From: Seamus Camplisson
Health Protection Branch

Date: 4 March 2020

To: 1. Richard Pengelly
2. Minister Robin Swann MLA

SUB/****/2020 – INFECTED BLOOD PAYMENT SCHEME - INTERIM PAYMENTS IN 2019/20

SUMMARY

ISSUE:	Interim payments to beneficiaries of the Northern Ireland Infected Blood Payment Scheme before the end of 2019/20 financial year.
TIMING:	Urgent – you have made a public commitment to an early decision. Also, the commitment in New Decade, New Approach (NDNA) has raised expectations. On 27 January 2020, following an allocation of £1.03m from DoF for January monitoring, you announced interim payments for infected beneficiaries of the NI Infected Blood Payment Scheme. These payments were 75% of the difference that accrued between England and Northern Ireland over the nine months 1 April – 31 December 2019.
PRESENTATIONAL ISSUES	This issue continues to attract media interest. Press Office will liaise with officials and draw on the contents of this sub to agree a response if asked to comment further. Cleared by Press Office PC 26/02/20
FOI IMPLICATIONS	Exempt under section 35 – policy in development.
EXECUTIVE REFERRAL:	Not required. A commitment has already been included in *New Decade, New Approach*.
FINANCIAL IMPLICATIONS:	The Executive agreed £1m of funding to meet costs in 2019/20. However, making additional payments to scheme beneficiaries in 2019/20 is likely to create a recurrent pressure into 2020/21, and a **£1m** recurrent funding requirement is included as an inescapable

	pressure in our 2020/21 budget requirement as advised to DoF. The Department's inescapable costs additional funding requirement in 2020/21 is **£322m** (this shortfall is net of the **£170m** agreed by the Executive for Agenda for Change pay parity with England and safe staffing on 13 January). In addition to the funding requirement of **£322m** for inescapable pressures, **£169m** is necessary to take forward the commitments set out in New Decade New Approach. (Cleared by Finance DK 26/02/20; Fiona White 3/3/20)
LEGISLATION IMPLICATIONS:	None at this point. Legislative change may be required in the future in respect of reform of other financial aspects of the scheme or, in due course, in response to recommendations from the Infected Blood Inquiry.
EQUALITY IMPLICATIONS:	None for this submission
SPECIAL ADVISOR COMMENTS:	
RECOMMENDATION:	That you: i. note the briefing and consider the options set out for how to allocate the remaining £400k, and ii. choose option 3, i.e. (a) pay 95% of the difference accruing (in the regular payments) between England and NI over the full financial year 2019/2020, and (b) split the remaining 5% (£54,298) equally between Northern Ireland's 17 non-infected widows / widowers, which would mean £3,194 each.

Introduction

1. This submission describes the most common impacts of contaminated blood and blood products experienced by the victims; examines options for making the best use of the

balance of the £1.03 million secured in January Monitoring for the Infected Blood Payment Scheme, and makes a recommendation.

2. On 27 January 2020, following an allocation of £1.03m from DoF for January monitoring, you announced interim payments for infected beneficiaries of the NI Infected Blood Payment Scheme. These payments were 75% of the difference that accrued between England and Northern Ireland over the nine months 1 April – 31 December 2019. Approximately £400k remains to be allocated in this financial year.

3. It is important to note that £1.086m is required to achieve parity with England for 2019/20. This is outlined at paragraph 47.

4. The following table sets out details of the interim payments:

Infected Blood Payment Scheme 75% difference between England and NI - April - December 2019			
Payment Category description	**Number of Beneficiaries in NI**	**Total Per Beneficiary**	**Total per category**
Hepatitis C Stage 1	59	£8,078.62*	£477,535
Hepatitis C Stage 2	20	£5,382*	£106,443
Hepatitis C Stage 1 Co infected	2	£8,703	£17,406
Hepatitis C Stage 2 Co infected	1	£4,014	£4,014
Mono HIV	1	£5,382	£5,382
Total	**83**		**£610,782**
To implement 75% payment parity between Northern Ireland and England from 1st April - 31st December 2019 the cost to NI is £610,780			
** Costings for Hepatitis C S1 & S2 includes one beneficiary who commenced S1 payments in May 2019 and one beneficiary who moved from S1 to S2 payments in June 2019 therefore the amount will differ from the figure in the table above.*			

5. This announcement of special interim additional payments is part of the first stage in a three-stage process. The interim payments were intended as an immediate measure to address the hurt caused by the unequal treatment between NI and England that resulted from the uplift in England, and to alleviate the financial hardship endured by those infected and/or affected by contaminated blood. You were not in a position to allocate the full £1.03m at that point as you wanted to consider how to make the best use of the remainder of the monitoring round allocation in addressing the needs of our

beneficiaries. Whilst the short-term, non-recurrent allocation of temporary funding towards the end of a financial year was to be welcomed, it is not sufficient to address all the issues sustainably and consideration needs to be given to how this issue can be sustainably resolved going forward. You have given a commitment publicly that you will spend the full amount allocated in January monitoring before the end of this financial year.

6. The second phase of the review will address other aspects of the scheme, with a view to working towards greater parity of support across the UK schemes, taking account of local circumstances and beneficiaries' needs in Northern Ireland. Further reform of the scheme will be required to address recommendations from the UK-wide Infected Blood Inquiry, chaired by Sir Brian Langstaff. It is due to deliver its report in 2021.

7. For information, normally BSO write to all beneficiaries in mid-March to inform them of their uplifted rate for the new financial year, based on inflation. Departmental economists are calculating the new 2020/21 rates, applying the Consumer Price Index.

Background

8. Each UK country has had its own infected blood payment scheme since autumn 2017. Before then there were five UK-wide schemes, each for a different category of beneficiary. Northern Ireland had parity with the English scheme in most respects (including regular payments) until England announced on 30 April 2019, the eve of the London hearings of the Infected Blood Inquiry, significant increases to its regular payments.

9. In response to representations from the Chairman of the Infected Blood Inquiry about severe hardships experienced by people who have been infected or otherwise affected, English ministers announced a £30-million uplift for the English Infected Blood Support Scheme, effective from 1 April 2019. This announcement by the then Health Minister Jackie Doyle-Price included an undertaking to *"reach out to the devolved administrations to look at how we might provide greater parity of support across the United Kingdom."*

10. This increase in payments by the English scheme resulted in an unforeseen and sudden disparity with Northern Ireland. Since May 2019 there has been continued lobbying from campaign groups and elected representatives to increase Northern Ireland's regular payments to align with those in England.

11. On 4 September 2019, in his Spending Round speech announcing Northern Ireland's Barnett consequentials allocation, Chancellor Javid said: *"And in Northern Ireland we are providing an extra £400 million from today's announcements. I welcome the case made by the DUP for improved hospice care, and support for those that have been tragically wronged in the contaminated blood scandal. Those are rightly devolved matters, but I sincerely hope that the Northern Ireland Administration will use some of the new funding we're providing today to address those issues."* However, there was no new money allocated to Northern Ireland specifically for infected blood in the spending round and these comments only served to raise expectations.

12. Submissions HE1/20/6930, HE1/20/13505 and HE1/20/17894 provide further background on infected blood.

NI Infected Blood Payment Scheme

13. The Business Services Organisation administers the Scheme on behalf of the Department. The Scheme consists of:
    - regular payments to infected individuals;
    - annual winter fuel payment to all individuals / bereaved spouses (£531);
    - lump sum payments - £20,000 for stage 1 Hep C; £50,000 for those who progress to stage 2;
    - HIV lump sums (ranging from £21,500 to £80,000 depending on circumstances);
    - income top-ups (NI continue to use the old Caxton Fund rates for Hep C which range from £2,000 - £3,500 and the old Macfarlane Trust (MFT) rate of up to £1,400 for HIV);
    - discretionary support (one-off grants);

- £10,000 one-off lump sum for partners or spouses at the time of death of a primary beneficiary where the HIV/hepatitis C infection contributed to the death of their partner or spouse.

