Expert Report to the Infected Blood Inquiry: Health Economics

June 2023

Infected Blood Inquiry

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Note by Counsel to the Inquiry in relation to the Expert Report on Health Economics

The Inquiry commissioned a number of reports about the impact of infections consequent to the use of infected blood and blood products, including from the Psychosocial Expert Group and the Statistics Expert Group. This report by the Health Economics Expert Group endeavours to examine the economic and health costs to the extent that those costs can be estimated.

The Expert Group has provided both qualitative and quantitative analysis. The qualitative analysis uses evidence provided by witnesses to the Inquiry to describe social and psychological impacts that can be difficult to quantify. The quantitative section uses data about costs collated from published literature to inform health economic analysis to examine some of the societal impact for the UK.

This quantitative health economic analysis involves constructing a simplified model and then using published data about health and economic losses to populate the model with healthcare, productivity (earnings) and health-related quality of life costs for cohorts of hypothetical people modelled. The report acknowledges – and the Inquiry is well aware - that some of the simplified disease trajectories for the modelling do not reflect the real life experiences of people infected.[1]

The Expert Group found significant limitations to the extent that the costs could be quantified with published data, and the wider evidence available to the Inquiry suggests that the published health economic data about people infected with HIV and HCV, usually obtained and analysed for the particular purpose of evaluating the cost effectiveness of new treatments, does not in reality reflect the full experiences of people infected.

The expert analysis identifies that the societal cost of infections consequent to the use of infected blood and blood products runs into billions of pounds. The Expert Group describe the estimates[2] as likely representing a gross underestimate of the true economic costs to infected individuals, their families, and to wider society, of the use of infected blood and blood products.

Jenni Richards KC
Counsel to the Inquiry
May 2023

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1 See, for example, Table 15 (p72) which uses published data to identify QALY weight reductions for each of the simplified disease stages in the model. Only persons infected with less than 2 years to live are assigned QALY weight reduction greater than 0.25. This does not reflect the wider evidence available to the Inquiry.

2 See the final bullet of the Executive Summary p6. The nature of the analysis does not provide a central estimate of the costs but the range for the total health, productivity and health and social care costs for 1970 to 2021 suggested by the model runs from more than £4 billion to more than £16 billion. See Results p78 'economic costs due to healthcare and productivity losses ranged from £1.9bn to £4.2bn' and p80 'assuming a value is placed on a life year … the total valued health losses would range between £2bn and £5.9bn (for £30,000 valuation) and £4.1bn and £11.8bn (for £60,000 valuation).'

Contents

Glossary of Key Terms

AHO – Alliance house organisation

AIDS – Autoimmune deficiency syndrome

APPG – All-Party parliamentary group

ART – Antiretroviral treatment

AZT – Azidothymidine/zidovudine

BDs – Bleeding disorders

BHIVA - British HIV association

CI – Confidence interval

DC – Decompensated cirrhosis

ESLD – End stage liver disease

GBP – Great British Pounds

HAART – Highly active antiretroviral treatment

HBV – Hepatitis B

HCC – Hepatocellular carcinoma or primary liver cancer

HCV - Hepatitis C

HEG – Health Economics Expert Group

HIV – Human immunodeficiency virus

HQoL – Health-related quality-of-life

IBBP – Infected blood and blood products

InfA – Interferon alpha

LD – Liver disease

LEB – Life expectancy at birth

MFET – McFarlane and Eileen Trust

na – Not applicable

NHS – National Health Service

NNRTI – Non-nucleoside reverse transcriptase inhibitors

Non-ESLD – Non-end stage liver disease

NRTI - Nucleoside reverse transcriptase inhibitors

PI – Protease inhibitor

PwBD – People with bleeding disorders

QALE - Quality-adjusted life expectancy

QALY – Quality-adjusted life year

rLE – Remaining life expectancy

SEG – Statistics Expert Group

SVR – Sustained virological response

UKHCDO – United Kingdom Haemophilia Center Doctors' Organisation

UKHSA – United Kingdom Health Security Agency

vCJD - Variant Creutzfeldt-Jakob disease

VWD - Von Willebrand disease

1. Preamble

This report has been written by the Health Economics Expert Group (HEG) appointed by Sir Brian Langstaff in 2020 on behalf of the Infected Blood Inquiry ('the Inquiry'). In the Letter of Instruction from the Inquiry,[1] we were asked to undertake an analysis of the societal impact of infected blood and blood products. Our report chronicles and quantifies the health and economic consequences of infected blood and blood products in the United Kingdom from 1970 to the present time. We are instructed to express our opinion on the matters set out from today's perspective and, where we identify changes or developments, to make reference to them. We have endeavoured to source verifiable data to underpin each of the estimates and assumptions made within our analyses. Where it has not been possible to do so, we have made this transparent.

We adopted two complementary approaches to analyse the societal impact of infected blood and blood products:

a. Qualitative analysis: What were the impacts for those infected and affected by infected blood and blood products in the United Kingdom, and what impact did these have on the lives of individuals and their families?

b. Quantitative analysis: What are the economic and health costs of infection from infected blood and blood products and its consequences from a societal perspective for the United Kingdom and its people, to the extent that it can be estimated?

The first part (a) of our report provides a qualitative analysis of witness testimony data to elucidate the ways in which individuals and their families were impacted by infected blood, with a particular focus on the suffering experienced through treatments and the adverse impacts on education and employment, financial difficulties, and the social and psychological impacts on their lives.

The strength of a qualitative study is its detailed description, in this case of how viruses contracted through NHS treatment impacted the lives and experiences of individuals infected and their families. The necessary focus on a relatively small number of cases, however, means that a single study cannot include all variations that may exist among the wider witness population, nor provide the basis for statistical comparison or assessment of prevalence.

The second part (b) of our report uses a quantitative cost-of-illness analysis to quantify the health and economic impacts. However, we acknowledge that there are profound limitations to the extent to which these costs can ever be quantified and our simplified model does not capture the full societal impact for the United Kingdom. We endeavoured to estimate the impacts of infected blood and blood products in terms of economic losses (measured in British pounds) and health losses (measured in a generic measure of health-related quality of life) where there was published data available.

We have captured the economic consequences of infected blood and blood products to the best of our ability in the cost of illness model given the data available to us. However, we were unable to fully capture all aspects of economic disadvantage and hardship experienced by infected individuals, their families, and those accruing to the wider society, as a consequence of infected blood and blood products. The qualitative analysis is better equipped to capture

some of these wider impacts, and those that cannot be easily quantified. The two analyses should be read and considered together as complementary sources of information in respect to answering the letter of instruction.

1.1 Change in approach considering constraints

Both qualitative and quantitative study approaches were adapted from the original letter of instruction in the face of limitations and constraints related to the availability of data, and problems related to the sensitivity of the contents of witness statements. We explain these adaptations below in turn.

1.1.1 Changes to qualitative study

Originally, our intention was to undertake a qualitative study of typical patient pathways. This was attempted but forming a selection of illustrative cases was difficult due to the substantial individual variation based on age/life stage, access to treatments and individual circumstances. It was also recognised that individual case studies might present issues of confidentiality for witnesses whose witness statements were analysed in detail. We therefore modified the approach and, after discussion with the Inquiry, it was agreed to undertake a thematic analysis. It was also agreed to organise the analysis in terms of the three main routes of contracting infections, namely through blood products, through single or multiple blood transfusions, and indirect transmission among family members.

1.1.2 Changes to quantitative study

Originally, our instruction included conducting a retrospective cost-effectiveness analysis to determine what value could have been estimated for surrogate testing of blood donations before HCV screening became available and also of introducing earlier HCV screening. However, it became clear that it would not be possible to undertake this analysis due to data constraints regarding the availability of blood and domestic and imported blood products in the UK, the need for and benefit of blood and blood products at the time, and social, ethical, and political factors that were considered important at the time which informed decision-making and subsequent policy.

Furthermore, we were not able to calculate cost and health impacts for those infected with hepatitis B. This is because the Statistics Expert Group report did not furnish estimates of the number of individuals infected with this disease due to the limitations in the data available.

Their report did not provide estimates of secondary infections and so they are considered only in the qualitative study.

We could not estimate all social and financial impacts of infection, and we were also limited in estimating the extent to which medical treatment for other conditions was compromised because of infection. Similarly, we could not estimate most of the impacts for partners, children, parents, families, carers and others close to those infected. This was not possible due to lack of data. We explain in detail in the report which impacts are included and excluded.

2. Executive Summary

- The instruction to the Health Economics Expert Group was to estimate the economic and health costs of infected blood and blood products to the United Kingdom between 1970 and 2021. We undertook a qualitative analysis of 63 witness statements to document the wide-ranging economic, social and health impacts of infections by mode of transmission of infection. We further employed a cost-of-illness model to quantitatively estimate three types of economic costs: healthcare, productivity and health-related quality of life costs.
- The qualitative study was based on a large sample in qualitative terms with 63 cases, of which 33 cases related to bleeding disorders of different kinds and severity, and with different infections and combinations of infection, 17 contracted infections following transfusions for various reasons and 13 were different types of indirect (familial) transmission. The witness statements varied in their detail, but all focused on describing the impacts of infected blood on individuals' lives. They do not provide quantitative data but rather offer context in which the modelling should be viewed.
- The qualitative analysis identified the multiple impacts and sources of suffering associated with treatment with infected blood and blood products, including physical and mental impacts and severe side effects of treatments, impacts on employment, financial difficulties, and stigma. These impacts were particularly severe in the early days due to relatively low success rates of treatments, limited financial assistance, and the high prevalence of stigma in the population.
- The qualitative study described the impacts not only for infected individuals but also for affected family members. Both parents of young children infected and those with an infected partner experienced considerable worries and fears for the future and often shared the sense of stigma that led to family secrecy with its psychological costs. Guilt for infecting a child through administering Factor VIII or unknowingly infecting a child at birth were also important themes.
- Partners took on increasing responsibilities for finances and family as their partner's health declined and often gave up employment to provide care during later stages of illness. Widows often had difficulty returning to employment but were not eligible for long-term financial support. Children were often severely affected by the suffering of a parent, managing family secrecy and not being a 'normal family', with the illness of a sibling also often having negative psychological effects on the well sibling.
- A further theme was the suffering caused through the multiple impacts of the virus on their lives which severely disrupted individuals' hopes, plans, and expectations for the future in terms of careers, family, finance, home, and leisure activities. These perceptions of what life could have been without the virus remain extremely painful.

- The quantitative analysis generates estimates of the aggregate economic impact of infected blood and blood products to UK society by modelling simplified life trajectories from infection for the cohorts of persons infected with hepatitis C (HCV) and human immunodeficiency virus (HIV). This model considers only the most measurable drivers of cost in aggregate and is a significant simplification. It does not simulate the exact experience of every individual infected or affected. There were key economic impacts that could not be estimated.
- The quantitative analysis accounts for the healthcare costs that arise from the medical treatment of the infected and are borne by the NHS, patients, and their families. Productivity costs are the lost earnings due to inability to work productively. Health costs recognise that many infected individuals died earlier than they would normally have and that they spent sometimes many years in ill-health.
- We express lost health (in terms of excess mortality and morbidity, and lost healthy life years) in quality-adjusted life-years (QALYs).
- The sum of healthcare and productivity costs ranges between £1.9 billion to £4.2 billion for the time period 1970 – 2021, when converted to 2021 values. This is comprised of health and social care costs ranging between £900 million and £1.6 billion, and productivity costs ranging between £900 million and £2.6 billion.* The simplified nature of the model means these estimates likely represent an underestimate.
- The total loss in healthy life years due to ill-health and early deaths ranges between 70,000 and 200,000 QALYs. Around 60,000 – 100,000 QALYs are lost to premature deaths and 10,000 – 90,000 QALYs to ill health during the lifetime of the infected persons.
- The costs and health loss can be calculated by dividing estimated values by the total number of individuals ever infected. The average healthcare and productivity costs per infected person range between about £45,000 and £202,000 over the period 1970 – 2021. Lost QALYs range between 1.8 and 9.5 per infected person. The simplified nature of the model means these estimates likely represent an underestimate and also do not include lost QALYs for people affected such as bereaved partners, parents, children and carers.
- The quantitative cost estimates are highly uncertain due to the considerable limitations on available data, and many assumptions and model simplifications that were required. Important impacts could not be included because of unavailability of data, for example, the adverse impact on educational and employment opportunities, and altered life paths. As explained in the Preamble, we were unable to fully capture all aspects of economic disadvantage and hardship experienced as a consequence of the use of infected blood and blood products. We recognise that the estimates presented in the quantitative analysis likely represent a gross underestimate of the true economic costs to infected individuals, their families, and to wider society of infected blood and blood products.

* Due to rounding, some totals may not correspond with the sum of the separate figures

3. Impacts for individuals and families: qualitative analysis of witness statements

3.1 Introduction

This qualitative study aims to provide a detailed account of the lives and experiences of infected individuals who experienced HIV/HCV coinfection or were infected with a single virus through NHS-supplied blood or blood products, together with the impacts on affected family members. The study data comprises witness statements for a sample of 63 cases. Thirty-eight witness statements were provided directly by the infected person and 25 by a parent, partner, child, or sibling on behalf of the infected person due to their death, or on occasion reluctance to recount very painful experiences.

This descriptive study of the impacts of treatment with contaminated blood and blood products on individuals' lives complements the quantitative analysis in section 4 by describing social and psychological impacts that are difficult to quantify and informs some of the modelling assumptions. The study also contextualises individual experiences by considering the changing contexts in which individuals coped with HIV, HCV, and HBV, with notable changes occurring over time in three areas: the development and increasing availability of more effective treatments, the increasing eligibility for financial assistance and levels of payment, and changes in the level of stigma associated with HIV and hepatitis.

The framework for the study is provided by the three routes of transmission:

1) those with a bleeding disorder treated with blood products, 2) those infected through transfusions, and 3) indirect transmission among family members. Analysis of each route of transmission includes some data on particular subgroups, including people with haemophilia who had HIV & HCV co-infection, those with HCV as a mono-infection (i.e. without HIV), and people who were infected with a virus through a single transfusion associated with a medical or surgical procedure or who received multiple transfusions for chronic conditions. It was not feasible to provide comprehensive coverage of each subgroup but their inclusion contributes to an understanding of the different situations and circumstances of people who were infected. The section concludes with a discussion of the major themes identified from witness statements across the overall sample.

3.2 Methods and data

This study of the experiences and impacts of treatment with contaminated blood and blood products for both individuals and families is based on witness statements submitted to the Infected Blood Inquiry in 2018 – 2020. The witness statements were submitted in response to a letter and invitation that was distributed widely by the Inquiry team, including to those who had been in touch with the Inquiry team during the consultation on the terms of reference, and to the four national financial support schemes who sent the letter and invitation to their contacts list. The letter and invitation were also sent for distribution to charities and organisations whose members were affected by the use of contaminated blood and blood products as well as to law firms representing people who had been campaigning about infected blood and blood products. Both the letter and invitation were also posted on the Inquiry website.

At the time of writing, a total of 3,825 people were recorded by the Inquiry to have provided a written witness statement and 85 people chose to speak to an intermediary. People who provided a written statement either spoke to an inquiry investigator, their own legal representative, or drafted a statement themselves, with statements completed by either infected individuals or by a parent, partner, child, or sibling. Each statement required witnesses to respond to eight broad topics in their own words: an introduction, how the person was infected, any other infections, consent, impact of the infection, treatment/care/support, financial assistance, and other issues. This format allowed witnesses to provide statements that differed in length, detail, and emphasis to reflect their personal concerns and experiences.

3.2.1 Study sample

Testimonies were collated by Counsel to the Inquiry and redactions were made to personal details to ensure confidentiality in line with the Inquiry's published Statements of Approach. For the purposes of this study, a group of 232 witness statements were initially made available to the Health Economics Group (HEG) and were placed in a secure portal using the legal & compliance software, Relativity, for the HEG to review and extract data from. These statements were submitted in 2018 – 2019 and when a witness had given oral evidence at the Inquiry's hearings in 2019 the transcript was also reviewed. This was the first tranche of statements to be processed and was drawn from submissions from different parts of the UK.

Cases for analysis were initially identified through the systematic sampling of the 232 witness statements on the Relativity portal. A further 23 witness statements submitted in 2018 – 2020 were also made available at the request of the HEG from categories identified as important to the analysis, but for which a relatively small number of cases had been identified through systematic sampling. The number of cases analysed reflected both feasibility and the need to ensure sufficient numbers to cover key issues. The final sample was large for a qualitative study, comprising 63 cases, of which 38 were submitted by the infected individual and 25 by a parent, partner, or occasionally a child or sibling. In terms of routes of transmission, the sample comprised 33 cases of transmission through receipt of blood products by people with inherited bleeding disorders, 17 cases of transmission through either a single or regular transfusion, and 13 cases of indirect transmission by a family member. For three cases a total of 5 statements from additional family members who were children or a parent of the infected person were also provided. These gave valuable information on their own experiences and were analysed alongside the main witness statement.

3.3 Analysis background

Initially, individual witness statements were read to identify and record themes and subthemes. The charting of individual cases was then undertaken based on the approach in Ritchie et al.[2]

Charting involved abstracting information for each witness statement and recording on a proforma, which summarised information and verbatim extracts from the statements for each witness under six headings: 1) Personal characteristics and infections, 2) Impacts of infections and treatments, 3) Employment and financial circumstances, 4) Social impacts including family, 5) Psychological impacts and stigma, and 6) General reflections. The analysis of groups and subgroups involved identifying common themes in terms of individuals' perceptions and experiences and where possible explaining variations, for example, in feelings and experiences of stigma, the impacts of unemployment, and other life circumstances.

As a background to the study, a brief overview is provided initially of the causes of the high rates of infections between 1970 and late 1991. This is followed by a description of the developments in three areas that occurred from the early stages of the epidemic with implications for individuals' lives.

