

Principles for Fair Compensation

Terrence Higgins Trust's submission to
Sir Robert Francis QC's Infected Blood
Compensation Framework Study



Foreword – by Ian Green

It is impossible to reverse the catastrophic damage done by the contaminated blood products that the NHS gave to many people with haemophilia and other bleeding disorders and that resulted in their contracting HIV – and the effect that this had on their parents, siblings, wives, partners and children. There is no magic wand that can take away the pain endured by those who live with this trauma or those who died well before their time. Nothing will change the abuse inflicted by the state when it covered up, hid and misplaced documents to stop the truth coming out over decades. Most regrettably, we can never bring back the loved ones of the parents, siblings, wives, partners and children who are still grieving.

At the very least, those impacted deserve fair compensation.

When we started to develop this piece of work on a set of ‘Principles for Fair Compensation’ in response to the Infected Blood Compensation Framework Study, I had a long phone call with Terrence Higgins Trust’s Community Engagement Officer for the infected blood community. We are men of a similar age. Both of us are living with HIV. Yet even though we share these things in common, our experiences have been in many ways very different.

I cannot imagine what it was like to be diagnosed with HIV at the start of the AIDS crisis aged just 12 years old. To spend several years with no one to talk to about it, while watching on TV and in the media the unfolding horror story of this new virus that the wisdom of the time thought to be a death sentence. To be strong-armed into signing away a right to take legal action for next to no money by your own government.

To eventually find a group of 17 young men all in the same position and watch every one of them die and to live with the guilt of being the only one today who has survived. To have spent decades hiding from most people that you were living with HIV because the stigma still feels so great. To know that your government is hiding the truth from you about why you contracted HIV and then after four decades to watch an inquiry prove that it could all have been avoided.

When I asked him ‘what could possibly compensate’ him, he told me he wanted a time machine, so he could go back and stop this from ever happening – not just to him but to his whole community. As that isn’t possible, he wants a fair compensation package that takes account of the damage that has been done and provides for him and his family to live comfortably in the future. He doesn’t want to have to keep fighting the system just so it treats him and his community fairly.

“This time, for once, he'd just like the government to do the right things without having to be forced.”

What I have learnt through Terrence Higgins Trust's work with this part of our community is that every single person has a life story that revolves around the damage that contaminated blood products have had on their lives. That every single person deserves fair compensation.

To assist Sir Robert Francis QC, Sir Brian Langstaff, and the government as they make their decisions, we have developed a set of 10 Principles for Fair Compensation. These have been co-produced with those both infected with and affected by HIV as a result of contaminated blood products given by our National Health Service. We will judge any recommendations made around compensation against these principles.

This must be a time of listening, and of change. A new approach from the state. The opportunity to see the start of the end of this trauma for everyone involved.

Ian Green

Chief Executive

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About Terrence Higgins Trust

Terrence Higgins Trust is the UK's leading HIV and sexual health charity, offering support, information and advice services for those living with HIV and affected by HIV or poor sexual health.

Our vision is a world where people with HIV live healthy lives free from prejudice and discrimination, and good sexual health is a right and reality for all.

Following the closure of the Macfarlane Trust in 2018, we are supporting those living with and affected by HIV as a result of the Contaminated Blood Scandal.

This is inclusive of those who were directly infected with HIV because of blood products used by the National Health Service to treat people with haemophilia or other bleeding disorders, any individuals who were infected with HIV by those directly infected because of those blood products used to treat haemophilia or other bleeding disorders, plus their partners, parents, carers, children and dependents.

www.tht.org.uk/macfarlane

How we arrived at the Principles for Fair Compensation

Our starting point for developing the Principles for Fair Compensation was to find a space where Terrence Higgins Trust could add value and complement the work already being carried out by grassroots campaign groups, advocacy groups and the legal representatives of the Macfarlane Community.

The life experiences of those infected with and affected by HIV as a result of contaminated blood products and the expectations around compensation are different for every member of the community. The Principles for Fair Compensation have been co-produced to bring together those different experiences and expectations into a set of broad criteria that can reflect the requirements for compensation for the whole community.