14. In Northern Ireland in 2018/19, £788k was spent on the Infected Blood Payment Scheme with an additional £35k on scheme administration costs, £160k additional spent on ex gratia lump sums and £800 on discretionary one-off grants. It is estimated that the total spend on scheme payments for 2019/20 will be around £1.8m (opening budget of £768k plus the £1.03m January allocation) on the scheme, plus £140k on lump sums and approximately £2.5k on discretionary grants awarded, as well as approximately £35k administration costs. In total, this represents £1.98m for 2019/20. The following table shows the current number of beneficiaries on the NI scheme.

Payment Description	**Number of Beneficiaries**
Hepatitis C Stage 1 *	59
Hepatitis C Stage 2 *	20
Hepatitis C Stage 1 Co infected HIV	2
Hepatitis C Stage 2 Co infected HIV	1
Mono HIV	1
Monthly Discretionary(Income Top Up & Winter Fuel Widows/Widowers/Partners only)	7
Widows/Widowers/Partners receiving winter fuel payment only	10
Total	**100**
Number of infected Beneficiaries receiving monthly discretionary payments (Income Top Up) (included in above)	8

<u>Impacts on people infected / affected - the case for improved financial assistance</u>

Evidence given to the Inquiry

15. There is a strong and widely supported case for improving financial support for those who have been infected or affected. In written statements and oral evidence to the Inquiry, as well as in media interviews, meetings and correspondence to the

Department, the victims of contaminated blood have consistently reported common impacts of their Hep C and / or HIV infection as including:

- being unable to work due to the impacts on their mental health including anxiety, depression and feelings of low self-worth;
- being able to work only part-time due to mental health problems;
- having had to leave a previous, better job, job role or career due to mental health problems and, as a result, suffering a permanent impact on their career;
- earnings reduced as a result of mental health problems;
- mental health problems directly resulting in the breakdown of marriage or other important relationship and still having a significant effect on the person's life;
- mental health problems making it very difficult to leave one's home or socialise;
- being unable to work full-time or carry out day-to-day activities due to physical health impacts caused by Hepatitis C.

Psychosocial Report

16. The Infected Blood Inquiry Psychosocial Expert Group, led by Professor Weinman, published its report in January 2020 into the psychosocial impacts of infection on people infected and affected. The Psychosocial Expert Group considered the impact of financial hardship and dependence on financial assistance from schemes set up by Government. The group reported that due to frequent periods of ill health, together with fatigue and depression associated with Hepatitis C treatment, many found it difficult not only to attend work regularly but also to perform well in the workplace. As a result, many infected adults reported reduced job opportunities and job prospects. In couples, this often placed an increased responsibility on partners to provide sufficient income. For the infected person, limited work capacity and the financial effects of this only served to increase feelings of low self-esteem.

17. The Psychosocial Report, which is UK-wide, also found that the cumulative effects of limitations in employment potential arising from interruptions in education, together with continuing health effects, had negative financial consequences for many infected and affected individuals. While this varied depending on social circumstances and life stage, overall the costs were considered to be high.

18. Of the variety of financial support available, the report found that these were insufficient. Many witnesses described feeling ground down in their attempts to seek financial assistance and many gave up. The difficulty in accessing and receiving financial payments from the schemes had negative consequences including continuing financial hardship, feeling let down, angry and helpless, and, as a consequence, aggravated depression.

19. The Psychosocial Report concluded that it should be possible to conduct a proper health economic analysis of the financial impacts of Hepatitis C and HIV infections following the receipt of infected blood or blood products and this should be carried out by economists as an addendum to the report and to quantify the full range of major financial impacts on the lives of those infected and affected.

20. Evidence was heard from both Inquiry intermediaries (who acted on behalf of those who were unable to give evidence) and from the Psychosocial Group on Monday 24 and Tuesday 25 February 2020. Inquiry intermediary Kay Durrant said *"there were some who felt that payments were inadequate, for others, across the differing areas, different awards, and they'd like some kind of agreement moving forward, that there's parity with that."*

21. At the meeting held on 13 February, some members of Families and Friends of Haemophilia NI highlighted the IBI Psychological Report which said treatment can cause dementia, and this naturally has caused concern. In addition to this, Paul Kirkpatrick of Families and Friends of Haemophilia NI, has by email indicated that the Inquiry oral evidence week commencing 24 February was emotionally tough for those infected – in particular the evidence from the psychosocial experts which confirmed reduced life expectancy and physical side effects which are likely to persist for a lifetime.

Professional testimony

22. The following section is a number of testimonies from professionals who work with those infected and/or affected with contaminated blood in Northern Ireland.

Dr Neil McDougall, Consultant Hepatologist, Royal Victoria Hospital

23. I am a Consultant Hepatologist and have led the hepatitis C treatment programme since my appointment to RVH Liver Unit in 2004. I have observed several specific impacts that a diagnosis of chronic hepatitis C virus (HCV) infection has had on my patients who acquired the infection through infected blood.

- *Emotional.* There is a stigma for all those with a diagnosis of liver disease due to the association with alcohol. This stigma is even more pronounced with HCV due to the fact that a large proportion of patients acquire the illness through illicit drug use. In addition, there is usually a sense of injustice that an infection with such potentially devastating long term consequences has been 'given' to the patient.
- *Impact of chronic damage.* One in five HCV patients will develop cirrhosis and this often occurs 'silently'. Often the first time patients realise they have cirrhosis is when they have scans carried out or present to our specialist service with decompensated liver disease. Most patients are aware of this and then worry about developing cirrhosis.
- *Risk of cancer.* Those who have cirrhosis have a 1-2% risk of liver cancer per year. They are enrolled into screening programs for a scan every six months. The haemophilia community is small and many are aware of patients who have developed liver cancer over the years. Understandably, this risk leads to considerable worry. Our treatments for liver cancer are not great and only a minority of those with such a diagnosis are suitable for curative therapy (such as liver transplant or resection).
- *Impact of treatment.* Our current treatments are highly effective and extremely well tolerated. Unfortunately this was not always the case. Until as recently as 3-4 years ago, interferon was the backbone of treatment and caused very severe side effects both physically and mentally. Many patients had to endure up to 12 months of interferon based treatment with numerous side effects and a success rate of only 30-40%. In those where treatment failed, they simply had to sit and wait for a new treatment to be developed. Some waited more than 10 years for the advent of interferon free treatment.
- *Liver transplantation.* This can be a fantastic intervention and today we are able to prevent HCV recurring in the new liver. In the past, we had patients who acquired HCV through infected blood, got decompensated cirrhosis or a liver

cancer, underwent a liver transplant and then developed aggressive recurrent hepatitis C in the new liver leading to death within a few years. Again, due to the tightly knit community in NI, patients (and their families) are aware of these bad outcomes for HCV in the past and understandably fearful about the future if they have cirrhosis.