3.3.1 Medical conditions, blood and blood products

The two main groups contracting the viruses through blood and blood products were people with haemophilia and other inherited bleeding disorders, and those infected through blood transfusions associated with medical or surgical procedures or blood disorders. Those with inherited bleeding disorders either lack or have a low level of a specific clotting factor with a replacement required to relieve pain, shorten recovery time, and reduce the risks of complications and permanent damage through bleeding inside the joints and on the brain. Before 1965, there was no effective treatment for haemophilia, where bleeds were managed through bed rest and whole blood transfusion to compensate for severe blood loss. From 1965, the management of bleeding was transformed through cryoprecipitate derived from (thawed) fresh frozen plasma. This was mainly administered at hospitals but could be injected at home and stored in a domestic deep freezer, although disadvantages were the need to wait for the product to thaw when a person was suffering and difficulties extracting the concentrate into the syringe.[3]

From the late 1960s onwards, many of the difficulties of administration were overcome with the availability of a crystalline powder derived from cryoprecipitate, known as Factor 8 concentrate (for haemophilia A) and Factor 9 concentrate (for haemophilia B). These concentrates were simple to administer by being dissolved in water and injected, with a much smaller volume of factor concentrates also required for each treatment. The concentrates were licensed for distribution (to haemophilia centres) in early 1973 and became popular with both medical staff and patients. Whereas there was a sufficient domestic supply of Factor 9 concentrate for most purposes, the demand for Factor 8 grew exponentially, leading to a shortage of domestic NHS supplies.[4,5] As a result, clinicians began to supplement UK-produced Factor 8 concentrate by using, initially on a 'named patient' basis, a large quantity of commercial preparations of Factor 8 concentrate imported from the US,[3] along with greater use of whatever the UK could produce domestically from plasma donated by voluntary non-remunerated donors.

The terrible downside of imported factor concentrate was the high level of contamination with HIV and HCV. A major cause was that whereas UK donors were non-renumerated and gave blood as a gift on a voluntary basis, many blood banks in the US operated commercially, often collecting from blood donors motivated to donate by payment. This included large numbers of prison inmates, sex workers, and injecting drug users, with high risks of both HIV and HCV infections. Risks of contracting these conditions were also increased through batches of factor concentrate involving pooled blood, often from over 20,000 donors. This increased the chance that one or more infected donations would be added to the pool and capable of infecting the whole pool.[3]

Problems of contamination were further compounded by the lack of availability of screening tests for several years, with screening for HIV beginning in the UK in October 1985 and in September 1991 for HCV. The first heat-treated blood products were used in the UK in 1984 but most patients did not have access to them. Commercial products were also rarely free of hepatitis risk until around 1989, largely when heat treatment had been slowly superseded by solvent detergent processing, although blood products that had not been through these processes remained in circulation for some time. High rates of infections in the UK thus arose from the contamination of blood and blood products, together with the time taken for

comprehensive screening and heat treatment to be fully implemented. It is estimated that in the UK, among those with a bleeding disorder, 1,250 people were infected with HIV, with a further 2,400 – 5,000 people infected with HCV over the period 1971 – 1991. In addition, over the same period between 79 and 100 people were infected with HIV through a blood transfusion and some 22,000 (range 17,300 to 31,900) were chronically infected with HCV through a blood transfusion and survived to at least 6 months post-transfusion (SEG Expert Report to the Infected Blood Inquiry, tables ES1 to ES4[6]).

3.3.2 Changes in treatments, financial assistance and stigma

Major societal changes which influenced the experiences of individuals infected and their families occurred in three key areas. One change was the developments in drug therapy that led to more effective treatments with fewer side effects. A second change was in the provision of financial assistance, with increasing eligibility and levels of payment to support those infected via NHS-supplied blood and blood products. A further change at a societal level was a lessening in the stigma attached to the viruses and thus in the negative and discriminatory responses by both the public and through institutional policies and practices.

This section gives a brief overview of these changes and begins by describing the main viruses, with changes in their treatment then summarised in **Box 1**.

3.3.2.1 Viruses and changing treatments

3.3.2.1.1 HIV (human immunodeficiency virus)

HIV (human immunodeficiency virus) was identified in 1983 as causing AIDS by destroying the immune system. In the initial acute stage (2 – 4 weeks from initial infection) the virus multiplies very rapidly and the viral antibodies can be detected. This is followed by a chronic stage where viral levels gradually increase, resulting over time in a significantly weakened immune system that leads to cancers and opportunistic infections (e.g. pneumonia, lymphoma, tuberculosis, neurological problems, genital sores, and severe fatigue). The formal diagnosis of AIDS is established when the patient has either an AIDS defining condition or the CD4 count is below 200 (normal CD4 count 500 – 1600), which is an indicator of immune function and the strongest predictor of HIV progression to AIDS.

3.3.2.1.2 HCV (hepatitis C virus)

The HCV virus was initially identified in 1989 (previously Non-A Non-B hepatitis) and is one of the most common viral causes of chronic liver disease and cirrhosis. During the initial acute phase of HCV, which lasts for 6 months, about 20% to 30% of people have symptoms including jaundice and non-specific symptoms such as low-grade fever, fatigue, and nausea. At this initial phase the HCV can be self-limiting if the immune system is strong enough. Otherwise, after 6 months patients enter the chronic stage where symptoms are often mild and non-specific for many years even while liver damage is taking place. This eventually leads to cirrhosis of the liver, hepatocellular carcinoma (HCC), and end-stage liver disease (ESLD).

3.3.2.1.3 HBV (hepatitis B virus)

HBV affects cells in the liver, although the majority of adults with a competent immune system are able to clear HBV. However, for a minority, the condition becomes chronic with the virus continuing to reproduce in the liver for 6 months or more. Inflammation of the liver is initially low but then moves to more significant damage, with the combination of HBV and HCV increasing the risks of progression and more severe liver disease (**Box 1**).

Box 1: Developments in treatments for viruses

Human immunodeficiency virus (HIV)

1987: development of AZT (azidothymidine, or zidovudine), the first antiretroviral agent with a positive impact on clinical progression & survival – the median survival rate increased by 9.5 months with treatment.[9] Challenges were high pill burdens, inconvenient dosing, stringent food requirements, treatment limiting toxicities and incomplete virological suppression.

1995: development of Highly Active Antiretroviral therapy (HAART). A combination of three or more drugs taken daily was capable of virological suppression and became the standard treatment. HAART started to be administered in 1997 and it is still the gold-standard treatment for HIV. There is currently no cure for HIV, with current treatment aiming to stop the virus from replicating and to reduce morbidity and mortality and onward transmission in those infected with HIV.

Hepatitis C virus (HCV)

1990s: treatment required injections of recombinant interferon-alpha (IFNa) but had low effectiveness (8-9% success).[12] Interferon is a naturally-occurring molecule that the body makes to fight infection and can generate 'flu-like' symptoms when used as a medicine.

From 1998: combined interferon with the antiviral drug ribavirin had a cure rate of 33-41%.[13] Ribavirin therapy was very challenging to use, particularly for long periods, due to its levels of toxicity. Common side effects include anaemia, neutropenia (a low level of the white cells-neutrophils), depression, insomnia, headache, dizziness and impaired concentration.

Early 2000s: a new pegylated interferon treatment combined with ribavirin had a success rate of 40-80%.[14] There is a long list of contraindications to PEG-interferon from potential hypersensitivity, to severe liver dysfunction or decompensated cirrhosis of the liver or severe pre-existing cardiac disease, meaning that treatment was contraindicated for patients with End-Stage Liver Disease (ESLD).[15]

2011-14: first generation of direct-acting antivirals (DAAs) were prescribed together with interferon (and ribavirin). These significantly improved cure rates but there were additional toxicities from this approach and the drugs were more successful against only certain targeted genotypes of the HCV virus.

2014-15: oral therapy with DAAs started being used for HCV treatment as a combination treatment of sofosbuvir with other agents, though cost was initially a major limiting factor in availability of treatment. This improved further the cure rates without the need for additional use of interferon. These drugs are administered in the form of oral tablets given for 8-12 weeks, are highly tolerable, and are still the safest and most effective medicines for treating hepatitis C, clearing the infection in more than 90% of people.[15,16] Drug combinations used include sofosbuvir and ledipasvir (Harvoni), velpatasvir and sofosbuvir (Epclusa), amongst others.

Hepatitis B virus (HBV)

Initially, the only available treatment for chronic HBV infection was interferon therapy, which was an injectable medication with a high side effect profile. However, in 1998, oral lamivudine became available for treating chronic HBV. Over the next decade other antiviral drugs, including tenofovir and entecavir, which are safer, more effective, and with a lower risk of developing resistance, were introduced. A vaccine against chronic hepatitis B has been available since the 1980s but there is no cure for chronic HBV. See Expert Report to the Infected Blood Inquiry: Hepatitis.[15]

3.3.2.2 Changes in financial assistance

Prior to 1988, there was no special provision of financial assistance for people infected due to NHS-supplied blood products who therefore had to rely on the means-tested welfare benefits system. This provided financial assistance on an ad hoc basis for specific needs, including unemployment, housing, and child benefit.

The system of special financial assistance for those infected by NHS blood and blood products began in 1988 when a charity (The Macfarlane Trust) was set up and funded by the Department of Health. This charity initially provided lump sum and ongoing financial support to people with haemophilia who contracted HIV, as well as additional discretionary payments to those judged to be in special need. Changes to both eligibility and levels of payment occurred over time, often in response to public campaigns that were sometimes followed by inquiries, including the Archer Inquiry (2009),[3] the Penrose Inquiry (2015),[7] and an inquiry conducted by the All-Party Parliamentary Group (2015).[8]

Key early changes in financial provision were the extension in 1993 of non-discretionary lump sum and monthly payments to people with HIV infected through transfusions. The first payments to people with HCV did not begin until 2004, with those who had chronic HCV (stage 1) entitled to a lump sum payment but no ongoing monthly payments, and those with advanced liver disease (stage 2) who received both an increased lump sum payment and ongoing monthly payments. In 2011, top-up discretionary payments were also extended to people with HCV stage 1, to address particular needs arising from a lack of automatic entitlement to ongoing payments. These payments mainly involved one-off grants to buy required items, such as replacing a bed or washing machine, assistance with school uniforms, or vouchers for specific shops, as well as necessary renovations to property and holidays, with each charity having discretion in both the eligibility criteria employed and the amount of support they gave.

The system for provision of financial support developed in an ad hoc manner and by 2015 comprised five organisations, known collectively as the 'Alliance House Organisations' (AHOs), which received funding from the Department of Health. These comprised two private companies providing non-discretionary payments guided by the Department of Health, namely MFET Ltd (for HIV) and Skipton Fund (for HCV), together with three charities that awarded discretionary, and often means-tested, payments and developed their own guidance. These were the Macfarlane Trust (for people with haemophilia and HIV), the Eileen Trust (for people infected with HIV through transfusions), and the Caxton Foundation (for those infected with HCV).

Table 13 (Section 4.3.3) shows the level of non-discretionary payments (lump sum and monthly payments) up to 2016 for both HIV and HCV. However, the report by the All-Party Parliamentary Group (APPG) in 2015 identified many shortcomings of this system.[8] Problems

identified included the low take-up among the HCV-infected community. This reflected both low awareness of the financial support available and a particular difficulty in proving entitlement through providing what was deemed sufficient evidence of being infected with HCV through NHS blood or blood products during a defined period (prior to 1st September 1991), as medical notes were often missing or incomplete. There was also considerable criticism of what was regarded as unfair differences in eligibility and levels of payments between HIV and HCV.

A particular criticism of the operation of the discretionary schemes run by charities also related to issues of equity, due to the different needs catered for by individual charities and their varying discretionary criteria and levels of payment. The provision of one-off discretionary payments in response to particular needs was also regarded as involving processes that were complex, confusing, and time-consuming, which made it difficult for people to get help in a timely way when needed. Furthermore, many potential applicants lacked knowledge of the provision available and of their own eligibility for these discretionary payments.

More fundamentally, the APPG questioned the underlying aim of financial assistance as being to ensure that individuals infected with NHS-supplied contaminated blood were brought to a level just over the poverty line, rather than the aim of enabling people to live comfortably, and without the need to use partners' earnings to keep beneficiaries out of poverty. It was also recognised that the AHOs themselves experienced financial difficulties arising from the increasing number of beneficiaries that were not reflected in changes to the size of their grant, thus leading to cuts in the support provided.

Following the APPG report a major reform of the system was undertaken. This involved replacing the AHOs in 2017 by new schemes for each of the four nations of the UK. Subsequently, changes have been made in the four national schemes in a rather piecemeal fashion with the aim of achieving greater parity in payment levels and eligibility between the four nations. Greater parity was achieved by 2022, although some remaining variations continue to be of concern.

Both the increased levels of payment and greater eligibility from 2017, together with the uplifts in 2019 and 2021, ensured that witnesses were able to live more comfortably after years of financial uncertainty and hardships, with similar levels of annual payments for people with HCV who experienced substantial impacts on their ability to go about routine daily activities (stage 2) or with advanced HCV (stage 3) as for HIV, with higher levels for HIV/HCV and increased payments for bereaved partners (see **Table 14** Section 4.3.4 and further details in the Francis Report).[83]

3.3.2.3 Changes in stigma

A further key influence on an individual's general experience of a chronic health condition is whether their condition is viewed by the wider society as a 'normal' and thus a socially acceptable illness, such as current views of heart conditions, or if it is viewed as an illness that marks the individual as unacceptably different and inferior and is thus invested with a 'social stigma'. This was described by Goffman as an attribute that is viewed as deeply discrediting and reduces the bearer '*from a whole and usual person to a tainted, discounted one*'[17]

People who possess a stigmatised medical condition generally experience what Goffman termed 'felt stigma'.[17] This occurs through individuals' own awareness that their condition carries a social stigma, which leads to feelings of shame with negative impacts on their self-identity. Felt stigma is also often accompanied by fears of 'enacted stigma.'[17] This describes the negative responses that may be experienced by the stigma bearer and often involves

various forms of avoidance and exclusion, or in some cases direct verbal or physical abuse. Moreover, those closely associated with a stigma bearer, such as family members and close friends, may themselves receive what is termed a 'courtesy stigma' through this association.[17]

The social stigma associated with particular medical conditions often arises from fears of contagion, together with notions of personal responsibility and blame, reflecting the assumed links between the condition and behaviours that depart from societal norms in negative ways, such as being associated with some sexual practices or injecting drug use. The conditions that carry a stigma and the level of stigmatisation may therefore vary over time and between societies and social groups, reflecting the levels of fear invoked and prevailing norms and values. This is illustrated by the initial development of HIV as a stigmatised condition in the UK in the 1970s and 1980s, which was strongly influenced by fears about the epidemic spread of a disease for which there was no effective treatment. This led to perceptions of HIV as more highly contagious than medically warranted and associated with considerable fear of contagion.[5] These community fears were also further increased by the widespread public health campaigns that aimed to reduce the transmission of HIV from the infected to the non-infected population. These campaigns were hard-hitting and led to HIV/AIDS understood (incorrectly) by the public as a 'big killer' that could be 'caught' through normal social interaction with an infected person, such as by shaking hands or coughing, with everyone therefore potentially at risk.[18,22] The initially high prevalence of HIV and HCV among other groups regarded as deviating from prevailing social norms, particularly homosexuals, sex workers, and injecting drug users who were themselves stigmatised, formed a further layer of stigma, leading to risks of HIV and HCV having a double stigma, which in turn increased negative responses and the felt and enacted stigma experienced by stigma bearers.[18]

Whereas the stigma literature traditionally focused on the perceptions and negative social responses to stigma bearers by family, friends, neighbours, and others in the local community, more recently there has been greater emphasis on the ways in which stigma may extend beyond individual responses and involve structural discrimination.[19] For example, prevailing stereotypes of a disease, particularly in terms of risks of contagion, may inform institutional policies and practices that in turn lead to the differential and discriminatory treatment of people with a stigmatised condition. An example is through employing excessively strict practices to control contagion that are not warranted in medical terms and often had a negative effect of reinforcing the stigma bearer's negative self-image.[20,21]

Since the peak of the AIDS epidemic, there has been a lessening of both community and institutional stigma surrounding HIV and HCV, largely reflecting the increased availability and effectiveness of treatments that reduced public fears. However, despite some positive changes, witnesses often described still being affected by the profound impacts of the situations they experienced earlier in their lives, as well as some continued stigma.[22]

3.4 Experiences of infected individuals and family members

This section examines the medical, financial, social, and psychological impacts of being treated with contaminated blood and blood products for individuals and families based on samples of witness statements from each of the three main routes of transmission. It focuses initially on people with bleeding disorders who were infected through receiving a contaminated factor concentrate. This first considers the experiences of people with haemophilia A who contracted HIV/HCV co-infection and then focuses on a group with one of three inherited bleeding disorders (haemophilia A or B and Von Willebrand disease) who were infected with HCV as a mono-condition (i.e. without HIV).

3.4.1 Haemophilia A and experiences of HIV/HCV co-infection

Analysis of the experiences of people with haemophilia infected with HIV/HCV co-infection was based on 15 randomly selected cases of haemophilia A, which is a bleeding disorder associated with a lack or low level of clotting factor 8. These witness statements all refer to men with haemophilia infected with HIV/HCV, as males inherit the haemophilia gene on their X chromosome, whereas females are generally protected by having two X chromosomes. Females therefore only inherit haemophilia A in rare cases and are thus mainly carriers of the condition. The witness statements were usually made by the infected person, with just three statements by a partner or parent in cases where the infected person had died.

3.4.1.1 Parents' knowledge and views of Factor 8 concentrate

Haemophilia is generally diagnosed before a child is one year old. The recommended practice was to treat bleeds among very young children with cryoprecipitate. This was due to cryoprecipitate being less risky than Factor 8 concentrate as it was produced in the UK from non-commercial blood donations from either an individual donor or a small pool (usually of around 10 individual donations). However, children were often transferred to Factor 8 concentrate when still very young.