Working from a very rough draft of what could be included in a set of principles as a framework, we held several consultation panel events to which we invited all members of the Macfarlane Community who are registered with Terrence Higgins Trust and have consented to receive communications from us. These meetings – small in nature – started in July 2021 and concluded in November. By that time, those members of the community that had chosen to engage had shaped what we believe was the makings of a representative and robust set of Principles for Fair Compensation.

We then produced a survey that went to all the members of the Macfarlane Community who are registered with Terrence Higgins Trust and have consented to receive communications asking for their views on the draft Principles for Fair Compensation and for any amendments that they would like to see in the finished document. This engaged another 25 people in the process. The average rating in favour of each principle ranged from 4 to 4.8 out of 5.

The principles were then updated to reflect the feedback from the survey and sent to all those who had attended the consultation panels to give them final sign-off of the Principles for Fair Compensation that we present in this report.

As the leading HIV charity in the UK, we are passionate about this issue. We do not claim it is or can be representative of the Macfarlane Community in all its diversity but it has been co-produced with members of the community at every stage.

What compensation means to those impacted

We asked those in the Macfarlane Community with whom we work what fair compensation means to them. The following people have agreed to share their feelings.

'It means that it's been recognised that through no fault of my own I've been harmed by the NHS. It will give me peace of mind for some strange reason.'

A survivor of HIV, HepV, triple bypass, vCJD

'To live comfortably and at peace without begging others for help.'

Amer, 58, New Jersey, USA, co-infected haemophiliac

'Fair compensation means it will help me cope better. For example, have the heating on in winter without worrying; pay for my vitamins which were taken away from my hospital prescription because someone had no comprehension of how important it is to boost the immune system and to keep as healthy as possible; help with household bills and upkeep; [mean I can] save for my children; allow me to have a break and share quality time with my family; help with the upkeep of my mobility scooter and insure it; and reduce financial worries. Fair compensation would signify the injustice that has been done to me, the suffering I have and still go through each day.'

Anon

'Being in a financial position to put my declining health before work.'

Anon, 47, co-infected haemophiliac

'Security for me and my partner and son. As my body stops working properly, I'll have enough money to have a comfortable home and not have to worry.'

Anon, 53, Yorkshire

'The ability to afford to live reasonably.'

Anon, 54, co-infected haemophiliac

'Regular income guaranteed and gold standard health care.'

Anon, 57, Wales

'Almost impossible to put into words.'

Broken hearted

'Nothing can compensate for the loss of a person you love, the sadness and deep feelings of loss lasts forever. Compensation in the form of money should help those who are still suffering from this tragedy to live a better life for whatever time they have left. In the case of the estates of the deceased, compensation in the form of money may help to relieve the stresses of everyday life without their loved one(s), bringing some peace.'

Child of a co-infected deceased haemophiliac

'The chance to make up for a hard life struggling with appointments, strange illnesses, sickness, accusations, fear, depression, hiding, secrecy, a provision for future needs. Safety, a house, freedom from a tyranny benefits system.'

Co-infected haemophiliac

'A payment that reflects the loss of life, income and opportunity, factoring in emotional losses.'

John, 43, son of a haemophiliac father who died of AIDS

'Fair compensation means justice at last. Aged nearly 60 and not in good health as a result of the stress of my partner's illness, I will be able to finally afford a cleaner.'

Kate, Guernsey, bereaved fiancée of a haemophiliac

'To live a comfortable life, without needing anyone's help.'

Mo, 49

'It will make up for all the problems I have suffered such as additional health problems, extra visits to the hospital, additional inpatient stays, extra reliance on my wife and children. It will hopefully mean my family and I will have no money worries and when I have gone they will be financially stable also.'

Neil1701, North Yorkshire, co-infected haemophiliac

'Compensation will never replace the loss of my father – but would hopefully mean his grandchildren will get a posthumous legacy from him.'