Patricia McGrath, Social Worker

24. I have been the Social Worker for people with bleeding disorders in Northern Ireland for the past five years. I have had direct contact, to varying degrees, with most patients with a bleeding disorder currently under the care of The Regional Haemophilia Centre at BCH who have contracted Hep C or/and HIV through contaminated blood products. In my role, I also provide social work support to children with a bleeding disorder attending RBHSC and patients' families, many of whom have been "affected" by their relative receiving contaminated blood products. I think it is important to note that Northern Ireland in the 1980s and early 1990s was different to other parts of the UK. In certain areas in NI people tended to live, work and socialise in close knit communities and this brought unique challenges for individuals trying to manage "the secrecy of their diagnosis". From my perspective, I believe the biggest impact has been on the whole area of relationships:

- *People have avoided forming close personal relationships*. Some choosing not to have life partners while the pressure of living with uncertain diagnosis has contributed to relationship breakdown and many couples separating.
- *Impact on family relationships has been extensive*. Fathers who were infected choosing only to share their diagnosis with their partners hence their children maybe never knowing or finding out since Infected Blood Inquiry after their father has passed away.
- *Parents feeling guilty* - because they unknowingly gave contaminated products to their sons and left with the burden of who to tell and run the risk of being blamed.
- *Tension in sibling relationships* - whereby the siblings with the bleeding disorder were seen as being treated differently in the family.

- *The diagnosis has influenced family dynamics* - and elements of transgenerational trauma are evident today in my work with children with an inherited bleeding disorder.

25. The financial impact has included the impact on career or employment opportunities:
    - Individuals with a diagnosis often choose to be self-employed, which meant they could work alone.
    - Others opted for part-time, casual, lower paid work often-moving jobs when ill or when employers began to ask "difficult questions" about their health, needing time off for hospital appointments etc.
    - Many did not achieve their full potential in their career, turning down offers of promotion. Thus many individuals' earning potential is limited.
    - Some were unable to work due to their health difficulties or the fear of having to disclose information to potential employers and they became dependant on benefits.

26. The financial cost of living with a chronic illness is well documented. However, for some people with a diagnosis they did not receive all the benefits entitled to them and many were, and still are, reluctant to avail of local welfare advice services as they are frightened of being found out. Concerns re having to disclose their diagnosis to an advisor or DSS staff working in an agency where someone may know them. This fear of discovery also manifested when BSO took over the management and administration of the Claxton, Skipton and Macfarlane Trusts. People became very anxious that a local agency would hold information about their diagnosis and required a lot of reassurance before consenting to their details being transferred to Belfast. A number of individuals, for a variety of reasons, did not provide written consent initially and as such did not receive all the payments that they were entitled to.

27. In NI the roll out of the transition from Disability Living Allowance (DLA) to Personal Independence Payments (PIP) coincided with the increased media and political awareness of the contaminated blood issues. People had been told that they were on DLA for life but now they were being asked to complete a written application and attend for assessment as many saw it they had to prove their entitlement. The majority of our

patients did not receive the benefit at this stage, many had to request a mandatory re-assessment and go to appeal before being awarded a payment which was frequently less than what they had previously received, some had to return their mobility car, some were not awarded at all with many giving up as the process took so long

28. The issues I have identified have undoubtedly had a significant impact on the "infected" and "affected" individuals' mental health and overall wellbeing and many were prescribed anti-depressant and anxiety medication. In trying to manage their emotional pain, some individuals used alcohol and other drugs as a crutch, a way of helping them cope, which brought added problems and difficulties for the individual and their families to try and manage. As a result of their diagnosis most individuals then made very difficult life choices and some have engaged in risky behaviours for the reasons highlighted; others having seen friends and family pass may think "sure why not - I`m not going to live long".

29. With the increased media and political attention and the Infected Blood Inquiry many people have been forced to review their lives, bring to the fore painful memories and family secrets which had been buried for a number of years and are again being re-traumatised. Children, who are now adults, are reviewing their experiences with this new information and current knowledge. They are revisiting the bereavements and losses they experienced when they were younger, reflecting on how this has impacted on their life - often evoking painful emotions and grieving for relatives and lost opportunities which is very challenging.

Dr Susan Kirk, Specialist Clinical Psychologist, Royal Hospital

30. I am a Specialist Clinical Psychologist working within the Department of Clinical Health Psychology at the Royal Victoria Hospital in Belfast. Since January 2019 I have been meeting with individuals or family members affected directly or indirectly by the Infected Blood Inquiry (IBI). I have been offering providing psychological assessment and therapy to:

- Individuals with a diagnosis of haemophilia and who have received infected blood and have contracted HIV and/or Hep C as a result;
- Partners who have been co-infected with HIV and/or Hep C;

- Siblings of the infected and affected;
- Children of the infected and affected.

31. Collectively individuals infected/co-infected and affected have reported at various time points throughout their life high levels of anxiety, post-traumatic stress disorder (PTSD), obsessive compulsive disorder, complicated grief, low mood, depression, thoughts of life not worth living (TLNWL), suicidal intent, ideation and plans to end their life. They have also reported feelings of fear, anger, shame, guilt, loss, sadness and low self-concept/self-esteem as they have processed:
    - The physical and emotional changes due to the acquired infections and associated treatments. Fatigue, pain and problems with processing information;
    - Ongoing anxiety about their health and whether long term they will require and survive a liver transplant;
    - Being tested for HIV/hep C without consent;
    - Uncertainty regarding treatment of hep C. Thoughts that the virus is lying dormant and will either return and/or cause other health conditions;
    - Having to take HIV medication and that this may cause other health conditions
    - Being told that they would not live long and therefore expecting to die before a certain age;
    - The impact on their schooling and academic achievement as a result of reduced attendance due to poor health, treatment and hospital appointments;
    - Social exclusion and being bullied at school;
    - Being told by professionals not to tell anyone about their diagnosis of haemophilia and/or HIV/Hep C;
    - The death of others who had received the infected blood;
    - Not being told by parents and/or health professionals until they were adults that they had been infected;
    - Poor communication and receiving insufficient or misleading information from professionals;
    - Missing hospital notes and inaccurate information reported in their notes;
    - Not being able to able to gain, stay or progress within their employment;
    - Financial hardship;

- Not being able to obtain life insurance and the impact on their family following their death;
- Whether to have a partner, marry and/or have children;
- Breakdown in relationships with parents as they struggle to understand why their parents followed the advice of professionals;
- Breakdown in marital relationships;
- Whether they would infect others and if they had infected their partner already.
- Not being emotionally available for their partner and/or children;
- Lack of support as a result of stigma which resulted in secrecy, shame and fears associated with how others would react if they did disclose such information;
- The Infected Blood Inquiry. Listening to others reports, reading their notes, finding out information which they did not know and particular to NI, the lack of parity with England as regards the increase in payments.

32. As mentioned previously I have also been offering psychological support and intervention to those not infected but affected. I have met with siblings and children of those who have died as a result of having contracted either HIV and/or Hep C. The psychological impact on these individuals is also apparent. The family members I have met have had diagnosis of anxiety disorders, depression, complicated grief reactions and fibromyalgia. They have reported either struggling to manage difficult feelings or suppressing them altogether in an attempt to cope. These individuals have also experienced difficulties with their schooling, employment and adult relationships as a result of their experiences of having a parent or sibling who had been infected and the impact on their family before, during and after the death(s). Reports of loss of the family home, impact on remaining parent and other family member's mental health and having to take on roles such as looking after the parent and/or siblings have frequently been told. They have also reported of finding out during the Infected Blood Inquiry that they too were tested and their parents and themselves were not told. Reading the deceased person's notes has also impacted negatively on their own emotional wellbeing as they have become of aware of information which they had not previously known.

Meeting with infected / affected people

33. On 13 February, you met with Haemophilia NI and Families & Friends of Haemophilia NI to hear at first hand their individual stories and experiences of the impact of diagnosis and to listen to their concerns. While the groups welcomed the interim payments, they were disappointed that the full £1 million had not been allocated, describing this as insulting. Some attendees said felt that the disparity in payments that exists between Northern Ireland and England was a "human rights issue" and wanted to see the same payments as England introduced immediately, with any further reform, such as improved financial support for the bereaved, to be considered in the next phase. The Haemophilia Society have said that one person is dying from infected blood every four days and "time is life". Attendees at the meeting felt that they have had to battle their whole lives, both with their health and for financial support.