Witness statements indicated that most parents were not informed of the risks of contaminated supplies of Factor 8, and therefore generally welcomed this new treatment which was regarded as having several advantages. One was the belief that the injection of Factor 8 concentrate would be less painful for their child as a smaller volume was necessary. Factor 8 concentrate was also regarded as convenient, as it was freeze-dried in a small volume and easily reconstituted and administered when required, whereas treatment with cryoprecipitate often required going to the hospital. As a father stated (W1805) *'I was happy with this arrangement because it meant we no longer had to wait at hospital for him to receive painful injections*.' The greater convenience of Factor 8 concentrate is illustrated by parents who described days when they took one son to the hospital because of a bleed and sometimes returned the next day as another son had a bleed. Some children also went through a stage of having many bleeds each week, as illustrated by a witness (W0008) who was diagnosed with severe haemophilia A age five months. He initially experienced 3 to 5 bleeds a week and had to go to the children's hospital for treatment. However, by 1986 he began home treatment with Factor 8 concentrate which was initially administered by his mother but by the age of 7 years old, he injected himself.

Self-blame by parents for their child's accidents and ill health is common;[23] and was described by some parents who felt guilty about administering the factor concentrate and thus unknowingly infecting their son. For example, a son (W0008) explained that his mother '*..had been told that Factor 8 was clean and safe to use and that with this knowledge and the fact that I would sometimes be screaming in pain, my parents did not have a choice but to allow the Factor 8 to be administered to me*.' He stated that his parents felt destroyed by hearing he was HIV positive and his mother still *'feels heavily responsible for the fact that she was plumbing me with this product. It's likely that she's injected it into me thinking it was safe*.' Another son (W1139) described his father as blaming himself for the infection as he put his trust in doctors when Factor 8 was recommended and did not look into the risks himself, whereas he thought that if he had been better educated his son may not have been infected. The son observed that although his father was not to blame, he *'has never forgiven himself*.' Emotional distress is common in these situations,[24] with parents' feelings of self-blame and associated distress reflecting basic notions of parents' responsibility to protect and support

their children and ensure they do not come to harm. However, in this situation harm arose from parents following medical procedures in the belief that this was in the best interests of their child.

3.4.1.2 Diagnosis and communication

Parents were sometimes informed that their son was HIV positive fairly soon after the diagnosis, but in many cases, there was a considerable delay in communicating with parents. When informed, most parents did not tell their son until he was older, in order to both protect their child from this distressing medical situation, and to ensure information about the viruses was not communicated to others who might then treat their child badly. For example, a witness (W0008) described his parents knowing he had HIV when he was 6 years old and subsequently that he also had HCV and HBV, but they only gradually told him when he was 14-16 years old. Similarly, the parents of a witness (W0125) were told in 1985 that their son, aged 5 years, had tested HIV positive and would be lucky to see his 10th birthday. However, they only told their son when he was 12 years old. He described then feeling totally devastated about being HIV positive and sometimes cried himself to sleep thinking he was going to die.

Children were occasionally initially told of their viruses by hospital staff who also often informed them of their limited expectation of life. For example, a witness (W1139) stated that he believes his mother was informed that he was HIV positive when he was 9 years old. However, he was not made aware of this until aged 13, when a doctor spoke to him about the infection and told him that he had a life expectancy of 4-5 years. His witness statement described how very difficult it was to hear this extremely shocking information and he doesn't believe he fully absorbed it until later, when he then suffered severe depression. He was subsequently told by his mother when he was 15/16 years old that he was also HCV positive, but he is unsure when this diagnosis was made. Another witness (W1591) described first receiving Factor 8 aged 14 years when having major surgery for a fused knee joint due to internal bleeds and spent 6 weeks in hospital. A doctor told him following the surgery that he was HIV positive, and '*I might live another 3-5 years*,' although at the time his parents had not been told of his diagnosis or expected life span. At the age of 22, he was told by medical staff that he was also HCV positive, but believed that he had contracted HCV much earlier. When he asked staff about the effects on his liver he described the response as, '…*you don't need to worry about that because you'll be dead from AIDS long before that (HCV) can affect your liver*.'

In contrast with the early experiences of witnesses born in the 1980s, those born in the 1960s were not usually diagnosed as HIV positive until early adulthood. This is illustrated by a witness (W1291) who was born in 1960 with severe haemophilia A, which was treated with cryoprecipitate for many years prior to being given Factor 8 concentrate. However, in 1985 at the age of 25, a consultant told him that he had HIV. He then met with the consultant three years later when he was informed that his HIV would be fatal. He described asking what could be done, and the consultant responded with just one word, '*nothing*'. When he asked when he might die, he described being told '*it would likely be within two years. There is no cure and no treatment… I was then dismissed, and he shut the door behind me*.' This extremely blunt approach occurred at a time when the diagnosis of HIV was associated with a very bleak future due both to the lack of any treatment for HIV prior to the development of zidovudine (AZT) in 1987, and the considerable public awareness and fear surrounding the large numbers of HIV deaths. As a witness (W1005) observed, it was widely known that '*infected people were dying a few years after diagnosis [of HIV], and dying a horrible, painful and scary death. This [situation], I gleaned from sensational media coverage and government leaflets*'.

3.4.1.3 Impacts of diagnosis on parents and siblings

Parents' immediate response to being told their child had HIV was naturally one of terrible shock, fear, and anxiety, together with worries about the future. Most felt they were just left to cope alone, with no professional support, or any information about how to manage the condition, including how to avoid risks of infecting others in the household and how to deal with handling blood, bodily fluids, and washing clothes. It was also difficult for families to access this information themselves, especially prior to widespread personal access to the internet.

The chronic illness of a family member is known to have major impacts on the functioning of the family and on individual family members.[25] This situation was described by a number of witnesses. For example, a son (W1139) observed that when he was diagnosed with HIV at 9 years old '*the atmosphere at home changed and everyone became on edge…..my parents spent a great deal of time worrying…..There was a strain put on my parents' relationship and as a child I blamed myself for the breakdown of their marriage*.' He also described his parents panicking over bleeding events and the fear of infecting others in the house.

Similarly, another son (W1006) explained that when he was seven years old his parents were told he had HIV and that he would only live for a couple more years. As a result: '*a happy household filled with laughter and dance suddenly became quiet and pensive….The impact of this news changed all of our lives forever*.' Both he and his sister were affected by these changes, with his sister becoming what he described as, '*quite introverted, as she felt neglected, as most of the attention from our parents would have been directed to me*.' This forms a common experience of the well-child with a chronically ill sibling, as parents often have difficulty in attending to the needs of both children and worry and feel strained about the situation.[26] As a result, the healthy child may experience more cognitive and emotional problems than their peers.[27]

3.4.1.4 Nature and experiences of stigma

Families' worries about their child having HIV reflected not only the medical impacts of the disease but also their awareness of the social and psychological impacts of having a 'stigmatised' condition that marks the individual as unacceptably different and inferior, and which may lead to experiences of enacted stigma.[17,28,29]

Witnesses were well aware of the negative public beliefs and attitudes surrounding HIV. As the partner of a witness (W0047) observed, '*We felt there was very much a stigma about HIV. However it was contracted. This included adverse publicity and poor taste jokes within the community. It felt like we had the plague*.' Such negative public beliefs often led to their experience of felt stigma in terms of feelings of shame and fears of enacted stigma.[17] They also described various instances of enacted stigma, in terms of people no longer talking with them or inviting them or family members into their homes, and they were sometimes subjected to taunts and verbal and physical abuse. An example of public abuse was given by a witness (W1591) whose mother was asked directly by the school if her son had HIV. As a result of this disclosure, her son was asked over and over again by other pupils if he had AIDS yet. He stated that as a result, '*Many days during the final year I dreaded going to school not knowing what I was going to face whilst being terrified I might even die there*' He, therefore, left school early, aged 15. In a few cases enacted stigma involved more direct physical actions such as people's homes being vandalised, which led a few families to move their homes and child's school to another area.

The felt and enacted community stigma described by people with HIV/HCV co-infection was mainly linked to HIV rather than HCV. This may have been influenced by the greater public awareness of HIV as this formed the focus of public campaigns in the late 1980s and early 1990s, when as a witness (W1291) explained, '*HIV/AIDS was all over the media and the papers, [including] Government 'tombstone' advert on billboards – you could not escape it*.' Witness W1122 also observed that the media connection between haemophilia and HIV meant that '*people… started putting two and two together and assumed that I had AIDS*.' In contrast, there appeared to be much less discussion or social awareness about HCV. For example, a witness (W1162) whose husband was diagnosed as HIV positive in 1985 and HCV positive in mid-1986 explained, '*We were more concerned about the HIV rather than the Hep C at the time due to the lack of information about Hep C*.' HIV also presented a more immediate medical threat, especially prior to the first available treatment for HIV in 1987, as people were often aware of others dying of AIDS. Some witnesses had also been told by medical professionals that HIV would kill them long before HCV had severely damaging effects. Nevertheless, the felt stigma associated with HIV may have been increased through the presence of HCV, with this and haemophilia both contributing to the level of stigma experienced. This is supported by a study of HIV/HCV co-infected patients, which indicated that for most people the stigmas associated with different conditions were hierarchically ordered, with HIV mainly regarded as more stigmatised than HCV. Although, a small number of patients perceived HIV and HCV as being equally stigmatising.[18]

A common response by families was to put considerable effort into keeping the stigmatised condition private, as a 'family secret,' that no one outside the immediate family was told, or only one or two selected people. This strategy of concealment and secrecy is widely practiced in relation to a range of stigmatised conditions that are not immediately obvious or otherwise known about, including some instances of mental illness, alcohol-related disorders, and drug abuse, with the aim of avoiding public shame and 'enacted stigma'.[30] Secrecy can however be very demanding. For example, a witness (W1297) explained that he did not tell people about having HIV as he was worried about the stigma and he also did not tell people about haemophilia as this was commonly connected with HIV. He described himself as, '*very good at hiding things and feel as though I have been living a double life*,' explaining that he always had to be on his guard and monitor what he says. Other negative effects of this strategy is that it usually leads to having few social contacts and feelings of social isolation, together with few opportunities for social support.[31] These negative impacts often affected not only the infected person but also their partner and children. For example, a father (W1122) described his daughter experiencing adverse effects of secrecy and going without lunch at school because she was too worried to accept free school meals in case anyone asked why she had free school meals. This was because she was aware of only being entitled to this because of her father's HIV diagnosis and ill health.

Although secrecy was a common strategy to reduce community stigma, there was an expectation of disclosure when using dental services. Such disclosure often led to problems accessing services due to fears surrounding HIV and HCV. For example, a witness (W1162) described her husband going to a local dentist in 1985 and out of courtesy telling the dentist he was HIV positive. As a result, the dentist did not want the family to continue to be registered with his surgery and although his wife told the dentist that she did not have HIV, he still refused to treat her. Similarly, other dentists explained they could not treat a patient with HIV or at risk of vCJD due to the risks of pricking themselves. This resulted in what was described by a witness (W1291) as being '*passed like a parcel from dental service to dental service and none of them want the music to stop. It's horrible*.' Witnesses therefore often attended hospital dental clinics which they described as engaging in institutional practices and precautions that were much greater than medically warranted and made patients feel

they were being treated like a 'leper' or an 'outcast'. For example, a witness (W1212) who was diagnosed with HIV in 1985, described the early years of going to the dentist as being like going into a quarantine room, and explained, '*The dentist and nurse would be dressed in barrier clothing and the chair etc. would be covered in plastic. ... But it is not like that now.*'

3.4.1.5 Experience of treatments

The severe side effects of the early treatments available for HIV and HCV are well documented (**Box 1**) and were often described by witnesses. For example, a man with HIV (W1122) who was treated with AZT stated, '*Over the years I have suffered from numerous serious health problems due to both my HIV and the medication that I have had to endure.*' He described the side effects of AZT as '*terrible*', and had led to his having peripheral neuropathy, feeling extremely sick, and experiencing terrible nightmares. Another witness (W0008) described being prescribed AZT in 1997 when aged 17 years, but he came off the treatment in 2000 because of '*the side effects of taking the HIV pills being so unbearable*', although he later went back to taking AZT to be less of a risk to his girlfriend.

Early treatments with interferon and ribavirin for HCV also led to considerable physical and mental suffering, with these treatments often described as '*unbearable*' and '*absolutely horrendous*.' For example, a witness (W0125) regarded undergoing this treatment as '*like the worst flu I have ever had multiplied by ten.*' Another witness (W1006) prescribed interferon and ribavirin for 12 months described this as '*one of the hardest treatment regimes I have ever had to complete.*' He explained that the effect of the drugs was that '*they changed me on a mental and physical level; gave me severe depression; incited rage and made me extremely weak; and anaemic. Needless to say, I was a very unpleasant person to be around.*' Such feelings were widely reported by witnesses. It is now recognised that interferon and ribavirin produce not only physical side effects but also neuropsychiatric effects that can be short or long-term, including effects on mood, depression, delirium, anger, and anxiety.[32]

Newer treatments, including HAART (Highly Active Antiretroviral Therapy) for HIV and DAA's (Direct Acting Antiretroviral Therapy) for HCV, were both more effective and had fewer side effects compared with the older drugs (**Box 1**). However, the availability of these newer drugs often developed slowly following the date of first licensing, particularly for HCV, and often reflected limited funding for these treatments. Some people gained access to new treatments through participating in a drug trial facilitated by their hospital specialist or general practitioner (GP), while those treated in a specialist unit sometimes had greater access. Doctors are also known to vary in the speed of adoption of new drugs, with the most powerful predictors of early adopters identified as doctors' strong scientific commitment, high prescribing volume in total or within the therapeutic class of the new drug, high exposure to marketing, and intense communication with colleagues.[33]

3.4.1.6 Impacts on education and early post-school

This group of witness statements described difficulties in gaining and/or retaining employment, with problems for younger people infected with HIV often beginning with schooling. Children with haemophilia who were infected with HIV often missed a large amount of schooling due to bleeds and infections contracted as a result of a weakened immune system. In addition, children diagnosed as HIV positive who were aware of having a short expectation of life often described losing interest and motivation in catching up with missed work and succeeding at school, regarding this as pointless in their situation. An example is a witness (W1139) who had aspired to be the first family member to go to university and pursue a career, but was told aged 13 years that he had HIV and had only 4 to 5 years to live. This led to what he described as his '*conscious decision that I would do exactly what I wanted from then*

on. I left school, even though I had worked really hard to get into one of the best schools in London.' Similarly, a father (W1805) described his son as leaving school at 15 years because, '*Suddenly, an education meant little to him. His whole life plan was destroyed.*' Sadly, his son died aged 21 years.

The early post-school period was also often described as a time of considerable anxiety, with the feeling of a lack of direction due to fears of dying and an awareness that they would be unlikely to fulfill the normal expectations of their peers. This is illustrated by a witness (W0009) who left school at 16 years and described experiencing '*a period that was a bleak time for me, as I struggled with my infections and I never felt like I could be completely open and transparent with other people.*' Although he went back to college, he was not able to finish the course due to his ill health.

Another major worry for young people was their difficulty in forming long-term relationships due to their HIV status. For example, a witness (W0008) described having a mental breakdown at age 17 because of the implications of meeting a girl. He stated that '*My brain couldn't deal with it because I'd built so many mental walls to protect everybody else…..your body just wants to interact normally, but your brain tells you that you're dangerous.*' However, he married his first girlfriend when he was 25 years old. A devastating situation described by other witnesses was rejection by a potential partner who was not able to live with the knowledge of their HIV and possible early death. A number of people described experiencing severe depression and withdrawal during the early post-school period as a result of their situation, and occasionally resorted to alcohol abuse and illegal drug use as a way of coping. For example, a witness (W1005) explained how he began to seek ways of escaping from the mental torment of knowing he had HIV/HCV and could not experience life without these viruses. This led to him initially taking opiate painkillers that had been prescribed to relax him and he then progressed to illegal drugs. Similarly, another witness (W1139) resorted to drug taking in his late teens, which was fuelled by waiting to die from HIV/AIDS and feeling depressed.

3.4.1.7 Impacts on employment

Some people who suffered particular problems during school and in the early post-school period were never able to gain employment, which led to severe financial difficulties. They usually continued to live at home and felt considerable regret that they could not advance in life in the same way as their peers. Other people gained employment, although not necessarily in their preferred job. However, working lives were often cut short due to deterioration in health as the HIV/HCV progressed. This initially led to reducing hours of work, later followed by having to leave employment altogether. For example, a witness (W1291) who retrained as a teacher felt compelled to give up his job after a fairly short period because his pain levels did not allow him to concentrate for long enough to teach. People with small businesses such as courier services, carpentry, or decorating companies, were also often at particular risk of having to close the business as a result of periods of ill health, whereas people employed by large organisations were often more fortunate and were sometimes able to continue in employment while also taking lengthy periods off to cope with the demands of treatment.

A further influence on individuals' ability to obtain or retain a job were the social impacts of their condition in terms of stigma and discrimination. For example, a witness (W1005) described being first forced by discrimination to leave a successful career and then to give up a second career due to ill health. As a result, he had not been employed since the age of 35.

Other ways in which stigma and discrimination often affected employment and career progression were through not feeling able to undergo the health checks required to be employed by a new organisation, thus reducing job opportunities and career progression.

Several witnesses also described difficulties in going abroad for meetings, particularly visiting the US, as they were first required to obtain a special visa and on arrival were taken into a special room to be questioned, which a witness (W0125) described as '*degrading and made you feel like a criminal*.'