Son of a haemophiliac who died from HIV when I was young

'The term compensation is essentially meaningless as in my opinion we can never be compensated for what has happened since receiving infected blood products. However, we can be recompensed for the trauma, stigma, pain, suffering, lies, deceit, anger, loss of opportunity, loss of earnings, loss of self. We also need to be confident that our future needs are met compassionately, speedily, medically, comprehensively, without compromise. Our partners and dependents are looked after emotionally, financially, educationally, fully. All of the above will go some way to making right the countless wrongs.'

The former

'Compensation to me would mean the opportunity to provide for my own family in a way that proves difficult when not given the start of basic family support of that of a mother and father. It would help towards my house, my wife and my son – and any future children we may have – who will never know their paternal grandparents as a direct result of this failure. Compensation would allow a certain level of closure for myself and would make what I've already been through – a troubled upbringing of mental and physical abuse – almost bearable and allow me to progress with my life knowing even though I would still be without my parents that justice has been served in some sort of way.'

Will, 29

Principles for Fair Compensation

These are the principles we believe must be applied to any compensation for those infected and affected by the Contaminated Blood Scandal. Getting this right will go some way to give some sense of fairness for those impacted and justice for all involved.

Principle 1

Compensation must reflect the extremely poor treatment of the infected blood community. It must take account of the damage done not just to those infected with HIV as a result of infected blood products but also to their families.

Compensation must reflect 40 years of justice delayed, the trauma of an HIV diagnosis when so little was known about the virus, the impact this had on life chances of those infected and their families, and the stigma of living with the virus still after four decades.

Principle 2

The compensation framework must give people the freedom to choose the structure they would like compensation to take. This should include the option of a choice between a lump sum plus monthly payments guaranteed by primary legislation and an individual tribunal outcome with one-off lump sum payment. Regardless of the option chosen, no one should be financially worse off at any stage in their life.

There should be provision to increase a compensation decision as medical knowledge around the impact of infected blood products develops, for example when additional tests become available to detect conditions, such as vCJD, or if new comorbidities as a result of the infection or past treatments come to light.

Principle 3

Where people choose a tribunal-based outcome, compensation must be assessed on an individual basis. The tribunals must be completed within one year of the legislation enacting this process. While this should be based on common law principles, that consider losses and the impact on the survivor's life, it needs to go much further in line with Principle 1.

Principle 4

Everyone must have legal costs funded during the process of awarding them compensation. Everyone must have a right of appeal against the final decision, with legal costs funded.

Principle 5

Compensation payments should be tax exempt and there should be a tax exemption ladder on interest that is paid on the compensation once it has been received. The government must supplement compensation payments to those domiciled overseas, so they are not disadvantaged as a result of taxes being imposed when they transfer their compensation to their home country.

Principle 6

No one should be left behind. Compensation must be inclusive of those who were directly infected because of blood products used by the National Health Service to treat people with haemophilia, bleeding disorders or other conditions; any individuals who were infected with HIV or hepatitis by those directly infected because of those blood products; plus their partners, parents, carers, children and dependents. This must be inclusive of the estates of those who have died before being awarded fair compensation.

Principle 7

The postcode lottery for those haemophiliacs with HIV, hepatitis and vCJD as well as the comorbidities associated with these conditions must end. Considering the mistreatment at the hands of the National Health Service, compensation must include a free 'gold standard' of health and social care provision guaranteed under law.

Principle 8

For decades there has been discrimination against those who are living with HIV as a result of infected blood products when accessing loans, insurance and mortgages. The government must either produce government-backed financial services or underwrite financial services in the market so that those affected are free from surcharges or penalties.

Principle 9

Previous awards from support schemes, ex gratia payments or money gained through court action should not be taken into consideration when calculating a compensation settlement.

Principle 10

There should be a UK-wide compensation system.

How we will use the Principles for Fair Compensation

The Principles for Fair Compensation should not only inform Sir Robert Francis QC's framework but also any recommendations around compensation produced by Sir Brian Langstaff's Infected Blood Inquiry (IBI).

We will use these principles – alongside ongoing work for Macfarlane Community members – to inform how we engage with the four UK governments as they respond to the IBI's findings, honour its recommendations and seek to provide a just settlement for everyone impacted.