34. Both the infected and affected individuals who attended the meeting described the significant impact of a diagnosis of Hepatitis C or HIV following receipt of NHS blood or blood products. These impacts included:

- **impact on physical health** – physical effects of being infected with Hepatitis or HIV at a young age, additional health problems as a result of diagnosis, side effects of treatment, being fearful that current treatment is a risk, some have to be checked every six months for signs of cancer;
- **impact on family life** – relationship / marriage breakdown, ex-partners fearing infection, having to wash children's toys that have been touched by someone infected, parental guilt because haemophilia is an inherited genetic condition; for those affected, there is a sense of being unable to afford to be unwell, unable to have children or adopt, spouse / partner / children having to be tested;
- **impact on career** – loss of job, successful careers ended, continuing to work but having to keep diagnosis a secret, restricted career progression, spouse having to leave job to care for loved one diagnosed with Hep C or HIV;
- **impact on finances** – loss of home, loss of income, unable to get life insurance, unable to support family;
- **impact on mental health** – anxiety, depression, suicidal ideation, suicide attempts, fear of "what is coming next", never cleared as virus lies dormant ("non-detectable"), some receiving psychological support, while others cannot travel to Belfast and cannot afford private psychological support, some younger

haemophiliacs fear they will end up the same as older relatives who were infected with contaminated blood; for those affected there is coping with the loss of one or more close relatives, fear that the next infection could lead to organ failure, having to repeatedly plan funerals for a loved ones;

- **stigma** – having to endure stigma their whole lives, dentists not wanting to provide treatment, fears of risk, have to carry a form saying they may have vCJD, stress of giving evidence to the Inquiry and decision on whether to do this anonymously; for affected people, many were made to feel like the diagnosis was a "dirty secret", having been told to keep it confidential, some did not tell their spouse and received treatment in secret;
- Many family members felt their loved ones were "treated like guinea pigs" or were simply "a statistic" and they experienced loss of trust in the healthcare system.

Infected Blood Inquiry

35. The issue of parity across the Infected Blood Payment Schemes is included in the Infected Blood Inquiry's Terms of Reference under section 8 'Treatment, Care and Support'.

36. In his opening comments to the last round of evidence sessions at the Inquiry in October 2019, Chair Sir Brian Langstaff, reflecting on a meeting for the preliminary hearings that took place just over a year ago with those infected and affected and noting that some of those people have since passed away, said that *"financial hardship is the everyday reality and that is through no fault of their own. No-one could fail to have been moved by what they heard, whether politician, press or public, nor lose sight of the fact that some would not see out the Inquiry, however hard the Inquiry tries to work quickly. So I wrote to the Cabinet Office that October outlining the inadequacies and variation in financial support and suggested that decisive action should be taken. A year on, evidence is being given by witness after witness which has underscored the point but also a year on some disparities remain. Of course, I'm not yet in a position to report final conclusions and make recommendations but I would hope that nonetheless there remains the will to take further meaningful steps forward."*

37. In his closing remarks on 1 November, Sir Brian again highlighted the issue of financial support across the UK, describing it as "*an overall picture of relentless hardship for many*". Sir Brian again referred to the letter he wrote, over a year ago, to Cabinet Office calling for decisive action to be taken to alleviate this, before any more fundamental review that might follow from the Inquiry's conclusions. He said that steps taken by Government so far, for example increasing payments in England, have helped, but many more witnesses have repeatedly drawn attention to the continuing variations between the home nations, although he noted that at the time of their infection there was no such thing as a devolved health administration. Sir Brian said "*the grinding hardship of many is not put on hold whilst the inquiry continues. If, as a number of witnesses have argued, there is in truth no proper justification for significant variations in financial support as between the nations of the UK, then there can be no proper reason for those variations to be perpetuated to await the outcome of the Inquiry*." Sir Brian has made clear his expectation that action will be taken before the conclusion of his inquiry. He also emphasised a Cabinet Office commitment to *"guarantee equal support*".

Meaning of "parity"

38. The commitment in "*New Decade, New Approach*" states:

> *"The Executive will bring about parity in financial support to victims of contaminated blood in Northern Ireland with those in England".*

39. There is no consensus as to what parity between the NI and English schemes would mean in practice. In particular, it could relate to going beyond simply the regular payments to include parity on areas where differences between the two schemes existed prior to April 2019, including discretionary support (one-off grants), income top-ups and the Special Category Mechanism (SCM). Work on these elements of the scheme was paused in 2017, in the absence of a Minister and following the announcement of the Inquiry.

40. The term "greater parity" is taken from Jackie Doyle Price's statement about the uplift in England. This expression implies that there are degrees of parity, i.e. that "parity" does not necessarily mean uniformity. The term "convergence" would have been more useful but English ministers have raised an expectation that parity effectively means uniformity

in financial support across the UK. This is despite specific agreement at the four-nation Ministerial discussion in July 2019 (in which Richard Pengelly took part) that we should aim for "parity of support" – i.e. ensuring that those infected and affected received a level of support (both financial and non-financial) which addressed their needs. In practice, such an approach would mean that individuals receive a higher or lower level of financial support in different regions, recognising local circumstances (e.g. relevant costs and other factors).

41. NI campaigners have taken up parity with England as their goal, focusing on seeking additional regular payments to restore the degree of parity which existed prior to the April 2019 announcement of an uplift to regular payments in England.

42. A further consideration is the preservation of devolved authority in this matter. A permanent or indefinite commitment to replicate the provisions in the English scheme may not be possible if this would bind the hands of any future NI Minister of Health as regards tailoring the NI scheme more closely to the needs of its beneficiaries. While some form of parity is agreed at ministerial level, GB Health Ministers are in agreement that this should be done while respecting the devolved status of health to allow some flexibility in each country's scheme.

43. While this Department is working to establish a defensible rationale for changes to the Scheme, we are aware that English Ministers' decision to raise payments in 2019 was a political decision not underpinned by any such rationale, so there is no DHSC analysis from which we could extrapolate.

44. There are many factors to be taken into account when considering potential changes to Northern Ireland scheme rates, not least – at the macro level – cost of living differences between the DAs and – at individual level – the different impacts of illness on those infected. Economic analysis carried out by the Department suggests that if "parity" is taken to mean "purchasing power parity", then there is likely to be a difference in payment across the four jurisdictions as prices vary across the UK. This analysis suggests that aligning NI rates with England could be adjusted by between 1% and 10% to reflect relative regional consumer price levels or adjusted cost of living estimates, reducing overall additional costs to the NI budget.

45. Officials in the four countries have adopted the following as a working definition of 'parity':

> *"As an interim step in advance of any recommendations in the Infected Blood Inquiry's final report, the governments of the four nations are working towards greater parity in financial and non-financial support across the UK schemes, taking account of local circumstances and beneficiaries' needs."*

Differences between the schemes in England and Northern Ireland

46. The tables below set out the differences between NI and the English regular (annual) payments that came into effect in on 1 April 2019, and the total cost of re-aligning these payments to the England scheme (£1.09m).

Beneficiary	**Current NI rate**	**Current England rate**
Hep C stage 1	£4,096	£18,458
Hep C stage 2	£18,432	£28,000
Hep C stage 1 co-infected	£22,528	£38,000
Hep C stage 2 co-infected	£36,864	£44,000
Mono HIV	£18,432	£28,000

- *There are a total of 100 beneficiaries on the NI scheme (99 individuals and one estate)*
- *The total cost of regular payments on the scheme in 2019/20 was £710,656 (total costs overall are set out in paragraph 15).*
- *Both England and NI pay beneficiaries an annual winter fuel payment of £531.*
- *In England Hep C stage 1 (with Special Category Mechanism) receive £28,000. This will be set out in detail in a future submission to address other financial aspects of the schemes).*

47. The following table sets out in more detail the differences in regular (monthly / quarterly) payments between NI and England, including annual total and total anticipated additional costs.