3.4.1.8 Financial impacts and assistance

Never being employed, or having to give up employment at a young age, led to considerable financial difficulties, particularly in the early years when the main form of assistance was state benefits for disability and lack of fitness to work. Witnesses described claiming state benefits as difficult, humiliating, and time-consuming, and often involved undergoing regular reviews that were surrounded by uncertainty regarding possible changes in benefits. This situation is illustrated by a witness (W1005) born in 1955 who had not been employed since 1991. He described encountering '*the nightmare which is claiming DWP (Department of Work and Pensions) benefits*' for which he had to provide multiple letters at regular intervals, underwent several DWP visits to his home, and had benefits stopped or lowered on many occasions partly because HIV was considered a '*long-term treatable chronic condition*' and living with coinfection with HCV and haemophilia was not properly understood.

In recent years, most people with HIV/HCV co-infection relied at some stage on financial assistance from the AHOs which provided lump sum payments, ongoing payments, and occasional special payments for particular needs (see section 3.3.2.2.). However, prior to the increased level of payments in 2016, the witnesses described a situation of *just getting by*,' and were constantly worried about money for much of their life. Widows of an infected partner with dependent children also had particular difficulties, as for many years they were not eligible for more than a small bereavement grant and funeral allowance. However, the level of financial support and eligibility criteria improved substantially in the years following 2016 (see **Table 13** and **Table 14**).

3.4.1.9 Impacts on partners

For couples, knowledge of their partners' HIV status caused considerable worry and fear for the future and had direct and major disruptive effects on their expected plans and hopes, and expectations in terms of their careers, financial security, holidays, and leisure activities. For young childless couples, a fairly immediate concern was in relation to having children due to the potential risks of infection to the mother and unborn child. Some couples decided not to try for children; a decision usually taken with great sadness. This cautious approach sometimes continued even if their partner's HIV was virologically suppressed, due to their continuing concerns about the risk of infecting their partner. An option that was successful for some couples was to undergo a round of sperm washing provided by the NHS with the hope of having a healthy child. If the first round of treatment was not successful payment might be required for a second round. However, couples were sometimes cautious about embarking on a second round given the low chances of success, especially as an effect of HIV treatment was to reduce the sperm count.

A witness (W1291) summarised the variety of impacts his HIV had on his partner, which were common more widely, in terms of '*being at risk of being infected with HIV, my health, my breakdowns, my brother's death, the obstacles in having children and, now, financially*' (due to his having to give up work). During episodes of treatment and at later stages of illness, the partner also often provided increased care, which could impact on their other roles and responsibilities including caring for dependent children and where possible continuing with their own employment which was often an important source of family finance. A spouse might also experience missed employment opportunities, which are difficult to quantify and

measure but are illustrated by a witness (W0047) whose husband had to retire from teaching at age 57 with a reduced pension due to deterioration in his health. As a result of his need for care and support, she was not able to finish her nurse training. She later qualified as a supply teacher, but gave this up when her husband experienced the progression of his HIV. She also described feeling guilty because due to her other commitments, she was not able to offer enough support to her children when they were teenagers.

This section has described some of the overwhelming effects of co-infection with HIV/HCV among people with haemophilia A. These impacted all aspects of the lives of infected people and for some began at a very early age. The impacts also extended to close family, with parents, partners, and children deeply affected in social, psychological, and often financial terms.

3.4.2 Inherited bleeding disorders and experiences of HCV

HCV was the main infection in the UK resulting from contaminated blood products, with an estimated 1,250 cases of HIV/HCV co-infection in the UK, with a further minimum of 2,400 confirmed, and up to 5,000 cases of HCV infection (SEG Table ES2[6]). This section describes the experiences of a sample of 18 people with a bleeding disorder who were infected with HCV as a mono-infection. Subsequent sections examine the experiences of HCV and other infections among people infected through transfusions.

The three main inherited bleeding disorders treated with factor concentrates through which people were subsequently infected with HCV as a mono-infection (i.e. without HIV) were haemophilia A, haemophilia B, and Von Willebrand disease (VWD). Haemophilia A and B are two types of haemophilia which differ in terms of which factor is missing or at a low level and thus the treatment required, with Factor 8 given for haemophilia A and Factor 9 for haemophilia B. Haemophilia A is more common in the population, which is also reflected in those infected (SEG Table 2.3[6]).

Von Willebrand disease (VWD) is an inherited bleeding disorder that is characterised by a lack or low level of the Von Willebrand Factor (VWF) that binds with Factor 8 to help deliver the protein to where it is required to form a platelet plug and thus contributes to clotting. VWD is equally prevalent among men and women - affecting up to 1% of the general population. This was usually treated with factor replacement that was plasma derived and rich in both VWF and Factor 8, thus leading to increased risks of HCV and other viruses, although mild forms are now treated with a synthetic factor.

Analysis of the experience of HCV as a mono-infection by people with one of the three inherited bleeding disorders is based on 18 witness statements, of which 14 were provided by the infected person and 4 by a relative. The statements for each inherited blood condition included both mild and severe cases, although severity was not always described. Reflecting known differences, almost all with haemophilia A and B were male, whereas nearly all with VWD were female. However, the main themes in terms of experiences of HCV were very similar across these three infected blood groups and are therefore considered together.

3.4.2.1 Diagnosis and responses

Symptoms of HCV are often initially mild and non-specific, although where there is some liver inflammation and scarring this leads to cirrhosis. However, neither screening nor testing for HCV was introduced in the UK until 1991. There was therefore often a considerable lag between becoming HCV positive through administration of Factor 8 or Factor 9 clotting factors and a clinical diagnosis of HCV. Furthermore, as with witnesses' experience of HIV/

HCV, once a clinical diagnosis of HCV had been made individuals were often not informed of their positivity for several years, which may have been partly influenced by a lack of availability of treatments prior to the 1990s (**Box 1**). For example, a witness (W2554) was informed of being HCV positive in 1993 but believes he was infected in 1985 when he received factor concentrate batches originating in the US. Another witness (W1170) believed he was infected with Factor 8 in 1985 but he did not receive notification until receiving a '*matter of fact letter*' in 1995.

Witnesses observed that the length of time between being infected and being notified meant there was a risk of infecting their family members unknowingly. However, even when informed of their HCV diagnosis they received little information about the condition, including the risks to others. When aware they usually took what precautions they could, such as keeping toothbrushes and towels separate and being careful with any bleeds. For some people, risks of transmission were a continuing worry, especially if they had children. For example, a witness (W1425) described being in constant fear of transmission before his HCV cleared, including being '*worried about every small bleed*...' explaining that '*they all presented the opportunity to leave spots and smears of contaminated blood around*'. Fears of infecting others in the household could also cause strains and affect relationships. For example, a witness who was married with two children (W0481) described being constantly worried about infecting her husband and young family. This affected her personal and physical relationships as she was scared to even touch her children and anxious when it came to hugging them. Unfortunately, a witness (W1705) who was informed of his HCV in 1994 (aged 16 years) described unintentionally infecting his mother, who showed symptoms in 1996 and sadly died of HCV in 2016.

Parents described similar responses as those whose child was infected with HIV/HCV in terms of guilt and responsibility for their part in administering the factor concentrate. For example, a son diagnosed with HCV (W1057) explained, '*My parents have been crippled with guilt from having given their consent to me being treated with factor concentrates… My parents would never have consented to me being treated with concentrates had they known the true risks*'. Parents also often described being devastated by their child being infected with HCV through actions of the NHS. For example, a witness (W1425) who was given Factor 8 concentrate when 13 years old was then diagnosed with HCV as an adult. He commented that this diagnosis '*had a devastating effect on my parents. They were never able to accept how I was infected with Hepatitis C through the NHS*.

As with other groups, it was extremely difficult for parents to see their children suffer and their lives be severely affected by HCV, especially as they felt this need not have happened. For example, a mother (W0343) whose daughter was diagnosed HCV positive when she was 19 years old and started interferon treatment 5 years later, stated, '*Seeing someone so young and ambitious being infected and facing a very uncertain future, has been very difficult. It has strongly impacted on me over the years*.' She also commented that she needed to devote a lot of time to supporting her daughter during her HCV treatment, which meant that her son lacked the support he should have received. This caused some problems later on, which reflect evidence that a 'well' sibling who grows up with a chronically ill sibling is often more susceptible to behavioural and emotional problems in late adolescence.[34]

People with HCV as a mono condition (i.e without HIV) were sometimes told that they also had HBV, or were at risk of variant Creutzfeldt-Jakob disease (vCJD). However, they were again given little or no further information, and often continued to worry about these conditions and their potential impacts. For example, a witness (W1372) was told that if he had vCJD he would have about 12 months to live, and the incubation period was up to 14

years but there was no test or cure for this disease. He described this as '...*shocking to hear*', and a continuing worry. Similarly, another witness (W1057) stated, '*The idea of developing symptoms of NvCJD terrifies me and I find it difficult to speak about; the psychological impact of knowing of my exposure is overwhelming*.' He was not given any information about the nature of this condition and therefore conducted his own research and admitted that the thought of developing vCJD led him to have '*protracted depressive moods*.'

3.4.2.2 Nature and experiences of stigma

People with HCV generally described experiencing felt stigma and usually feared enacted stigma. However, there were varying views of the reasons for their feelings of stigma. Some thought it was often assumed by the public that haemophilia was linked to HIV, probably influenced by the government's public health campaigns, together with their awareness of the abuse received by people with HIV. For example, a witness (W1367) explained, '*I have felt the stigma of my infections over the years but not as much as others whose stories I have heard [i.e. people with HIV]. I knew haemophiliacs were having bricks thrown through their windows long before I had been diagnosed with Hepatitis C*.' Others were concerned that they would be thought to be a drug addict or assumed to be an alcoholic, as these conditions are associated with HCV and liver disease in the general population.

These perceptions of stigma and fears of enacted stigma meant that, like people with HIV/HCV, they aimed to maintain secrecy and rarely disclosed their HCV beyond their immediate family group. For example, a witness (W0481) explained, '*I felt that there was a significant stigma about Hepatitis C so I only told members of my close family. There are still members of my family who do not know to this day. Part of why I am uncomfortable telling people is that I know that their relationship with me would be very different afterwards*.' People often did not tell their children about the infection until they were older to protect them from enacted stigma. For example, a witness (W1425) explained, '*We felt we had to protect our sons…from suffering the anguish and fears that both me and my wife have had as a result of the stigma associated with Hepatitis C and the potential link with HIV*.' Moreover, knowing that a person had haemophilia was described as often leading to being quizzed about their HIV status.

Although people with a bleeding disorder and HCV often experienced felt stigma and described this as a considerable burden, there were few reported instances of enacted stigma in a community context, with just two witnesses describing this among the 18 cases analysed. One witness (W1705) described being bullied as a child at school and called 'AIDS boy', due to the pupils' association of haemophilia with HIV. The other was a woman (W0096) who stopped telling people she had HCV and told them she had liver problems due to fears of enacted stigma. However, she explained that this '*led people putting the stigma of me being an alcoholic, even though I did not drink alcohol*.' The relatively small number of reported cases of enacted stigma in a community context may have reflected the generally limited knowledge of HCV in the community, which reduced fears compared with HIV, together with families usually maintaining secrecy about their condition.

People with HCV feared their HCV being known about at work and risks of enacted stigma and therefore mainly kept this secret, with just occasional disclosure on a need to know basis. For example, a witness (W1367) explained, '*I couldn't tell anyone at work …. I was terrified of them finding out....I couldn't take up private medical insurance offered because I was afraid someone would find out about the diagnosis'.* The felt stigma of HCV and fears of enacted stigma thus presented challenges at work but witnesses were able to avoid enacted stigma and loss of employment.

The main form of enacted stigma experienced by people with HCV took the form of institutional stigma in the context of access to and the provision of health care. This included barriers to accessing dental care in the community which is illustrated by a witness (W0140) who was told by her dentist that he did not have the experience to cope with blood-borne viruses and so could not take her as a patient. She, therefore, had to receive her dental care at the hospital, but even there described being treated differently and always put to the end of the list as a '*dirty case*'. Other forms of differential and stigmatising treatment included deviations from normal patient care in outpatient settings that were described as having big psychological and sometimes treatment consequences for patients with HCV. This is illustrated by a witness (W1705) who described his mother experiencing significant barriers to treatment for her HCV due to stigma, recalling '*the doctors insinuated that her condition was alcohol–related*,' while another witness (W1057) described having stickers placed all over the sample '*saying ''danger of infection'' - this leaves you feeling dirty*'. He commented that there is simply no reason why any necessary warnings cannot be placed on the samples after the patient has left the room.

A further example of institutional protective practices at a hospital level that went well beyond what was medically warranted and were perceived by patients as demeaning, included the experience of what a witness (W0481) who needed a gastroscopy described as, '*a hullaballoo because the doctors did not know how to decontaminate the scope afterwards*.' This included discussing the fact that they might need to use the old scope and then destroy it. She commented that in this situation, '*I felt disgusted and alienated. I was anxious that thousands of pounds of equipment would be destroyed just because it had been down my throat*.' She also experienced the common situation of being put last on the surgeon's list for the day, so as not to put anyone else at risk.

People also frequently commented that staff at hospitals and in local dental surgeries wore full protection in their presence. For example, a witness with HCV (W2167) described staff in the 1990s as '*dressed like a spaceman to treat me because I think they thought I had HIV or something*.' This was particularly common and distressing when admitted to give birth. A witness (W0096) described this occurring in 1995 when she was given her own bathroom and a hazard sign was placed on the outside of her doors. Additionally, her bedding, cutlery, plates, etc. were put in hazard bags after use, and her newborn son's bedding, bottles, and nappies were also put in hazard bags even though he had not been tested at this point. She was also not allowed to eat with other mothers. She stated that '*I feel like I am still treated, by medical professionals, as if I still have Von Willebrand disease and Hepatitis C even though doctors told me I was cleared of it. I just feel like an outsider, like I have leprosy and I am an outcast*.'

3.4.2.3 Experiences of treatment

Most people with HCV as a mono-condition were, like those with HIV/HCV, treated initially with interferon alone or with interferon and ribavirin, and reported a similar pattern of severe psychological effects during treatment. This included experiencing deep depression, and sometimes what was referred to as a complete change of personality, characterised by mood swings, anger, and a short temper, with some adverse effects often continuing long after the treatment had ended, even if their HCV had cleared. An example is a witness with VWD (W1168) whose HCV cleared, but she continued to experience constant fatigue, struggled with depression, and had short and long-term memory issues. As a result, she stated, '*If I had known what I know now I would have opted to wait for a new treatment with fewer side effects*.' Similarly, a witness (W2168) who was treated with interferon and ribavirin for 6 months described this treatment as '*hell on earth*' and felt depressed and suicidal. The

HCV was successfully cleared but his liver is becoming cirrhotic, and he continues to suffer chronic fatigue and general ill health. As a result, he is '*...always lying down and unwell. I have often vomited a lot*.'

Some people received newer, more effective treatments a few years later if they required a second round of treatment. For example, a witness (W1367) who was diagnosed with HCV in 1995, aged 27 years had an initial course of treatment with interferon as monotherapy but this was stopped after 6 months as it was not working. In 2003, he then started a course of pegylated interferon. This lasted for 48 weeks and again gave him very bad side effects, including general aches and pains, flu-like symptoms, wild mood swings, as well as '*horrendous*' depression, and feeling suicidal during the last six months of treatment. He described these mental and physical effects as decreasing after completing the treatment but they did not stop. He observed that he did not feel like the same person after treatment, '*I am a different man*.' Unfortunately, a couple of months after finishing the treatment the virus came back. In 2018 he started a clinical trial of a new drug (Zepatier) and began to feel better within a week of taking the treatment and was hoping it would clear the virus.

For some people, chronic HCV progressed to cirrhosis of the liver. This was a particular risk in the past where treatment was often limited to those who had signs of liver damage, whereas those with only mild liver disease were just monitored. The most effective treatment for decompensated cirrhosis is a transplant, which gave some people a much-improved quality of life. For others, their transplant was initially successful, but cancer of the liver was detected at the five-year check. They then usually had further treatments, occasionally including a second transplant, but for some people, this was not successful and they died of end-stage liver disease.

3.4.2.4 Psychological impacts on family members

People with HCV as a mono-infection, as with those co-infected with HIV/HCV, were very aware and concerned about the impacts of their illness on the well-being of family members. For parents of children diagnosed with HCV, this diagnosis, and fears for their future, were extremely upsetting, both at the point of diagnosis and as the child grew up. Fathers with HCV also often felt guilt and sorrow about not having the energy to go out and engage in activities with their young children like a typical parent and were concerned about the impacts of what they expected would be their own early death. For example, a father (W1057) explained that the '*lives of my children will be affected - bluntly, I will not be there to support them (in every sense of the word) for as long as I should be*.'

The various psychological impacts for families where a parent has HCV were described particularly fully by a woman (W1196) whose two daughters and mother-in-law also contributed separate witness statements. She described the problems of living with her husband when he was on treatment with interferon and ribavirin for HCV, and stated that on several occasions, things got so difficult she felt like walking out, but could not do so as she wanted to be there for him. He died from liver cancer, and she became a widow at 48 years of age. Her two daughters described the difficulties they had also experienced with their father's violent mood swings while he was on treatment with interferon and ribavirin, although prior to this treatment he was not a volatile person. As a result, one of the daughters (W2893) said they would '*walk on eggshells around him, always talking in hushed tones as we did not want to aggravate him*.' They also emphasised that when they were younger, they knew they were not a '*normal*' family but never really understood what was happening. However, they were aware they could not do normal things as a family because of hospital appointments that took two hours to travel each way, and their father was often too tired or could not be bothered to

engage in activities with them. Both daughters were badly affected after their father's death, with anxiety, stress and depression that affected their lives and careers, reflecting the known effects of the illness and loss of a parent in adolescence and early adult life.[36]

3.4.2.5 Employment

A few people recalled experiencing severe tiredness and difficulties concentrating on schoolwork and now think this was linked to an early stage of their HCV. However, despite these difficulties, all people in this sample with HCV as a mono-condition were employed at some stage, although not necessarily in their preferred job due to HCV, such as intensive care nursing or food manufacturing. Their employment had similar medical constraints to those with HIV/HCV, as it was often interrupted by needing to take long periods of sick leave due to the side effects of HCV treatment. In comparison to their peers, some people also felt held back and overlooked for promotion as a result of needing to take a large amount of sick leave or to work flexibly, while those offered a promotion often did not feel able to take on the additional responsibilities due to the residual physical and mental effects of their treatments, including chronic fatigue, memory problems, and a limited concentration span.

