (BSO)

The total number of individuals registered and the total number of individuals that have died between 1/11/2017 and 1/11/2021

Category	Registered	Died
HCV Stage 1	60	2
HCV Stage 2	23	5
HIV & HCV Stage 1	2	1
HIV & HCV Stage 2	1	0
HIV	2	0
Non Infected Bereaved	25	0