		NI payment level 2019/20		Revised to replicate England payment levels 2019/20	
Payment description	No. of	Current	Annual	Payment	Payment

	beneficiaries in NI	payment (annual)	total	(annual)	total
Hep C stage 1	59	£4,096	£241,664	£18,458	£1,089,022
Hep C stage 2	20	£18,423	£368,640	£28,000	£560,000
Hep C stage 1 co-infected	2	£22,528	£45,056	£38,000	£76,000
Hep C stage 2 co-infected	1	£36,864	£36,864	£44,000	£44,000
Mono HIV	1	£18,432	£18,432	£28,000	£28,000
	83		£710,656		£1,797,022
Total additional					**£1,086,366**

Other considerations

Bereaved

48. Another factor to bear in mind is that there are 17 widows and widowers on the NI Infected Blood Payment Scheme who did not benefit from the interim payments you announced on 27 January 2020. The interim payments were only made to the 83 infected individuals on the scheme, however you have received correspondence from widows and families asking for financial support to be extended to include them. GRO-A GRO-A (TOF-1072-2020) wrote to you describing how she lost her father 20 years ago as a result of contracting AIDS and Hepatitis C from NHS infected blood. As he was not entitled to life insurance, her family has struggled both mentally and financially and Ms GRO-A said they were given no emotional or financial help and asked if you had plans to *"extend the current support scheme to affected including children and parents of victims as we are just forgotten about as if our experiences don't matter?."* The Department has also recently received a claim for discretionary support toward home insurance for a widow whose husband died from Hepatitis C following receipt of NHS contaminated blood. He had no pension as he was unable to work due to his poor health and he was unable to get life insurance. His widow's only monthly income is an income top-up of £166, pension and pension credit plus a £543 annual winter fuel payment. Writing on her mother's behalf, the widow's daughter describes how her mother has tried to get a part-time job at the age of 69 and describes the situation *as "very irritable considering that additional interim payments are now being allocated to those infected but not to the spouses of those who suffered a life of illness and painful death, not to mention financial difficulty because of the whole situation."* GRO-A also wrote to you (TOF-1078-2020) following your announcement of interim payments

on 27 January 2020. Mrs [redacted]'s husband [redacted] died in [redacted] 2011 having contracted Hepatitis C from infected blood and she asked if you would *"consider further financial support for the bereaved spouses of the unfortunate victims of this scandal"*, adding that *"widows/widowers have lost out financially as well as emotionally through no fault of their own but through the fault of the infected blood used by the Health Service".*

49. In addition to this correspondence, at the meeting with Cabinet Office on 28 January 2020, a number of attendees highlighted serious concerns about what was described as very inadequate support for widows and bereaved partners.

50. As outlined in previous submissions, while its regular (monthly / quarterly) payments to the infected are not as high as in England, Scotland's Infected Blood Support Scheme is overall the most generous in the UK, **when annual payments to the bereaved are taken into account**. Details on payments to the bereaved are set out in **annex A**. Following a meeting with a group of infected / affected groups and individuals on 28 January, the then Minister for the Cabinet Office, Oliver Dowden, undertook to consider the plight of widows. Local campaigners have also called in recent media interviews for better financial support for the bereaved.

Psychological support

51. A consistent theme in the evidence of the infected and affected to the Infected Blood Inquiry has been the lack of proper counselling and psychological support either at diagnosis or subsequently. While some witnesses have a note in their medical records that they have been "counselled" about HIV, they gave evidence that this was usually just a matter of informing them about their diagnosis and, at most, making them aware of the possible risks of transmission. Witnesses often reported being provided with very limited information about HIV. Occasionally a social worker or specialist nurse was highlighted as someone who was willing and able to listen to their concerns and provide some limited emotional support. However, they were not trained counsellors and had limited resources or training in this area. The evidence before the Inquiry has been consistent as to a lack of psychological support by trained individuals.

52. From January 2020, individuals registered with the Welsh Infected Blood Support Scheme, their family members and bereaved family members can access psychological assessment and treatment concerning the emotional difficulties of being given and living with a diagnosis of Hepatitis C and/or HIV. Following his meeting of 28 January, Oliver Dowden undertook to consider the issue of mental health support.

53. A number of attendees at the meeting with Cabinet Office on 28 January 2020 highlighted concerns about a lack of bespoke psychological support for the infected and affected in England. They noted that this is particularly significant now that the Inquiry is underway and those infected and affected are having to relive particularly painful and difficult periods in their lives. They suggested that Wales presents a good example of how psychological support could be approached. It was suggested that funding should be provided for specialised psychology/counselling services, and there should be an increase in funding for Haemophilia Centres which should provide medical care and social work support.

Other financial support

54. Prior to April 2019, Northern Ireland had parity with England on regular payments. However, there was no parity on other financial aspects of the scheme, including:

- Special Category Mechanism (SCM) – in England, there is a SCM allowing stage 1 Hep C beneficiaries to receive the same annual payment as a stage 2 Hep C recipient;
- Income top-ups – in England, both the rates and income thresholds are higher than in Northern Ireland (where the legacy Caxton and Macfarlane lower rates are still used), and;
- Discretionary support (one-off grants) – England has a formal policy on discretionary support, while a policy is yet to be adopted in Northern Ireland.

55. The issues that need to be considered as part of phase 2 of the interim reform are set out at **annex A**. These will be explored in detail in the second phase of this review.

Options for the 2019/20 financial year

56. The Department was allocated £1.03 million in January monitoring, of which £610,780 was committed in the interim payments announced on 27 January and has been paid out. Therefore **£419,220** remains, which you have committed to allocating before the end of this financial year. Three options are set out below for your consideration. Options are limited at this point to payments to infected beneficiaries and bereaved as any wider reform will be considered in the longer term and would require consultation. These calculations are based on the £1.086m figure in paragraph 49 as this is the total amount that would be needed to achieve parity with England on the regular payments. While £419,220 is the amount remaining from the January monitoring allocation, we have a total of £497,000 remaining in the Contaminated Blood programme budget line, as there was already some residual money not yet allocated to BSO.

<u>Option 1 – Award 100% of the accrued difference between England and NI in regular payments</u>

57. Pay all infected beneficiaries 100% of the difference that accrues between England and NI over the financial year 1 April 2019 – 31 March 2020. Beneficiaries will have received 75% of the difference accrued over the nine months April – December. The additional cost would be **£475,186.** This totals £1.086m outlined in the table at paragraph 49. This is set out in the two tables below.