Some people were not able to return to work as a result of continuing physical and mental health difficulties. This is illustrated by a witness (W0096) with VWD who contracted HCV in 1989 aged 17 years and gave up work in 1994 due to deteriorating health following a second round of treatment. At this stage her HCV virus was successfully suppressed but she no longer felt capable of performing the job due to multiple residual problems, including bowel paralysis, basal cell carcinoma, and chronic fatigue syndrome. She sadly reflected about having had a job that *'I loved and excelled in with great promotional opportunities all gone! Through no fault of my own!'*

3.4.2.6 Financial assistance

Witnesses with HCV often experienced severe financial problems after having to give up work, especially as during the early years there was no entitlement for financial assistance for people with HCV until 2004 (see section 3.3.2.2). They therefore often ran up debts and loans and suffered housing problems through being unable to pay the rent or mortgage. This put a severe strain on both the infected person and their partner who sometimes took on extra employment to pay the bills, as well as often looking after their sick partner during HCV treatments and the onset of liver disease, and sometimes caring for children.

Over time, financial assistance became available for people with HCV, with lump sum payments for people with HCV introduced in 2004 and annual payments from 2017 (see **Tables 13 and 14**). This increased financial support made a major difference to the lives of many people with HCV. For example, a witness (W1168) who was originally ineligible to receive a stage 2 payment as her liver damage was not regarded as sufficiently severe was subsequently eligible to receive £1,500 monthly through the introduction of the Special Category Mechanism (SCM). She stated that this meant she can now contribute to household bills which had given her back some level of self-worth. Similarly, a witness (W2167) who was infected with HCV was dismissed from his job on health grounds in 2013, aged 39 years, initially suffered severe financial difficulties, explaining that at one point they were feeding the children properly but both he and his wife were living on beans on toast until they were allocated a council house. However, he now receives £1,575 monthly from the updated scheme and described this as, *'an absolute weight off my shoulders and it really is keeping us afloat now. It is almost like a wage for me and we can put money aside for things if we need to now*'.

3.4.2.7 Similarities and differences in experiences: HIV/HCV and HCV as a mono-infection

This section has identified people with a bleeding disorder and either HIV/HCV or HCV as a mono-infection as having many similar experiences, including parents' worries, fears, and feelings of guilt about a child receiving contaminated blood, and the experience of severe adverse side effects of early HCV treatments which often continued after HCV cleared and could lead to needing to give up employment. For both groups, the experience of felt stigma and fears of enacted stigma also had a major impact on their lives and commonly led to the strategy of family secrecy. However, fears of enacted stigma by members of the public appeared to have been greater for those with HIV/HCV, due to HIV being a condition that invoked considerable fear in the late 1970s and early 1980s as being an untreatable and 'deadly condition', while awareness that HIV was contracted through sexual contact and injecting drug use further increased the stigma associated with this condition. In contrast, some witnesses thought there was less awareness of the nature of HCV among the general population, and it was sometimes regarded as a more 'normal' illness affecting the liver.[22] However, people with HCV as a mono-condition appeared to report more institutional stigma at a hospital level, particularly as they were more likely to be admitted for maternity care, while investigations for people with HIV may have often been undertaken in specialist HIV departments. In contrast, people with HIV appeared to have greater implications for stigmatised responses and job loss in work settings, while the working lives for both groups were often cut short due to the physical and psychological effects of the virus.

The other major difference in the experiences of those with HIV/HCV and HCV as a mono condition was that provision of financial assistance initially focused solely on people with HIV, with lump sum payments for people with HCV as a mono condition not introduced until 2004 (**Tables 13 & 14**).

3.4.3 Transmission through a single or multiple blood transfusions

Transmission through transfusions forms the largest group of people infected through blood or blood products, with almost all infected with HCV.[6] It is estimated that 26,800 people were infected with HCV through transfusions in the UK, 1970-1991 (SEG Report: Table S4), and at least 79 and possibly up to around 100 were infected with HIV (SEG Report: p33).[6] The majority were infected through a blood transfusion associated with a medical or surgical procedure, with a small number infected as a result of regular transfusions for a chronic condition. This section is based on 17 cases of whom ten were infected following a transfusion for a medical or surgical procedure and seven through regular transfusions for a chronic condition.

3.4.3.1 Single transfusion for medical or surgical procedures

This group differed in important ways from those with haemophilia or other inherited bleeding conditions. Firstly, people in the medical and surgical sample group were all adults, mainly born between 1940 and 1970, and admitted for a medical or surgical procedure. Secondly, women comprised six of the ten people and were highly represented as a result of receiving a transfusion for conditions such as menorrhagia, ectopic pregnancies, haemorrhage after birth, and surgery for breast cancer. HCV was the condition most often contracted through transfusions, and in the present sample seven contracted HCV and three contracted HIV or HIV/HCV.

3.4.3.1.1 Experiences of treatment

Like other witnesses seeking treatment for HCV, several people described being informed that their local health authority did not have funding for treatments, or gave priority to those whose HCV had already progressed to cirrhosis, thus leading to delays in treatment. Their experience of the older types of interferon based treatments for HCV were also similar to those of other transmission groups and described as extremely demanding, causing physical symptoms, including various aches, pains, and fatigue. This led to what witnesses described as a change in character, becoming short-tempered, depressed, or constantly anxious, lethargic and fearful. Most people infected with HCV cleared it, sometimes after a second round of treatment, but often experienced long-term side effects, usually including constant fatigue.

3.4.3.1.2 Employment and financial impacts

Not all women were employed prior to the effects of receiving contaminated blood. However, the virus had a significant impact financially on some households where the main earner was affected, especially for widowed or divorced women with dependent children. This was the situation of a witness (W0065) who had previously held a senior position and was very fit before having a colectomy in 1991 during which she contracted HCV. She was very worried about finances, with responsibility for a mortgage and her two daughters. As she stated, '*In a funny way my health was not the thing at the top of my list. My first thought was how do we survive if I cannot work? I was very much on my own, my only living relative to hand was my dad, who died in 2000 in the middle of all of this. My girls were 16 and 17 years old at the time of the diagnosis. I was under increased pressure as the breadwinner with a mortgage and two teenagers.*' She could not continue in her previous post after clearing HCV as she developed chronic fatigue but found it difficult to obtain new part-time work due to her prior HCV status. She was eventually fortunate to be employed part-time in an administrative role by her general practitioner. She subsequently retired due to chronic fatigue and received financial support from the AHOs. However, whereas most of those in the sample who were infected received some financial support from the AHOs, there were two cases where families struggled financially and did not report receiving this assistance.

3.4.3.1.3 Managing stigma

Parents who received infected blood or blood products were aware of the social stigma associated with HIV and HCV and often did not disclose the condition to their children straightaway to protect them, with this being of particular concern in relation to HIV. For example, a witness (W0021) who had contracted HIV following hospital admission for an ectopic pregnancy, described not telling her son until after he was married, as she was concerned that her HIV would hinder his prospects of finding a wife. When she told her children they were scared for her, as they thought she was dying. She had also not told her elderly mother or sisters because as she explained, *'the more people that know, the greater the risk of someone else finding out and I don't want it to affect my children's or grandchildren's lives, especially whilst the latter are still in school.*' A witness (W2810) who gave evidence about his late mother, described feeling terrified when first finding out about his mother having AIDS as it was a massive shock and at the time, *'[AIDS] was a big taboo and people would not shake hands or use the same toilet as people infected with HIV.*

Instances of enacted stigma by individuals in the community in this sample were rare, but several examples were given of institutional stigma in health settings. This included a witness (W0023) who told nurses of his HCV when going for routine blood tests to ensure the staff could exercise caution, but he described feeling judged and assumed to be a drug

user. Another witness (W0686) whose wife contracted HCV recalled feeling she was badly treated by a dentist who thought by treating her he would be placing his other patients at risk. Following a call to the British Dental Association, he was forced to treat her, but covered all surfaces with cling film prior to providing treatment. A witness (W2103) giving evidence about his stepmother's co-infection with HIV and HCV also described her health centre notes as having HIV written two inches high in bright red letters on the front cover. Although she demanded this was removed, the large red letters were still evident the next time she went in. She also experienced the common practice of people infected always having the last appointment of the day at the dentist, with the room laid out like an operating theatre with everything covered in blue wrap and the dentist covered from head to toe.

3.4.3.1.4 Family and childhood experiences

Children recalled how family activities and relationships changed as a result of a parent being treated for an infection. For example, a son (W0688) and daughter (W0687) explained how they needed to fit their lives around their mother's injections for HCV and could never go away for longer than a night, because with three injections a week their mother effectively had flu every second or third day. Both parents were also exhausted and often did not get up for the day until it was dark again. They were also often late for school due to their mother's fatigue and the need to treat her photosensitive skin before going out. As a result of their mother's ill health the daughter described herself and her brother as experiencing different childhoods from other children they knew, and feels this explains why she still feels anxious at social events, which reflects the well documented impacts of parental health and family functioning on childrens' and adolescents' emotional states and behaviours that may continue long-term.[106]

In another family, the son, who gave evidence about his mother (W2103), described the terrible shock of being told that his mother had AIDS and not having anyone to talk to about it. As a result, he was unable to concentrate at school and left with few qualifications while his father struggled financially as he was told by his employer that he could not work there anymore. The son described his family as *'imploded*', falling out with each other for silly reasons and going their separate ways. He regarded this as reflecting *'the stress of dealing with what had happened, the hiding and people's reactions really caused our family to split apart. I cannot express how bad the stress of all this was*.'

3.4.3.1.5 Anxiety and guilt

Many witnesses described how their infection had caused them considerable anxiety and guilt, with a major worry being the risks of infecting family members. A witness (W0139) who was infected with HCV following a transfusion due to septicaemia, also had particular concerns as she had been an active blood donor for ten years, and was only identified as having HCV in 1991 when the government began testing donated blood for HCV. She was therefore worried about how many people she may have unknowingly infected. Anxiety and guilt also affected children, especially the feeling that they were in some way to blame if their mother was infected with a virus through giving birth to them. This has been described as 'magical' thinking and feeling that they have caused their parent's illness or death.[86]

People infected with HCV, or less commonly with HIV, through a blood transfusion following a medical or surgical procedure thus experienced similar types of medical, social and psychological impacts as those infected through blood products, although they often differed in their older age and family circumstances. Infection of a parent as a result of a transfusion often had profound consequences both in financial terms and for their children's well-being.

3.4.3.2 Transfusions for treatment of chronic conditions

This section is based on cases where people contracted infections as a result of having regular blood transfusions to treat one of three chronic conditions that affect the bone marrow in different ways - acute myeloid leukaemia (AML), beta thalassemia major (BTM), and sickle cell disease (SCD). These conditions were not common among witness statements and this analysis draws on just seven cases, with the main aim of ensuring recognition of small groups who form part of the wider community of people infected or affected by contaminated blood. All witness statements in the sample were made by a widowed partner, parent, or adult child on behalf of their deceased relative.

3.4.3.2.1 Acute myeloid leukaemia

This is a form of blood cancer where a large number of abnormal leukaemia cells (myeloid blasts) overcrowd the bone marrow and spill into the bloodstream causing a low level of normal blood cells and platelets. Treatment protocols differed in terms of the provision of chemotherapy and/or radiotherapy and might be followed by having blood irradiated for a bone marrow transplant when a transfusion was given.

3.4.3.2.1.1 Diagnosis and treatments

AML was diagnosed at ages between mid-twenties and late thirties among the cases analysed, although AML is more common at older ages. All the witness statements reviewed described having a bone marrow transplant. This involved being given a transfusion that unfortunately led to HCV or HIV/AIDS.

There was again a general problem of delayed communication of the diagnosis of an infection. For example, a witness (W0179) described how her husband was diagnosed with AML in 1989, aged 28 years, and contracted HCV in 1989. However, he was only told he had HCV about 13 years later and he died in 2009. Similarly, another witness (W0136) described her husband as having many transfusions and many infections including oral thrush. However, she only found out ten years after her husband had died that he had HIV/AIDS. As she stated, '*The shock of thinking that I could have had AIDS and passed it onto the girls was unimaginable*.' A witness (W0407), whose husband was diagnosed with AML in 1980 and had a successful transplant, also described her husband as suffering many infections including pneumonia for which he was on life support. However, his widow only found out about this diagnosis of HIV/AIDS nine years after his death. She was then tested and fortunately was clear.

Financial problems were particularly great if a diagnosis of HIV or HCV was not communicated, as infected individuals were therefore not eligible to apply to the AHOs for financial assistance. Not knowing a family member has HIV/AIDS can also put others at risk, but fortunately did not lead to others being infected in these cases.

3.4.3.2.1.2 Stigma

In the sample, those with AML were not at risk of social stigma, as neither they nor their family were aware of their being infected with HIV or HCV. However, after their partners' death they often undertook very limited disclosure. For example, a witness (W0407) when told of her husband's HIV (after his death) informed her mum, brother and sister-in-law, but decided to only tell the children of the cause of their father's death when they were adults, given her fears of her children receiving stigmatising responses if this were known. However, she later disclosed to friends and at that time felt that people's understanding of AIDS had moved on, saying there is now '*not as much prejudice, and from my experience people are sympathetic and appalled*.'

3.4.3.2.2 Beta thalassemia major (BTM) and sickle cell disease (SCD)

BTM and SCD are both genetic disorders that are identified in childhood. They are caused by errors in the genes for haemoglobin and occur among both men and women. BTM is usually diagnosed by 2 years of age and can lead to severe fatigue, delayed growth and weak bones. It is a rare condition in the UK and has mainly affected people of Mediterranean, Middle Eastern, South Asian, and South East Asian origin.[37]

SCD is usually identified by the time a child is 5 months old, although if mild it may not be evident until much later. It is the most common genetic disorder in the UK, with over 14,000 living with SCD,[87] and is particularly common in people with an African or Caribbean family background. The Inquiry undertook special efforts to reach people with SCD or their relatives, but received only two witness statements from this group. This may reflect both early deaths with a median life expectancy of 42-47 years for people with SCD;[38] as well as a possible reluctance to participate as a witness due to issues of stigma.[39,87]

Sickle cell disease leads to abnormally shaped haemoglobin cells ('sickled cells') that can become stuck and block blood vessels resulting in extremely painful sickle cell crises, sometimes lasting for several days. For example, a daughter (W4729) described her mother's sickle cell crises as involving pain, '*comparable to a hot knife being stabbed into her as well as being hit by a hammer in the same place at the same time*.' People are often admitted to hospital for severe SC crises and given morphine or other drugs to control the pain, are kept hydrated, and sometimes given antibiotics and other drugs. Blockages caused by the sickled cells can reduce oxygen in the blood and affect the bones and various organs, including the kidneys.

Routine treatment for both BTM and SCD involves blood transfusions (together with chelation therapy for BTM), with the only cure involving bone marrow and stem cell transplants.

3.4.3.2.2.1 Experiences of treatment

As with other groups, people with BTM were not aware of the risks of transfusions and were very shocked to be informed of their HCV infection and described interferon-based treatment for HCV as causing numerous mental and physical effects. For example, a witness (W1821) described her husband as having extreme and sudden violent outbursts which were out of character for him, and thought he was not given treatment with fewer side effects due to budgetary constraints. Another witness with BTM (W1876) described having different treatments for various periods over 24 years and finally received DAA drug treatment for 12 weeks at the insistence of a consultant haematologist. This was successful in suppressing her HCV, although she does not have the strength to lead a normal life.

People with SCD varied in their age at onset of sickle cell crises and in the number of sickle cell crises they experienced. A parent (W1823) of a child with SCD described how her daughter '*was in a lot of pain*' having experienced her first sickle cell crisis at five years old, after which, she was given a transfusion, although her mother described being against this. The daughter did not show any symptoms for several years, but when aged 16 years she collapsed and was identified as positive for HCV with cirrhosis of the liver. A suitable match for a transplant was identified, but she experienced recurrent sickle cell crises and unfortunately died in 2003 aged 17 years.

The other witness statement for SCD was given by a daughter (W4729) whose mother was 50 years old when diagnosed with sickle cell disease and had received regular transfusions 3-4 times a year. HBV was detected in 2013, and she died the same year, aged 76.

3.4.3.2.2.2 Stigma and family impacts

People of Greek-Cypriot heritage perceived HCV as having a '*big stigma*.' They were therefore particularly fearful about telling people. For example, a daughter with BTM and HCV (W1876) stated '*I have been scared all my life to tell people about my HCV, all throughout my life…..I have been scared to be labelled that I am contaminated. I have never told people straight away for fear they will run a mile and not give me a chance*.' She was positively surprised that when she told her close family about her BTM, they were understanding and accepted it, reflecting the considerable public acceptance of BTM in Greece and the social integration of people with beta thalassemia.[82] In contrast, her close family agreed they would not tell others about her HCV as this was perceived to carry a greater stigma.

In contrast, a mother (W1823) whose daughter had sickle cell disease and HCV focused on what she regarded as the stigmatising and stereotypical assumptions held by doctors. As she commented, '*Once it was discovered that [she] had hepatitis I felt that a stigma was attached to her by doctors. Although she was only 16, doctors immediately assumed she had contracted it sexually or through drugs and began questioning her about this, without my consent and despite her medical history of transfusions*.' This situation may have reflected cultural assumptions among doctors, with implications for doctor-patient relationships and patient care, including the prescribing of drug treatments for painful crises.[88]

3.4.4 Indirect transmission

Analysis of indirect transmission between family members was based on thirteen witness statements, six related to transmission between sexual partners, and seven to transmission from mother to child (in utero or during delivery), or from child to parent.