First special interim payment (remaining 25% of accrued difference) 1 April – 31 December 2019

Payment Description	**Number of Beneficiaries in NI**	**Payment Per Beneficiary £**	**Arrears £**
Hepatitis C Stage 1	59	2,692.88*	159,179
Hepatitis C Stage 2	20	1,794*	35,481
Hepatitis C Stage 1 Co infected	2	2,901	5,802
Hepatitis C Stage 2 Co infected	1	1,338	1,338
Mono HIV	1	1,794	1,794
Total	**83**		**203,594**

** Costings for Hepatitis C S1 & S2 includes one beneficiary who commenced S1 payments in May 2019 and one beneficiary who moved from S1 to S2 payments in June 2019 therefore the arrears payment will differ from the figure in the table above*

Special Interim Payment (100%) 1 January – 31 March 2020

Payment Description	Number of Beneficiaries in NI	Payment Per Beneficiary £	Arrears £
Hepatitis C Stage 1	59	3,590.50	211,839.50
Hepatitis C Stage 2	20	2,392	47,840
Hepatitis C Stage 1 Co infected	2	3,868	7,736
Hepatitis C Stage 2 Co infected	1	1,784	1,784
Mono HIV	1	2,392	2,392
Total	**83**		**271,592**

<u>Option 2 – (a) award 90% of the difference accrued in regular payments during 2019/20 to infected beneficiaries, and (b) split the remaining 10% equally between the bereaved beneficiaries</u>

58. Pay 90% of the difference that accrues between England and NI, in the regular payments, over the full financial year 1 April 2019 – 31 March 2020. Infected beneficiaries have received 75% of the difference accrued over the nine months April – December 2019. To pay 90% of the full financial year 2019/20 (excluding the interim payment already made), the additional cost would be £366,589. Then split the remaining 10% equally (£108,597) between Northern Ireland's 17 non-infected widows / widowers, which would mean **£6,388 each**. In total, this option would cost **£475,186.**

59. A NI beneficiary receiving 90% of the difference accrued in 2019/20, on top of their regular NI payment, will, in 2019/20, receive 92% of the total amount received by their counterpart beneficiaries of the English scheme.

Beneficiary	**NI rate £**	**England rate £**	**Difference**	**90% of difference**	**Amount due***
Hep C stage 1	£4,096	£18,458	£14,362	£12,926	£4,847
Hep C stage 2	£18,432	£28,000	£9,568	£8,611	£3,229
Hep C stage 1 co-infected	£22,528	£38,000	£15,472	£13,925	£5,221
Hep C stage 2 co-infected	£36,864	£44,000	£7,136	£6,422	£2,408
Mono HIV	£18,432	£28,000	£9,568	£8,611	£3,229
Total Expenditure					**£366,589**

**Amount due is 90% of difference minus interim payment already made*

<u>Option 3 – (a) award 95% of the difference accrued in regular payments during 2019/20 to infected beneficiaries, and (b) split the remaining 5% equally between the bereaved beneficiaries</u>

60. Pay 95% of the difference that accrues between England and NI for the full financial year 1 April 2019 – 31 March 2020. Infected beneficiaries will already have received 75% of the nine months April – December. The additional cost would be £420,888. Then split the remaining 5% (£54,298) equally between Northern Ireland's 17 non-infected widows / widowers, which would mean **£3,194 each**. In total, this option would cost **£475,186**.

Beneficiary	**NI rate £**	**England rate £**	**Difference**	**95% of difference**	**Amount due***
Hep C stage 1	£4,096	£18,458	£14,362	£13,644	£5,566
Hep C stage 2	£18,432	£28,000	£9,568	£9,089	£3,707
Hep C stage 1 co-infected	£22,528	£38,000	£15,472	£14,698	£5,995
Hep C stage 2 co-infected	£36,864	£44,000	£7,136	£6,779	£2,765
Mono HIV	£18,432	£28,000	£9,568	£9,089	£3,707
Total					**£420,888**

**Amount due is 95% of difference minus interim payment already made*

61. A NI beneficiary receiving 95% of the difference accrued in 2019/20, on top of their regular NI payment, will, in 2019/20, receive 96% of the total amount received by their counterpart beneficiaries of the English scheme.

Consideration

62. It is clear that the impacts on people bereaved through infected blood and their needs in terms of financial and other assistance, demand serious and urgent consideration and appropriate responses. For immediate purposes the main parameter for this decision is the amount secured in January Monitoring. This was based on the sum needed to provide 'parity' with the English scheme, albeit in 2019/20 only. NDNA commits to 'bringing about parity'. The focus of groups of infected/affected people campaigning for parity has been the restoration of parity in those payments where there was parity between NI and England until April 2019. While there are interpretation issues with the word 'parity', in plain English it is synonymous with 'equality'. Options 2 and 3 would sacrifice parity-in-regular-payments, each to some degree. Either of these options would attract criticism from infected beneficiaries, as they would not receive full parity with England which is what they have campaigned for and is a commitment in New Decade New Approach. With each of options 2 and 3, the variables are continuous – they have no obvious steps or natural, defensible break-points, so any such option not underpinned by a more rigorous analysis of need than is possible in the time available will unavoidably be arbitrary to a degree. Option 1 is sub-optimal but would come closest to meeting the expectation of parity in the short term.

63. On the other hand 17% of beneficiaries on the NI Scheme are widows / widowers. Unlike those infected who are represented by groups such as Haemophilia NI and Families and Friends of Haemophilia NI, the bereaved are individuals who have not had a collective voice through which to seek meetings with Government representatives to put across their case. Yet they too have suffered greatly in their lives through the impacts of contaminated blood and blood products. Allocating a contribution to alleviate financial hardship of the bereaved is a recognition that for some the main breadwinner of households died as a result of receiving infected blood/blood products. The financial

plight of the bereaved has been highlighted by the Infected Blood Inquiry, and awarding them even a modest part of the January Monitoring allocation would be an acknowledgment of this fact. Option 3 is defensible as an equitable use of the one-off January monitoring allocation.

Recommendation

64. I recommend that you defer a decision of the potential reform of the issues outlined in **annex A**. These issues will form phase 2 of the ongoing, interim review as they require longer-term consideration, consultation and potentially legislation, as well as a recurrent funding commitment. This includes:

- Financial support;
    i. SCM;
    ii. Income top-ups;
    iii. Discretionary support;
    iv. Support for the bereaved
- Non-financial support, including psychological support.

65. Given the short timeframe available before the end of the 2019/20 financial year, I recommend that you agree to option 3 as outlined at paragraph 60: pay 95% of the difference that accrued between England and NI for the full financial year 1 April 2019–31 March 2020. This would amount to 96% of full parity with English regular payments, when the regular payments already made are taken into account. Infected beneficiaries will already have received 75% of the difference accrued over the nine months April – December. The additional cost would be £420,888. Then split the remaining 5% (£54,298) equally between Northern Ireland's 17 non-infected widows / widowers, which would mean **£3,194 each**. In total, this option would cost **£475,186.**

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Annex A

Phase 2 – interim reform

The following is for information only and is a summary of the areas that will need to be considered as part of the phase 2 interim reform in 2020/21.

Options – 2020/21 financial year – Phase 2 of reform

1. "*New Decade New Approach*" states that; *"The Executive will bring about parity in financial support to victims of contaminated blood in Northern Ireland with those in England".* This Department was allocated £1.03m in January monitoring, of which you have used just over £600k to make interim one-off payments to the infected, to address the disparity which occurred from April to December 2019. As part of this announcement, you undertook consider how best to allocate the remaining £400,000 (approx.) before the end of this financial year. However, it is important to consider how best to use this allocation to meet the needs of NI beneficiaries.

2. There are four broad areas which need to be considered going forward:

   A. Financial support (where there was previously parity with England);
   B. Financial support (where there was never parity with England);
   C. Non-financial support to beneficiaries;
   D. Financial support for the bereaved.

(A) Financial support (where there was previously parity with England)

3. There would be valid arguments to reduce payments to reflect cost of living or income differential. The economic analysis (available on request) shows the costs of implanting an alternative scheme to reflect that of Scotland or England ranges from around an additional £636k to and additional £1.09m. This increases to between £711k to £1.15m should the policy decision be taken that no one should be made worse-off by moving to the new payment regime (i.e. the Scottish "no day to day impact" category).

4. Within the first area, financial support (where there was previously parity with England) there are (at least) six potential options for payments to the infected beneficiaries:
    i. Align with England's regular payments with no adjustment for cost of living;
    ii. Align with England's regular payments minus 1%;
    iii. Align with England's regular payments minus 10%;
    iv. Align with England's regular payments with no adjustment for cost of living – including SCM;
    v. Align with England's regular payments minus 1% – including SCM;
    vi. Align with England's regular payments minus 10% – including SCM.

5. The following table is a summary of the additional costs of each of the above six options. A further submission in phase 2 of the review will outline the pros and cons of each option.

England	**Additional cost to NI £**
England (no adjustment)	£1,086,366
England minus 1%	£1,068,396
England minus 10%	£906,664
England (no adjustment) - inc SCM	£1,191,328
England minus 1% - inc SCM	£1,172,308
England minus 10% - inc SCM	£1,001,130

(B) Financial support (where there was previously parity with England)

6. While Northern Ireland used the same rates of regular payments as England until the announcement on 30 April 2019, there were other financial aspects of the scheme were NI was not aligned with England. These include:

- Special Category Mechanism (SCM) – in England, there is a SCM allowing stage 1 Hep C beneficiaries to receive the same rate as a stage 2 Hep C recipient;
- Income top-ups – in England, both the rates and income thresholds are higher than in Northern Ireland (where the legacy Caxton and Macfarlane rates are still used), and;
- Discretionary support (one-off grants) – England has a formal policy on discretionary support, while a policy is yet to be adopted in Northern Ireland.

Special Category Mechanism (SCM)

7. While the Northern Ireland scheme was the same as the English scheme in most respects (until April 2019), there are some minor differences. One such difference is that the English scheme includes a 'special category mechanism' (SCM). A consultation on the SCM was planned in Northern Ireland, however this was paused when the Executive stopped operating in 2017.

8. The SCM was announced in England in September 2017 and is for those at hepatitis C stage 1 who consider that the impact of their infection may mean they could qualify for the larger annual payments. Individuals who apply for the SCM should consider that hepatitis C or treatment for it is having a substantial and long-term impact on their ability to carry out daily activities.

9. Upon receipt of an application under the SCM, the English scheme assesses the application, based on criteria provided by DHSC. If an application passes, the individual will receive the higher annual payment amount backdated to the date NHSBSA received the complete application. If an application fails, the individual can appeal or can choose to wait six months (from the date of the original application) to reapply – if their circumstances have changed.

10. The following table shows the annual payments to the different categories of claimant, including Hep C stage 1 with SCM.

England

Beneficiary	Annual non-discretionary

	payment (£)
Hepatitis C Stage 1	18,458
Hepatitis C Stage 1 + SCM	28,000
Hepatitis C Stage 2	28,000
HIV	28,000
Co-infected Stage 1	38,000
Co-infected SCM	44,000
Co-infected Stage 2	44,000

11. At present in England, 562 out of 3,048 (18.4%) of EIBSS's current beneficiaries receive SCM support.

12. Any decision to introduce the SCM in Northern Ireland would require consultation with infected and affected and other key stakeholder and this needs to be considered in the longer term.

Income top-ups

13. In Northern Ireland, both infected individuals and bereaved spouses can apply for income top-ups. These range from £2,000 - £3,500 for Hepatitis C and up to £1,400 for HIV. In Northern Ireland, the legacy scheme rates (Caxton and Macfarlane Trust) are still used and there are currently 15 beneficiaries (including widows) who are in receipt of top-ups.

14. England used the Caxton and MFT levels until June 2018 at which point they began to use only the MFT rates and thresholds. Beneficiaries were asked to reapply and we backdated to April 2018 if there was entitlement. As an example, Stage 2 beneficiaries were previously not entitled but now are. These rates were used up until the government announcement in May 2019.

15. From July 2019, the English Infected Blood Support Scheme introduced the current rates, which are shown in the table below. New applications were backdated to April 2019. These rates are more generous than the income top-ups in Northern Ireland.

Household income (£)	**Annual income top-ups (£)**
£0 - £10,000	£18,000
£10,001 - £15,000	£10,421
£15,001 - £20,000	£5,412
£20,001 - £28,400	£1,412
£28,401+	£0

16. If Northern Ireland were to increase regular payments in line with England, income top-ups may cease for many of those who currently receive them as these are means-tested as the monthly payment would be higher. Widows, however, would be entitled to apply.

17. Income top-ups are effectively being phased out and are an unpopular aspect of the schemes as they are means-tested.

18. As with the SCM, Any decision to introduce the SCM in Northern Ireland would require consultation with infected and affected and other key stakeholder and this needs to be considered in the longer term as part of phase 2 of the review.

Discretionary Support

19. The purpose of discretionary support available on the NI Infected Blood Payment Scheme is to provide additional, time-limited financial support to beneficiaries and their families in order to address immediate needs and is mainly targeted for those in financial hardship, such as financial support for respite breaks. Such needs are considered as those that have a direct effect on an individual's independence, have been brought about as a result of their infection or its treatment and are otherwise unable to be met. It is intended for support such as health-related adaptations to the home, other support or care to help a person remain in their home, or respite breaks and respite care due to treatment complications. Funding for discretionary support comes from the Department's Provisions account.

20. In the absence of a Minister no consultation has taken place and therefore no policy has been adopted for discretionary support in Northern Ireland. Legal advice from DSO on interim arrangements is to adopt a prudent approach to provide payment in response to all fairly reasonable requests for discretionary support until such time as the policy has been consulted upon and a final policy published. In the absence of a ministerial decision on a Northern Ireland policy on discretionary awards, the Department has used the England scheme discretionary award policy as a model to guide our decisions, in the interests of fairness to beneficiaries and the proper management of public money. Only where there is sufficient medical or other evidence to suggest otherwise, would the Department depart from the England scheme.

21. As with the SCM and income top-ups, developing a policy on discretionary support in Northern Ireland would require consultation with infected and affected people and other key stakeholders and this needs to be considered in the longer term as part of phase 2 of the review.

Lump Sums

22. Under the schemes in Northern Ireland, England and Wales, Hepatitis C stage 1 beneficiaries receive a £20,000 lump sum payment; on moving to stage 2 a further payment of £50,000 is made. In Scotland, this is reversed, with chronic hepatitis C (stage 1) infected individuals receiving a £50,000 lump sum payment and advanced hepatitis C (stage 2) infected individuals receiving a further £20,000 if they had already received the £50,000 lump sum (or £70,000 if they are a new applicant). Furthermore, in Scotland widows/widowers/partners of deceased beneficiaries infected with chronic hepatitis C (stage 1) receive an additional £30,000 payment if their spouse or partner did not receive their additional £30,000 lump sum while they were alive. All Stage 1 and Stage 2 co-infected SIBSS members have received £70,000 plus the variable HIV lump sum payment where applicable.

23. The following table sets out the additional costs to the NI Scheme if Hepatitis C Stage 1 lump sums increased from £20k to £50k in line with the Scottish Scheme. The Scottish scheme Hep C S1 ex-gratia lump sum is also payable to the bereaved whose partners

had a Hep C S1 infection. The Scottish scheme does not pay the £10k bereavement lump sum.

Category	Number of NI Beneficiaries who received £20K	Additional one off spend per Beneficiary £	Added Cost to NI Scheme £
Hep C Stage 1	59	30,000	1,770,000
Bereaved	2	30,000	60,000
TOTAL ADDED COST TO NI			**1,830,000**

24. In Northern Ireland and England, HIV lump sums are paid as follows:

- an infected child under 18 years old, will be £41,500
- single adult without dependents, will be £43,500
- married adult without dependents, will be £52,000
- infected person with dependent children, will be £80,000
- infected intimates - a partner or spouse who is entitled to payment due to HIV transmission by blood, blood products or tissue, will be £23,500
- infected intimates - before birth, time of delivery or by breast feeding from a mother who is entitled to payment due to HIV transmission, will be £23,500

25. Northern Ireland has parity with England on lump sums for Hepatitis C and HIV and there have been no calls to change this to align with Scotland on Hepatitis C lump sums.