3.4.4.1 Transmission between sexual partners

Transmission between sexual partners involved two cases of HCV and four of HIV. In five cases the witness statements were provided by the surviving but infected partner and in one case by a daughter whose parents had both died.

3.4.4.1.1 Impacts of delayed diagnosis for couples

The diagnosis of a partner's infection with HIV or HCV came as a terrible shock, with couples generally aged in their early twenties or thirties. In the sample, the virus occurred either as a result of the male partner receiving Factor 8 for haemophilia, or through a transfusion of contaminated blood following a medical or surgical procedure that occurred many years prior to receiving a diagnosis of HCV. Delays in the initial diagnosis of these conditions resulted in the female partner being unknowingly at risk, often over several years prior to her husband's diagnosis.

An example of the situation for couples in relation to HIV is provided by the statement given by a widow (W1589) whose husband was born in 1958 with severe haemophilia and was treated with Factor 8 from the 1970s. He married in 1983, aged 26 years, and he and his partner were looking forward to a long life ahead of them and a happy future. However, a blood test in 1985 identified he was HIV positive, a condition he would have contracted earlier, and years after his death his widow discovered he had also had HCV. Although he was prescribed large doses of AZT, he went on to develop AIDS and died in 1993 aged 34 years. His wife had tested HIV positive herself in 1987. She reflected, '*The effect of contaminated blood has impacted my whole adult life. It killed my husband …. It prevented me from having a*

normal healthy life and denied me the opportunity to have children and a loving family life. It destroyed the career I loved. It has impacted on family; my mother, my brothers and sisters. They have witnessed me suffering'.

A second example of familial transmission which relates to HCV is provided by a witness (W2019) whose late husband received several blood transfusions in 1990 following an accident that led to a leg amputation and being in hospital for several months. He was not tested for HCV until 22 years later when he had a large cancerous tumour on his liver, which appeared to have been caused by transfusions of contaminated blood in 1990. He died in 2012, suffering a '*horrific death*', and his wife then tested HCV positive with the same genotype, having been at risk herself since 1990. She was treated with interferon and ribavirin which she described as '*horrendous, the worst thing I have ever experienced*,' and although the virus cleared, she was left with heart problems and other side effects. The couple were also greatly affected financially, and experienced much mental anguish and grief, but were given little formal support, while her parents also '*suffered terribly*' as a result of their daughter's situation.

Familial transmission between sexual partners thus largely arose from the delayed diagnosis of their partners' infection. The infection of both partners compounded the psychological, social, and financial suffering they experienced and often strained the couple's relationship. In the sample, most of the initially infected partners died in their thirties, with the bereaved and infected partner struggling with her own health, and with a very uncertain financial future prior to the 2016 reforms of financial provision.

3.4.4.1.2 Impacts for children

Couples where a partner was HIV positive often decided not to have children due to the risks of transmission. However, one witness was a daughter (W1455), who was born prior to her parents' diagnosis of HIV, who experienced her father's death in 1993 (aged 35 years) and her mother's death of HIV eight days later (aged 40 years). The family broke up following the parents' death, with her two half brothers going to live with their own father and the daughter lived with another relative. The daughter felt she was growing up in a house where she was not wanted and was not able to fit in. She reflected on her own experience and described children of infected parents as being neglected, with no real support provided, and overlooked by the financial support schemes. The death of a parent is traumatic for children, affecting their educational achievement and often leading to complex psychological and behavioural disorders in adult life, with increased risks of psychological stress, loneliness, fear, and worry in their lives.[89,90]

3.4.5 Parent and child transmissions

This occurred mainly through parent-child transmission but the virus also passed from the child to the mother. In both situations, there was a lack of prior awareness of the virus.

3.4.5.1 Parent to child transmission

Parent to child transmission occurred through mothers transmitting a virus to their baby in utero or through blood-to-blood contact during birth, when unaware of having a virus and thus of any risk. This is illustrated by a case where three children were infected with HIV. The mother, unknown to her, received a transfusion of contaminated blood following a haemorrhage during the birth of her first child. Subsequently, three children were born. However, they were not all tested until after the eldest of the three became unwell. Testing indicated that the mother had been infected, the three later children had contracted HIV in

utero and the father had also contracted HIV. Two children died of AIDS at ages 3 and 5 years. The parents also died. The witness (W3771) has experienced significant health impacts and said: '*HIV has had a devastating impact on the lives of my family and I. Excluding my brother I am the only one left in the family. They have all died of AIDS-related illnesses. I have had to grieve the loss of my mum, dad and two sisters and witness their grief too*'

In the case of infection with HCV and HBV the presence of a virus often only became apparent when the recipients were young adults and gave them a big shock when they found out. This sometimes happened when an adult child, often in their early 20s, experienced fatigue and other symptoms that were investigated with various tests. In other cases, testing occurred as a result of documentation of the mother's own infection that had cleared many years ago but led to her child being tested.

Mothers expressed guilt and sadness about infecting their child, although they had not been previously aware of their virus and had probably cleared any virus naturally. The infected children differed in their responses. Some managed to cope, often with the support of a partner, whereas others experienced considerable anger and for a while engaged in anti-social behaviour, which led to a severe deterioration in their relationship with their mother. For example, one mother (W0043) described her son's anger as seeming to '*eat away at him*....' and described difficulty in coping with '*the shock, trauma and disintegration of my son*.' His HCV cleared, although he did not believe it and could not be reassured that it would not come back.

3.4.5.2 Child to parent transmission

Parents' exposure to the child's virus usually occurred through their involvement in comforting and caring for a child following an accident or injury, or in the process of administering Factor 8. For example, a mother (W1788) sucked out a splinter from her young son's hand and thinks this was how she became infected with HBV. Another mother (W2590) described a situation where her daughter had a head injury and several fractures at 9 months and was given blood plasma, with her recovery described as a '*miracle*'. However, when aged 4 years she jumped off a sofa which resulted in a pen going through the skin of her head which caused considerable bleeding. Her mother kissed and cuddled her daughter who went to hospital for stitches and made a good recovery. However, six weeks after the accident both the child and mother tested positive for HBV, and both had genotype D. It was thought that the daughter must have contracted HBV from the blood plasma she was given when 4 years old and then passed on the virus to her mother.

Cases of familial transmission thus identify the ways in which people were put at risk from delays in diagnosis of a partner's or other family member's infection, as well as through blood contact in the process of caring for a sick child. These forms of interfamilial transmission often led to particular feelings of responsibility, guilt, or blame. Moreover, when both partners were infected problems of providing care and financial difficulties were compounded, as well as presenting considerable worries for a surviving but infected partner. Having two parents infected also led to particular worries, risks, and difficulties for any children, with possible long-term psychological effects.

3.5 Discussion

This report takes a unique approach in complementing the economic modelling of the costs of illness at a societal level with a qualitative analysis of witness statements. As expected, the witness statements give little statistical or economic detail regarding issues such as healthcare costs, loss of earnings, early retirement or part-time employment due to ill-health or financial assistance received. Instead, they provide detailed descriptions of the varying circumstances of those infected in terms of the different routes of transmission, viruses contracted, age and family circumstances, and describe the hardships and suffering that were common experiences for both infected individuals and affected family members.

3.5.1 Sources of suffering

High levels of suffering were experienced whatever the route of transmission or type of virus and had direct and long-lasting impacts on people's lives. Firstly, there were high levels of bodily suffering which was associated with the effects of progression of the individual's virus or viruses, together with the often very severe side effects of the treatments available in the 1980s and the 1990s and their limited effectiveness. Witnesses also often described experiencing adverse physical or mental effects even if virological suppression of the virus was achieved. Secondly, financial hardships arose from limited possibilities of employment, as a result of both the individual's physical and mental health and a lack of opportunity arising from responses to their living with a stigmatised condition. These employment problems were further compounded by the limited coverage and low level of financial assistance that existed, particularly for those with HCV and widows of an infected partner. Thirdly, considerable suffering occurred through the experience of felt stigma and fears of enacted stigma. This was a major concern early in the era of infected blood, while some stigma continues to be attached to HIV and HCV. Awareness of having a stigmatised condition generally led to attempts to keep the condition a family secret, which resulted in having limited social contacts and sources of support, together with feelings of isolation and loneliness. In addition, both infected individuals and families often suffered as a result of institutional policies and practices, particularly in relation to dental and hospital services, which had a negative effect on people's identity and feelings of self-worth.

Witnesses sometimes reflected on the overall impacts of the viruses on their lives towards the end of their personal statements, describing both the different aspects of life affected by their virus and the general disruption and demoralisation experienced through the constant presence and limiting effects of having to live with a virus. This is illustrated by the brief excerpts given below.

'*I could sit here all day and describe situations where my infections have affected my life medically, emotionally, financially and socially.*' (Witness W1005, HIV)

'*Whatever I do, wherever I try to go the viruses are coming with me! This means there is never any way to escape their effects! This is deeply demoralising as well as incapacitating! It makes you feel as if there's no point trying to do anything!*' (Witness W0008, HIV/HBV/HCV)

'*The physical and psychological effects that my infection has had on me have been devastating. It has affected virtually every decision that my family and I have made for the majority of my life.*' (Witness W1425, HBV/HCV)

'*...my life would have been so much more fulfilling if I had not been given Hepatitis C*' (Witness W0096, HCV)

Witnesses who contracted HIV at an early age had not had a chance to experience life without a virus and their reflections therefore took a slightly different form. For example, a witness who was diagnosed with HIV at 7 years old reflected, '*What would my life have been like without HIV and Hepatitis C? This is a question which has affected my mental health considerably over the years*'. (Witness W1006, HIV/HCV)

3.5.2 'Loss of self'

The profound and long-lasting suffering described by witnesses accords with what Charmaz referred to as the 'loss of self'.[35] This describes a fundamental form of suffering that occurs when a chronic illness severely disrupts individuals' lives, and leads to their former self-image and their plans and expectations for the future, crumbling away without the simultaneous development of new ones. This was clearly evident in witness statements which described with great sadness the impacts of contaminated blood or blood products both for themselves and their family and often imposed overwhelming constraints on all aspects of their lives. This began at the point of communication of the diagnosis, which Bury refers to as forming a 'critical moment' that severely changes the direction of an individual's life and often threatens their self-identity, as well as changing the lives of those close to them.[91]

This critical moment often occurred at a young age for people with haemophilia and HIV, given its early diagnosis and treatment, although in many cases parents initially experienced this critical moment rather earlier and delayed disclosing to their child to protect them. For younger people with HIV their awareness of having HIV and a limited life expectation caused a level of distress that was extremely difficult to cope with. This both affected their schooling and caused considerable distress in the early post-school years, due to recognition of what would be a shortened life and an inability to engage in the activities and opportunities enjoyed by their peer group, including beginning further training or employment and participating in sport or social activities.

For those with HCV, their diagnosis and the onset of symptoms often occurred at a later stage when they were looking forward to advancing their careers, having a family, and enjoying a pleasant home. Recognition of their own realities again caused considerable 'biographical disruption' and distress through the loss of an expected life.[91]

These personal losses and impacts on feelings of self-worth were further magnified by occurring at the time of the 'AIDS epidemic' when considerable stigma was attached to HIV and was often extended to the public's perception of HCV. These negative responses at a community level were also sometimes reinforced by institutional stigma that affected both employment opportunities and access to health services and the delivery of care. These policies and practices were in turn perceived as confirming and reinforcing the negative views of the wider society towards their condition, involving assumptions of personal blame for a condition for which they were not responsible.[91]

3.5.3 Suffering by affected individuals

Suffering is mainly described in terms of the infected individuals, but it is widely recognised that severe chronic illness also has major impacts on the lives and well-being of affected family members.[25] For example, parents suffered considerable worry, fear, and sadness about the future of a child who had received contaminated blood or blood products. They also often experienced self-blame and guilt for unknowingly infecting their child through the transmission of a virus in utero or during birth, or through administering Factor 8 or 9 in the belief that they were acting in their child's best interests. Lives were also greatly affected by a partner's diagnosis, with the well partner often having to adjust to a changed life with

new demands and responsibilities, including sharing the emotional burden of the partner's illness and treatments, coping with stigma, and often taking on new financial and caring responsibilities as their partner's virus progressed. Many witnesses also had to cope with profound grief associated with the death of a child or partner and the long term impacts on their own lives.

Children also suffered psychologically as a result of a parent's or sibling's illness and death, which increases the risk of long-term psychological and behavioural distress.[36] Evidence of suffering by children included their awareness of changes in the atmosphere at home and tensions between parents, long before they fully understood what these were. Once aware of a parents' illness they also had to cope with the burden of secrecy and worries about this being found out which could limit close social relationships. Children also often described no longer feeling part of a 'normal' family due to the ways in which an infection restricted their parents' activity, increased stress and often led to abnormal routines due to requirements of treatment. There were also reports of the well sibling feeling neglected due to the focus on the ill sibling, a situation that is well documented in the chronic disease literature.[34]

3.5.4 Needs and access to support services

Social support is identified as of great importance in increasing resilience and helping people to come to terms and cope with major disruptive events in their lives.[92] However, a common experience among witnesses and their families was a feeling of great social isolation, especially as families usually adopted a strategy of secrecy that led to avoidance of social encounters and relationships outside the household to protect against risks of enacted stigma, although such concealment also has negative aspects in leading to social isolation and the lack of informal support.[31] This was acknowledged by some witnesses who felt they had no one to talk to about their situation and to provide emotional and instrumental support. Both social isolation and lack of informal support together with the lack of professional advice and support led to a situation where witnesses and their families described being largely left to cope alone with their virus and to just '*get on with it*.' This situation often led to witnesses identifying a need for referral to counselling services and reflecting that this would have been particularly helpful at key points. These included following the initial diagnosis and communication of the virus when many would have benefitted from both emotional support and greater knowledge about how to manage the condition, including coping with risks of transmission. Secondly, coping with the serious physical and psychological effects of treatment often placed severe strains on the relationship between partners and within the family unit, and later on, bereaved families had particular needs for support following the death of their partner or child from contaminated blood or blood products.[92]

Lack of referral to formal services for support may have partly reflected the limited availability of these services at the time, together with doctors' own lack of familiarity with the impacts of the viruses and with accessing support and counselling services. However, occasionally witnesses received support from staff who did not have a counselling qualification but were glad to assist. For example, a witness with HCV who was very concerned about infecting others, especially after experiencing a friend's husband refusing to shake his hand, described feeling very fortunate to receive support from a hospital sister whom he saw once a week and explained, '*It was extra-curricular for her. I saw her every week and it was good, she helped*.' Other people grateful for non-specialist support included a witness with HIV/HCV who described being physically attacked and following this incident was given support by social workers whom he described as '*extremely helpful, they were more like counsellors*.' There were also other positive comments about ways in which individual GPs and hospital doctors

had been helpful and supportive in an informal way. However, there was a considerable felt but unmet need for more formal provision, especially given the social isolation and considerable suffering experienced by both infected and affected individuals.

3.5.5 Psychological adjustment

Psychological adjustment to illness had significant challenges for people who received contaminated blood or blood products, given the importance of the meaning of illness and its profound effects on all aspects of their lives.[40] For both those infected and affected this could require accepting profound losses, which could include the early death of a partner, child, or sibling, not having children due to potential transmission of their partner's virus and fear of passing on to an unborn child. Other common losses requiring adjustment were having to leave a job or business they enjoyed, experiencing severe financial difficulties through loss of employment, and moving from independence to dependence on others for care and financial assistance.

Accepting negative changes was especially challenging as a result of both the severe negative effects of infections on all aspects of individuals' lives, together with the knowledge that their illness occurred through NHS-supplied contaminated blood or blood products. Witnesses were therefore generally not able to 'let go', especially without formal recognition and an apology for what they had suffered through no fault of their own, which most witnesses still felt angry about. The process of adapting was however described by a couple of people in the sample, including a witness who contracted HCV through a transfusion following surgery. As a result of this, her career was over at age 42 years, and she experienced considerable financial difficulties. However, she was helped to adapt by a supportive general practitioner and talked to a counsellor about her distress and coping strategies. Despite this support, it took her a long time to let go of the hopes and dreams that she shared with her peer group, and although she tried to make the best of everything in her life, she observed that even so, '*it is hard not to grieve for what might have been*'

3.6 Conclusion

Witnesses' accounts described great suffering as a result of receiving contaminated blood or blood products. This included considerable bodily suffering from the virus and the physical and mental impacts of treatment, which in turn affected multiple areas of their own lives and the lives of others. These included impacts on the infected person's employment that caused worrying financial problems and much sadness at the loss of a satisfying career or business, as well as the loss of an expected lifestyle this would have provided. There were also lasting impacts for some couples of not having children, as well as the considerable distress caused for parents due to risks of transmission of HIV or HCV between partners or to a child. More generally, the illness of a family member impacted the whole family in terms of strains in relationships between partners, their worries and fears, and the loss of hopes and plans for the future, with children also suffering from not having a 'normal' family and sometimes feeling neglected through parents needing to give greater attention to an infected partner or sibling. Having a condition that was stigmatised also added considerably to people's suffering, and if known about could lead to enacted stigma, while the frequent strategy of concealment to avoid enacted stigma had the adverse effects of people feeling that they were 'living a lie', and further increased the families' social isolation and lack of positive support.

The experiences and level of suffering by the individuals and families were influenced not only by individuals' personal characteristics including their age, life circumstances and type of virus, but also by the broader societal context. This included the initially limited

effectiveness of drug treatments and their severe side effects, the low initial provision of financial assistance especially for those with HCV, and the existence of a high level of public and institutional stigma during the era of the AIDS epidemic and beyond. However, whereas the circumstances of witnesses' lives have greatly improved in terms of more effective drug treatments, increased financial assistance for some, and changes in social attitudes and institutional policies, witnesses described experiencing continuing emotional pain and anger, reflecting the losses they had experienced and the life they expected and might have had if they had not been treated with contaminated blood or blood products. Most witnesses were therefore unable to put away the past, especially as they felt that they had experienced a situation that should not have happened.

4. Quantitative analysis of the societal impact of infected blood and blood products

4.1 Introduction

Infected blood and blood products (IBBPs) resulted in ill-health and early deaths, but also in wide-reaching economic and social impacts for the lives of infected individuals and their families. The qualitative analysis presented in section 3 provides insights into the individual experiences of some of the infected individuals, and those close to them. In this section, we endeavour to provide an aggregate estimate of the economic and health impacts for all individuals affected in the United Kingdom. The following analyses are intended to meet the objectives of the letter of instruction to the Health Economics Expert Group (HEG) to estimate the economic costs to society of IBBPs. These analyses represent our best attempt to meet this objective given data limitations. Interpretation of the results produced by these analyses should be made with caution. The quantitative analysis needs to be read in the understanding that these estimates provide a highly aggregate picture of the economic impacts experienced in the UK as a result of IBBPs, and provide a lower estimate for the order of magnitude of these costs. It is not a complete nor nuanced picture of the full health, social, and economic cost to infected individuals and their families.

We use a cost-of-illness analysis that seeks to quantify the health and economic impacts of IBBPs. As per the letter of instruction to the HEG, the primary population of interest pertaining to analyses undertaken as part of this report are all those who were infected with blood-borne viruses through treatment provided by the NHS in the 1970s, 1980s and early 1990s. We explain the construction of the cohorts in detail in section 4.2.

We assess a broad range of economic impacts, but there are many we cannot evaluate. Most notably, we regret that economic impacts relating to economic opportunity proved very difficult to assess. These are impacts pertaining to life choices in that individuals had to choose less skilled education and occupations due to the infections, which are associated with lower incomes. There was no data on the number of infected and affected individuals who experienced such impacts, and the time period over which they occurred. The qualitative analysis in section 3 assesses these impacts to a certain extent. We estimate the impacts of IBBPs in terms of economic losses (measured in British pounds), and health losses (measured in a generic measure of health). By expressing impacts in generic metrics, we can calculate the sum total of the losses over all infected individuals. The main caveat of the cost-of-illness study is that there are limits in quantifying life experiences in numbers.

The work produced by the HEG relies heavily on two primary sources of data: first, estimates in the Expert Report to the Infected Blood Inquiry: Statistics,[6] henceforth referred to as the 'SEG report', on the number of people infected, the number of infected individuals with and without bleeding disorders, key parameters and mode of transmission (blood products or blood transfusion); second, published literature pertaining to the cost of treatment, care provision, health-related quality-of-life (HQoL), informal care provision and employment during the period of interest. In regard to the former, we are bound by the data limitations and assumptions made clear by the SEG in their report, including incomplete data sources, opaque application of clinical criteria for inclusion/exclusion within certain data sources, and

inaccurate or conflicting information from different sources, which carry through as important limitations to the HEG. In the following sections, we first explain the methods we use to assess economic impacts, and calculate losses, and then present the results of our analyses.

4.2 Modelling cohorts of infected persons

Our overall approach to the economic modelling is as follows. We consider that a certain number of infected persons have spent a part of their lives living with HCV, or HIV and HCV co-infection, with which they were infected via the use of IBBPs. Many of these persons suffered ill health and some died prematurely due to one of these infections. The periods of ill-health and premature death will be associated with certain types of cost and health losses. In order to characterise these costs, we generate a hypothetical cohort of persons infected with HCV and/or HIV via IBBPs, and compute approximations for the number of persons that experience these different types of costs and when (in calendar time) they are incurred.[6] We describe below in turn, the assumptions for the composition of the modelled cohorts, the approximation of health states, age at death, the counterfactuals for the cohorts, and the economic modelling. We then in section 4.3 explain the computation by which each type of cost is estimated (healthcare costs, cost of lost productivity, and losses of quality-adjusted life-years). Section 4.4 summarises the results and section 4.5 describes the limitations of the quantitative analysis.

4.2.1 Estimation of cohort size, composition and outcomes

From the SEG report,[6] we extracted key pieces of information on the numbers of persons directly infected with HIV and HCV and numbers of persons who died from infection (**Table 1** below) and, from these, derived assumptions for the construction of the model cohorts.

	Statistic	Value	Source
HIV	Number of persons with BDs infected with HIV through blood products in the UK (A)	1,061 – 1,338	Page 1 (Executive Summary). SEG reports that ‘around 1,250 people with bleeding disorders were infected with HIV’; lowest and highest estimate originated from different organizations as cited by SEG. UKHCDO estimate that those infected with HIV were co-infected with HCV (page 2)
	Proportion of persons with BDs infected with HIV through blood products in the UK who have since died of HIV-related causes (at any time up to end 2020) (B)	50%	Page 1 (Executive Summary); SEG reports that ‘around half have died of HIV-related causes’
	Number of persons infected with HIV through blood transfusions in the UK (C)	79 – 100	Page 3 (Executive Summary). Lowest and highest quoted estimates, with the high estimate being ‘approximate’
	Proportion of persons infected with HIV through blood transfusions in the UK who have since died of HIV-related causes (at any time up to end 2020) (D)	85%	Page 3 (Executive Summary). This may be an upper bound as it includes deaths not related to HIV, but a high case-fatality rate as this for persons infected with HIV is consistent with a priori expectations

	Statistic	Value	Source
HCV	Number of persons with BDs infected with HCV through blood products in the UK (E)	2,400 – 5,000	Page 2 (Executive Summary). Range directly quoted as a judgement by the SEG; excludes around 1,250 co-infected with HIV, however there is uncertainty around the number co-infected
	Number of persons with BDs infected with HCV through blood products in the UK who have since died of HCV-related causes (at any time up to end 2020) (F)	273 – 900	Page 2 (Executive Summary). Range of estimates reported across different sources (UKHCDO, NHD and Skipton Fund). The UKHCDO estimate reported by SEG is multiplication of the confirmed deaths (700) with the estimate of the proportion of those that are from HCV-related causes (39%). The highest estimate is the approximate figure from the Skipton Fund
	Number of persons infected with HCV through blood transfusions in the UK (G)	17,300 – 31,900	Page 4 (Executive Summary). This is the estimate of those chronically infected that survived for at least six months as we assume that persons not with chronic infection would not suffer the same pattern of ill health and require the same care as those with chronic infection
	Number of persons infected with HCV through blood transfusions in the UK who have since died of HCV-related causes (at any time up to end 2019) (H)	650 – 3,320	Page 4 (Executive Summary)

Table 1: Data extracted from the SEG report[6]

In so doing, we make the simplifying assumption that there were distinct cohorts of infected persons (see **Table 2** for cohort construction):

1. Cohort 1: Those infected with HCV only (comprising those infected through use of blood products and through blood transfusions): We denote this group, ‘HCV only’. Cohort 1 is further split into cohorts of persons with and without bleeding disorders (BDs).
2. Cohort 2: Those infected with HIV (and likely also HCV), comprising those infected through use of blood products and through blood transfusions: We denote this group, ‘HIV & HCV’. Cohort 2 is further split into cohorts of persons with and without bleeding disorders.

Because of uncertainty surrounding the number of co-infected individuals, and the UKHCDO assessment that, in the main, HIV infected individuals with bleeding disorders were co-infected with HCV,[1]* we make the simplifying assumption that all individuals infected with HIV were also infected with HCV. For such persons, we assume that costs related to HCV are only incurred for those who do not die of HIV.

Condition	Disease stages	Clinical disease stages	Representation in the Model
Cohort 1 (HCV)	Non-ESLD	Non-End-Stage Liver Disease: F0-F3 fibrosis, and compensated cirrhosis; no/mild/ moderate symptoms	Individuals infected with HCV who have more than two years to live
	ESLD	End-Stage Liver Disease: decompensated cirrhosis and primary liver cancer; severe symptoms	Individuals infected with HCV who have less than two years to live
	HCV treatment	Anti HCV drug treatment, and possible treatment for advanced stages of infection	Individuals infected with HCV twenty years before date of first treatment
	Sustained virological response	Individuals who cleared the infection with successful treatment; may have continued symptoms related to treatment and prior disease	Individuals after treatment

* Note that this follows the guidance from UKHCDO, as reported in the SEG report on page 2, Executive Summary (IBI 2022) which states that it is reasonable to assume that all of those with a bleeding disorder infected with HIV will also have been co-infected with HCV.

Condition	Disease stages		Clinical disease stages	Representation in the Model
Cohort 2 (HIV & HCV)	Early years of infection*	Asymptomatic HIV	Symptoms related to recent or acute HIV infections; minor or no symptoms	Individuals infected with HCV and HIV who have more than three years to live
		Symptomatic HIV	Pre-AIDS and early AIDS related conditions and co-infections	Individuals infected with HCV and HIV who have less than three years to live because of death from AIDS
		AIDS	Advanced Stages of AIDS	Individuals infected with HCV and HIV who die that year from AIDS
	Later years of infection for those surviving HIV infection**	Non-ESLD and asymptomatic HIV	Non-End-Stage Liver Disease and asymptomatic HIV	Individuals who survived HIV infection, and have more than two years to live
		ESLD and asymptomatic HIV	End-Stage Liver Disease and asymptomatic HIV	Individuals who survived HIV infection and who have less than two years to live because of impending death from HCV
		HCV treatment and asymptomatic HIV	Anti HCV drug treatment and asymptomatic HIV	Individuals who survived HIV infection, and were infected twenty years before date of first treatment
		Sustained virological response and asymptomatic HIV	Individuals who cleared HCV infection with successful treatment; may have continued symptoms related to treatment and prior disease, and asymptomatic HIV	Individuals who survived HIV infection, and after treatment for HCV infection

Table 2: Cohorts of infected individuals, clinical disease stages and definitions

Note: *Early years of infection are from the year of infection with HIV & HCV to the year of death from HIV infection (for the proportion who die, the time from infection to death is varied in sensitivity analyses between 8 and 20 years); **For the proportion who survive HIV infection, later years of infection are varied from year of survival (varied between 8 and 20 years after year of infection in sensitivity analyses) until death from HCV infection or other causes, or the end of projection horizon, whichever is earlier; Disease stages are assumed to be the same for people with and without BDs, however, the duration and transition probabilities differ (see **Table 3**).

In order to constitute the cohort with a range of simplified trajectories for disease progression and outcomes allowing for statistical uncertainty in these trajectories, each represented person in the modelled cohort is assigned a year of infection, age at death and a determination of whether they die of the infection, another cause, or survive to the end of 2021. The values for these parameters are taken from a wide range (as explained below), and they are assumed to follow statistical distributions that are independent of one another. While the definition of the stages of the disease trajectories are the same for people with and without bleeding disorders, most of the parameters differ.

Persons in the model cohort can also die of causes unrelated to HIV or HCV. The risk of a death from an unrelated cause is based on the age-specific all-cause mortality rate in the period 1995-1997 in the UK (per the National Life Table published by the Office for National Statistics[100]), and subjected to an inflationary factor to represent the increased risk of deaths that persons with underlying bleeding disorders, or those receiving transfusions, may have.

We have simplified disease progression for both cohorts, for the purpose of the economic analysis. We define the progression as a logical succession of steps in alternative patient trajectories, for the purpose of attaching cost estimates to specific stages. The purpose of the disease progression model is not to model the progression of specific patients through time (for further detail on the estimation of the model see section 4.3.7). For illustrations of how costs attach to simplified alternative disease progression trajectories see Figure 1 and Figure 2 for Cohort 1 (HCV) and Cohort 2 (HIV & HCV), respectively. Disease stages and events are indicated by bars and circles, respectively. The stages and events that are filled with patterns are associated with specific costs, whereas those coloured in white are not associated with costs in our models. Different fill patterns indicate the types of costs that are accrued. Arrows indicate transitions between stages. The model has individuals experiencing different trajectories or pathways of disease progression, and consequently costs. The duration of stages and some transition probabilities are assumed to be uncertain and so are represented by random variables governed by statistical distributions, see section 4.2.3. The length of the bars (indicating disease stages) are merely indicative in the figure, and do not reflect actual lengths in years. Costs accrue over each year a state persists. The disease progression models are, in principle, the same for individuals with and without bleeding disorders, however, the duration of disease stages and some transition probabilities vary, as explained in section 4.2.3. The dashed vertical line on the right indicates the end of the projection horizon (the year 2021).

4.2.1.1 Cohort 1 (HCV infected)

In Cohort 1 (HCV infected with and without bleeding disorders), many individuals with HCV infection remain symptom free or experience relatively mild symptoms for an initial stage, after which progressive liver damage may develop, described as liver fibrosis. An estimated proportion (11-12%, see appendix **Table A 1**) of persons develop cirrhosis (severe scarring of the liver). Cirrhosis is classified as compensated or decompensated. Compensated cirrhosis is where the liver is coping with the damage and maintaining its important functions. In decompensated cirrhosis, the liver is not able to perform all of its functions adequately. Of those who develop compensated cirrhosis, some will progress to decompensated cirrhosis (DC) or primary liver cancer (hepatocellular carcinoma, HCC). DC and HCC are categorised together as end-stage liver disease (ESLD). A proportion of people infected with HCV receive clearance treatments. The efficacy, side effects and costs have changed substantially over our projection horizon.

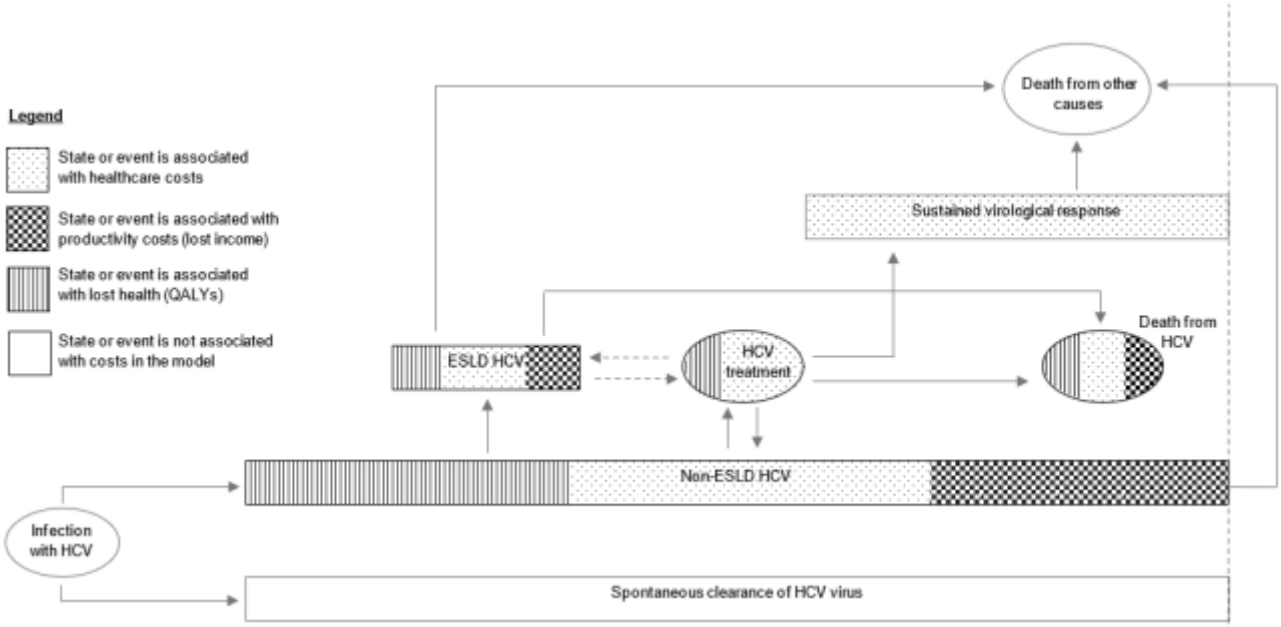

Figure 1: Economic model for Cohort 1 (HCV)

Notes: the diagram indicates how costs accrue over alternative disease progression trajectories; the bars represent states that last longer than one year, the circles events that occur in a year, and the arrows transitions between states; the pattern fills indicate one or more types of costs that are associated with a state or event; costs accrue over all years a state persists; dashed vertical line signifies end of projection horizon (2021); before 2014, HCV infected with ESLD did not receive HCV treatment, therefore the arrow is dashed.