(C) Non-financial support to beneficiaries

26. A consistent theme within the evidence of the infected and affected to the Infected blood Inquiry has been the lack of proper counselling and psychological support either at diagnosis or subsequently. While some witnesses have a note in their medical records that they have been “counselled” about HIV, they gave evidence that this was usually just a matter of informing them about their diagnosis and at most, making them aware of

the possible risks of transmission. Witnesses often reported being provided with very limited information about HIV. Occasionally a social worker or specialist nurse was highlighted as someone who was willing and able to listen to their concerns and provide some limited emotional support. However, they were not trained counsellors and had limited resources or training in this area. The evidence before the Inquiry has been consistent as to a lack of psychological support by trained individuals.

27. As part of its Infected Blood Support Scheme, Wales provide more than just financial assistance: specially trained advisers help beneficiaries in a number of key areas. They provide a holistic service that is bespoke to individuals and their family and can include, for example, referrals and signposting to other recommended providers, help with practical matters like applying for a parking badge (Blue Badge), free bus travel and concessions and help income, help with completing forms, paperwork and applications; assistance with accessing health services, such as additional care requirements and health care transportation and referrals for emotional support and guidance on relevant support groups. They also help advise on benefits to help individuals and families improve their overall financial circumstances. The psychological support team, specifically for the Infected Blood Support Scheme, has been established in Wales at a cost of £80k per year. The team began assisting all those registered with WIBSS and their families in December 2019. From January 2020, individuals registered with WIBSS, their family members and bereaved family members can access psychological assessment and treatment concerning the emotional difficulties of being given and living with a diagnosis of Hepatitis C and/or HIV.

28. In England, beneficiaries experiencing mental health difficulties are advised to contact their own GP or local NHS Trust in the first instance. England also offer a maximum fund of £900 if a beneficiary opts to use alternative or private mental health services. This is not currently available in Northern Ireland as work on discretionary support was paused in the absence of the Executive (see paragraph 20 above).

29. In Northern Ireland, the scheme only provides financial support. Patients and families affected by the Infected Blood Inquiry at present are able to access the services of a

psychologist. The Department funds a psychology service for three days a week at the Northern Ireland Haemophilia Comprehensive Care Centre at Belfast HSC Trust - this is shown in the table below. At present, funding has only been approved for the duration of the Inquiry and it will be important to consider ways in which this work can become embedded in the service to support patients going forward.

Psychological service

	Resource required	**2018/19**	**2019/20**	**2020/21**
Belfast HSC Trust	Medical Legal Team	£21,800	£87,200	£65,400
	Haematology Service	£14,875	£59,500	£44,625
	Psychology	**£18,375**	**£73,500**	**£55,125**
	General Administration	£ 700	£2,800	£2,100

30. The significant mental health impact and need for more psychological support is an issue that has been raised by infected / affected individuals both in meetings and in evidence to the Infected Blood Inquiry. At a meeting with Richard Pengelly and Michael McBride in December 2019, members of the group Families and Friends of Haemophilia NI stressed that support for the infected / affected should go beyond merely financial assistance and should include better mental health support for both those infected and their families.

31. In Northern Ireland, there is no signposting to employment training but limited signposting given regarding benefits via the BSO website or through NI Direct. Any new policy in relation to non-financial support for beneficiaries (including mental health support) would need to be developed in consultation with beneficiaries and other key stakeholders and would need to be a longer term piece of work, potentially taking into consideration any recommendations from the Inquiry.

(D) Financial support for the bereaved

32. In Northern Ireland there are 17 non-infected widows / widowers who are not entitled to regular payments (apart from income top-ups). The following support is available for the bereaved:

- £10,000 lump sum for bereavement (if cause of death is linked to beneficiary Hep C or HIV per the death cert or medical professional confirmation);
- winter fuel payment (currently £531 increases with CPI);
- income top-ups – based on the legacy providers thresholds (Caxton, MacFarlane);
- discretionary one-off grants (this could include funeral payment & counselling).

33. In England, there are no regular payments for bereaved spouses/partners of people with HIV and/or hepatitis C when their spouse dies. However, they are entitled to apply for:

- £10,000 bereavement lump sum (if cause of death is linked to beneficiary Hep C or HIV per the death cert or medical professional confirmation);
- winter fuel payment (currently £531 which increases with CPI);
- income top-up payments if under a net income of £28,401;
- discretionary one-off grants (limited access);
- up to £4,500 funeral costs for the beneficiary;
- a discretionary payment is available towards counselling costs for an infected beneficiary or bereaved spouse/partner (if support is not available through their GP or local NHS Trust, or if they have been on a long waiting list for counselling through the NHS, but require treatment more urgently);
- signposting to welfare/benefits advice and employment training.

34. In Scotland, annual payments are made to widows and widowers of those who have died and had advanced (Stage 2) Hepatitis C or HIV infection. These payments are 75% of the amount the infected person would have been entitled to if they were alive (with 100% of the amount being paid for the first 12 months after the infected beneficiary's death). If Northern Ireland were to align with the Scottish scheme, widows would stand to gain the highest increase in payments. Widows in Northern Ireland currently receive a one-off £10,000 payment when their spouse dies. In Scotland,

widows / widowers do not receive the £10k lump sum as they receive 75% of their spouse's regular payments for life. The difference in payments to NI bereaved (compared to Scotland) is shown in the table below.

Category	**No. of beneficiaries**	**Northern Ireland**	**Scotland**	**Additional cost to NI scheme**
HIV bereaved	1	£7,527	£20,250	£12,723
Total				**£12,723**

Category	**No. of beneficiaries**	**Northern Ireland**	**Scotland**	**Additional cost to NI scheme**
HIV & Hep C bereaved	1	£5,535	£27,750	£22,215
HIV & Hep C bereaved	1	£11,535	£27,750	£16,215
HIV & Hep C bereaved	1	£16,527	£27,750	£11,223
				£49,653

Category	**No. of beneficiaries**	**Northern Ireland**	**Scotland**	**Additional cost to NI scheme**
Hepatitis C stage 2 bereaved	1	£2,531	£20,250	£17,719
Hepatitis C stage 2 bereaved	1	£2,531	£20,250	£17,719
Hepatitis C stage 2 bereaved	1	£3,030	£20,250	£17,220
Hepatitis C stage 2 bereaved	8	£531*	£20,250	£157,752
Total				**£210,410**

Category	**No. of beneficiaries**	**Northern Ireland**	**Scotland**	**Additional cost to NI scheme**
Hepatitis C stage 1 bereaved	2	£531*	£14,175	£27,288
Total				**£27,288**

35. The Welsh Government also pays a £10,000 one-off lump sum for scheme registered spouses/partners of scheme registered beneficiaries. For the bereaved, regular payments are made to spouses / partners of scheme beneficiaries <u>for three years</u> following death at 75% of the annual entitlement.

36. Following your announcement on 27 January 2020, infected groups have been calling for greater support for the bereaved. Following a meeting with a group of infected/affected groups and individuals on Tuesday 28 January, the Minister for the Cabinet Office, Oliver Dowden, undertook to consider the plight of widows.

37. In Northern Ireland, the Department has received requests for £10k bereavement lump sum to be backdated and there have been calls across the UK for the bereavement lump sum to be extended to other family members, beyond spouse. This is a further consideration in going forward with reform of the scheme and is something that would need to be considered in consultation with beneficiaries and other key stakeholders.

38. All of the above issues need to be considered as part of phase 2 reform for the 2020/21 financial year. The immediate consideration is the completion of phase 1, as set out in the main submission.