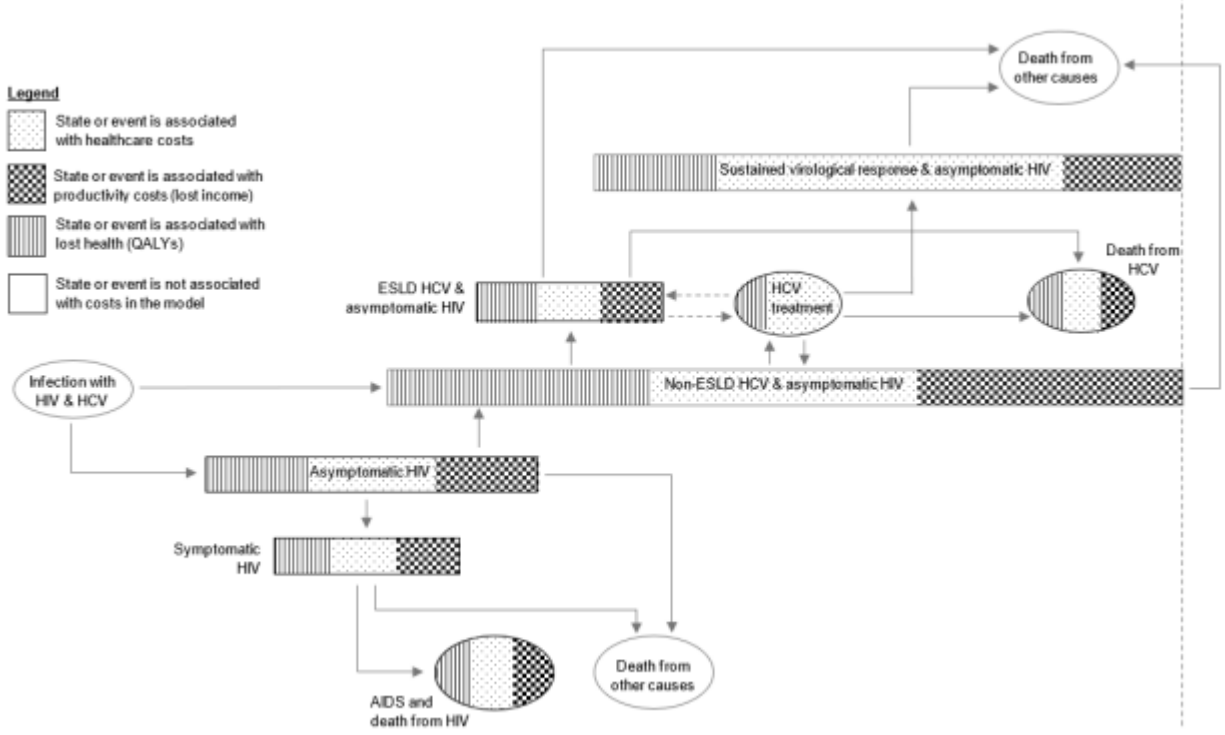

Figure 2: Economic model for Cohort 2 (HIV & HCV co-infection)

The disease progression of HCV is complicated, and the likelihood of suffering severe disease and the length of stages differs by age.[6] Unfortunately, it was not possible to obtain differentiated costs for each stage and age group. We had to simplify the disease progression trajectories for the purpose of the economic analysis, see **Figure 1**. In our model, after

infection, some individuals spontaneously clear the virus, and remain undiagnosed. They never enter Cohort 1, and do not accrue costs in our model. For those that do not clear the virus, for the purpose of this analysis, we classify the natural history of HCV infection into three disease stages: non-end-stage liver disease (non-ESLD), end-stage liver disease (ESLD), and sustained virological response (SVR). This categorisation, although a simplification of the stages of HCV infection, is an attempt to capture the stages in HCV infection where there are differential health impacts and costs.

Non-ESLD includes the stages of HCV infection where there are no symptoms, mild symptoms or moderate symptoms and F0-F4 levels[2*] of liver fibrosis, without evidence of decompensated cirrhosis. In each year lived with non-ESLD, individuals accrue healthcare costs, health losses due to morbidity and productivity losses associated with this stage. Some individuals only ever experience non-ESLD and are still alive at the end of the projection horizon or die in any year of causes unrelated to HCV infection. Some individuals with non-ESLD progress to ESLD. ESLD includes the stages of HCV infection where there is decompensated cirrhosis or primary liver cancer (hepatocellular carcinoma, HCC). Infected persons in these stages often have severe symptoms, which can include ascites, jaundice, confusion, variceal bleeding, abdominal mass and individuals are more at risk of infections.[42] Individuals accrue healthcare costs, health and productivity losses that are markedly higher than those with non-ESLD. Infected persons with ESLD have high healthcare utilisation with frequent hospital admissions, low HQoL and are usually not able to work.[43]

There is no data on what proportion of infected persons in the cohort received treatment and when – and there is likely to be heterogeneity based on factors like treatment year, region, age, comorbidities etc. Therefore, we have to make the simplifying assumption that a first course of treatment occurs 20 years after the year of infection, among those that have survived to that point. Some individuals emerge from treatment having cleared the infection, and experience SVR. A proportion of individuals with SVR do not experience further symptoms and therefore do not attract additional costs. However, some individuals with SVR continued to suffer ill-health after successful treatment, whether from prior interferon and ribavirin treatment or from irreversible liver damage from prolonged infection. We take account of continued healthcare costs for the proportion of individuals with SVR who suffer sustained adverse health impacts. They require continued monitoring and treatment which is associated with healthcare costs in each year until the end of the projection horizon, or until they die of non-infection related causes. However, we could not obtain productivity and health costs for individuals with SVR and continued symptoms. This will mean that our model underestimates the adverse health and productivity impacts for a proportion of individuals with SVR.

Individuals who do not clear the virus re-enter the disease stage they were in before they commenced treatment (i.e., either ESLD or non-ESLD). There is the possibility of repeating the treatment circle, of dying from HCV or other causes, or surviving until the end of the projection horizon. Patients may receive a second round of treatment with direct-acting antiviral (DAA) medications, either because they were treated unsuccessfully before, or they were not eligible for earlier treatments. In our simplified model, before 2014, individuals with ESLD do not receive anti-HCV treatment and live for a maximum of 2 years before they die of HCV (or other causes). Most people with ESLD had counterindications for interferon-based

[2*] There are five stages of liver fibrosis: F0: no scarring (no fibrosis); F1: minimal scarring; F2: scarring has occurred and extends outside the liver area (significant fibrosis); F3: fibrosis spreading and forming bridges with other fibrotic liver areas (severe fibrosis); F4:cirrhosis or advanced scarring.

treatment because of toxicity and poor tolerability, and therefore, before 2014, only infected individuals with non-ESLD receive the treatment in our model.[93] After 2014, and the arrival of DAA, both individuals with ESLD and non-ESLD may receive treatment.

Individuals who die prematurely of HCV accrue health and productivity losses due to premature mortality (productivity losses only for individuals of working age). We compound the health and productivity losses due to premature mortality in the year of death of the individuals. To this end, we calculate the sum of lost health and productivity for each lost life year, compared to their counterfactual remaining life expectancy, i.e., the longer life they would have lived without infection. Individuals who die of causes unrelated to HCV infection do not accrue health and productivity losses due to premature mortality, however, they accrue all costs associated with infection-related morbidity for each year they are alive, up until the year of their death. We obtained estimates of the number of individuals infected with HCV via IBBPs from the SEG modelled estimates and from estimates of other organizations as summarized in the SEG Report. The estimated range lies between 19,700 and 36,900 HCV infected persons, comprising 17,300 to 31,900 individuals without bleeding disorders and 2,400 to 5,000 with bleeding disorders (see **Table 1**). We allow for variation in the number of infected persons over the SEG estimated range in the economic model.

4.2.1.2 Cohort 2 (HIV & HCV co-infected)

For Cohort 2, (HIV & HCV co-infected individuals with or without bleeding disorders), we broadly divide the history into early years of infection, and later years of infection for those surviving HIV infection. We assume the experiences in the early years of infection are dominated by the progression of HIV. This is a realistic assumption for the 1980s and early 1990s when treatment for HIV was much less effective than in later years, and individuals became symptomatic a few years after infection. Symptoms of HIV infection would therefore have manifested earlier than those of HCV infection. **Figure 2** provides a schematic representation of how different types of cost attach to alternative trajectories of disease progression for HIV & HCV co-infection.

We divide the cohort in the early years into three distinct simplified phases: ‘Asymptomatic’ HIV, which assumes that individuals have more than three years to live; ‘symptomatic’ HIV, which assumes that individuals have less than three years to live; and ‘AIDS and death from HIV’, which assumes that individuals experience severe symptoms of HIV infection and related conditions in their last year of life and subsequently die of HIV. For HIV & HCV coinfected individuals, the majority develop AIDS and die of the infection, a realistic assumption for persons infected in the 1970s and 1980s. However, they may die in any year from other causes. The three phases define the specific cost impacts attached to subgroups of the cohort.

Our definitions of ‘asymptomatic’, ‘symptomatic’ and ‘AIDS’ map to those used by the National Prospective Monitoring System (NPMS) steering group for economics, whose numerous publications we have used to inform cost estimates.[9,10,63] We are not attempting to model the natural history of HIV in these simulated cohorts and are instead attempting to account for some of the most salient cost drivers, disaggregated by the patient groups described by the NPMS. We understand that progression of HIV varies greatly across individuals, driven by factors including age, and have therefore taken a simplifying approach to modelling disease trajectory based on the data reported by the NPMS economic steering group. The estimate of >3 years to live for asymptomatic individuals and <3 years to live for those who have progressed to symptomatic status are broadly reflective of the experience of the average person infected through IBBPs during the period of time in which our cohort of interest would

have been infected, as represented by the broad range of progression and survival estimates presented by the NPMS. Those who are considered by the NPMS to be symptomatic are experiencing significant interaction with secondary care.

In the model, people infected with HIV who do not die in the early years are assumed to be HIV asymptomatic for the remainder of their lives, because they are on effective treatment. We recognise that this simplified model does not fully account for the people infected through IBBPs who experienced and survived AIDS and live with the consequences, though account is made for costs due to HIV-related morbidity for the remainder of their lives. We assume they experience symptoms and costs related to healthcare, reduced HQoL and productivity for asymptomatic HIV. In addition, they experience the same stages as those with HCV mono-infection, as per the above condition-specific assumptions for Cohort 1, including death related to HCV or other conditions. Once in the later years, in our model, Cohort 2 individuals do not progress to symptomatic HIV, nor do they die of AIDS; however, they may die of HCV, or other causes. Co-infected individuals in SVR continue to experience costs associated with asymptomatic HIV infection, because successful HCV treatment only clears the HCV virus but not the HIV virus.

Three independent organizations recorded individuals infected with HIV & HCV via IBBPs. These underlie the estimates provided by the SEG. Across the three organizations, as reported by the SEG, the counts range between 1,140 and 1,438 HIV & HCV infected persons, comprising 79 to 100 individuals without bleeding disorders and 1,061 to 1,338 with bleeding disorders (see **Table 1**). We again allow for variation in the number of infected persons in the economic model.

4.2.2 Assumptions on counterfactual experiences

We evaluate impacts for infection due to IBBPs, compared to suitable counterfactuals wherever possible (see section 4.3 for details by type of impact). Where this has not been possible, we compare against values from the general population of similar age, i.e., assuming the average life trajectory of the UK population assuming no infection with blood or blood products (general population counterfactual). Some of the infected individuals may have been more ill than the general population of the same age even in the absence of infection. Transfusion patients tend to be of higher age and there is some evidence that they are of greater medical complexity compared to the general population.[45] While obstetric transfusion patients are on average of younger age than surgical transfusion patients, the predisposing factors for postpartum haemorrhage are also likely to place some of them into a higher risk category than women of the same age in the general population.

For individuals with bleeding disorders, we compare against values from individuals with bleeding disorders who were not infected wherever possible. This is necessarily speculative and based on small numbers of individuals. Generally, there is conflicting evidence on the morbidity and mortality of non-infected individuals with bleeding disorders. For example, a study by Darby et al. found that individuals with severe haemophilia but excluding liver disease and HIV had a life expectancy at birth (LEB) of 66 years,[46] and those with moderate and mild haemophilia 77 years (weighted average 75 years). This is only a few years shorter than life expectancy at birth (LEB) of 78 for all males in the UK in 1999. A Dutch study by Plug et al. found that LEB of individuals with severe and moderate haemophilia was 71 years, and 75 years with mild haemophilia, after censoring deaths because of HIV or HCV infection. The authors conclude that after exclusion of viral infections, patients with mild and moderate haemophilia have a LEB that is about equal to the average Dutch male population.[47]

The wide ranges in parameter estimates reflect uncertainty surrounding the experience of transfusion patients and people with bleeding disorders without infections. To establish realistic counterfactuals, we require not only evidence on mortality, morbidity and disease experience of transfusion and bleeding disorder patients without infection, but also evidence on healthcare costs, health-related quality-of-life and productivity for these patients. This has proven challenging for most impacts. By taking general population counterfactuals as comparators for specific impacts, we may overestimate the additional adverse impact of infection compared to a more realistic counterfactual. However, as most impacts are closely related to age, which we do take into account in our counterfactual, we believe the bias to be acceptable.

4.2.3 Parameters governing disease experience

The parameters governing disease progression for the cohorts are summarised in **Table 3**, together with the sources and existing studies from which we collated the values. There is uncertainty around the year of infection for some groups of infected persons. For model simplification, ***year of infection*** is obtained by allowing for infections occurring between 1979 and 1986, assuming that the year of infection follows a uniform distribution, i.e. with infections equally likely to occur in any year within this range. The total number of persons infected is directly obtained from the SEG report and all the infections between 1970 and 1991 are modelled as occurring in those 8 years. As we are costing all impacts at 2021 prices, this has no impact on overall costs. Similarly, the ***proportion who died due to infection*** is calculated directly from estimates cited in the SEG report. For Cohort 1, the HCV infection-related mortality rate is higher for people with bleeding disorders than for people without bleeding disorders. For Cohort 2, in contrast, the infection-related mortality rate is higher for people without bleeding disorders who were infected with HIV via transfusions, compared to people with bleeding disorders. This is likely explained by the fact that age at infection for persons without bleeding disorders who were infected via transfusions (outside obstetrics) was substantially higher on average than age at infection of people with bleeding disorders, many of whom were infected as teenagers or young adults. Another explanation for the higher mortality rate could be that the SEG did not have estimates that distinguish HIV from non-HIV related deaths for transfusion recipients.

			Values		Notes/source
			Minimum	Maximum	
Year of infection	All cohorts		1979	1986	Assumption
Proportion ever died due to infection	Cohort 1 (HCV only)	Persons without BDs	0.02	0.19	**H / G** in Table 1 using the ranges on each to create the widest possible ranges on this quantity
		Persons with BDs	0.05	0.38	**F / E** in Table 1 using the ranges on each to create the widest possible ranges on this quantity
	Cohort 2 (HIV & HCV)	Persons without BDs	0.85	0.85	**D**
		Persons with BDs	0.50	0.50	**B**

			Values		Notes/source
			Minimum	Maximum	
Years from infection to death due to infection	Cohort 1 (HCV only)	Persons without BDs	6	18	Harris et al. 2006[44]
		Persons with BDs			
	Cohort 2 (HIV & HCV)	Persons without BDs	8	20	Gueler et al. 2017[51]
		Persons with BDs			
Age at death	Cohort 1 (HCV only)	Persons without BDs	66	79	Average age at death for HCV infected persons; Expert Report to the Infected Blood Inquiry: Statistics (2022),[6] and Harris et al. (2006)[44]
		Persons with BDs	35	55	UKHCDO 12.3.1 Mortality trends in PwBD over time[99] and sNHD3 Report table 3.2.2[49]
	Cohort 2 (HIV & HCV)	Persons without BDs	32	41	Average age at death for HIV/ HCV co-infected persons, Gueler et al. 2017[51]
		Persons with BDs	20	40	UKHCDO 12.3.1 Mortality trends in PwBD over time[99]
Non-Infection Related Mortality Adjustment	All cohorts	Persons without BDs	1	1	Risk of death to non-infection related causes is equal to age-specific all-cause mortality rate in the period 1995-1997 in the UK National Life Table published by the Office for National Statistics).[100] In sensitivity analyses, increased mortality at 2 times above that of the general population values is investigated
		Persons with BDs	1.24	1.24	Adjustment for increased risk of death from non-infection related causes, at 20% higher than general population, and 40% higher for people with severe haemophilia (Plug et al. 2006).[47] Weighted average mortality adjustment of 1.24. In sensitivity analyses, increased mortality at 2 times above that of the general population values is investigated

Table 3: Parameters governing the experiences of persons in the hypothetical model cohorts

The ***age at death*** has a crucial influence on our estimates of productivity and mortality-related health costs: the lower the age at death, the higher these costs, because they accumulate over every year of premature mortality. We found it difficult to determine evidence-based parameter ranges for age at death. For Cohort 1 of HCV-infected persons without bleeding disorders, we first collate evidence on age at transfusion to help with determining age at death from infection. There are modelled estimates from the SEG report (**Table 4.14**[6]) on age at transfusion for those infected with HCV via blood transfusions between 1970 and 1991. Taking the midpoint for each of the 10-year age bands, we estimate a weighted average of age at transfusion of 60 years from the SEG report.

Time from transfusion (and infection) to death is estimated from the analysis in a 2006 study by Harris et al. of a cohort of 924 HCV-infected transfusion recipients in the UK.[44] The study identified 34 patients who died directly of a liver condition who survived between 5.6 to 18.0 years after transfusion. In a more recent (unpublished) update of this study, the authors identified 35 further deaths attributed directly to liver disease (LD) mortality, plus 60 patients with LD mentioned in their autopsy.[96] Despite the additional data, the updated study did not find strong evidence of an association between LD mortality outcomes and time since transfusion. The data suggest that deaths with LD mentioned were highest in the 10-15 year post-transfusion period, and substantially lower in the 25 years post transfusion. Results from the studies are likely biased upwards because estimates are affected by survivor bias, i.e. the outcome could only be observed in persons that survived. Moreover, the average age at transfusion was lower in Harris et al.'s study (44 years)[44] compared to the SEG report.[6] Considering this uncertain evidence on age at death, we decided to assume a wide range for age at death due to HCV-related liver disease in our model of between 6 to 18 years after transfusion for those who are modelled as having died. This gives us an estimated range for age at death between 66 and 79 years for people without bleeding disorders for those who are modelled as having died. This range for age at death does not capture the wide variation in characteristics of transfusion patients, particularly obstetric patients.

For Cohort 1 of HCV-infected persons with bleeding disorders, we first determine the average age of exposure to IBBPs. According to data from the Status report on the slim-National Haemophilia Database, version 3 (sNHD3), the weighted average age at which persons with bleeding disorders were first exposed to IBBPs was around 23 years.[49] Given that HCV-related deaths generally start to occur only after 10 to 15 years post infection, this means that infection-related deaths of people with bleeding disorders could become more frequent by the time they reached the age of 40. Using all-cause mortality data from UKHCDO,[99] deaths of persons with bleeding disorders and infected with HCV were most frequent among the age group of 51 to 70 years old (see **Table A 2**, **Figure A 1** and **Figure A 2** in Appendix). Taking this evidence into account, and to assume a range that covers the evidence found, we assume age at death for Cohort 1 for people with bleeding disorders to be between 35 and 55 years for those who are modelled as having died. In terms of disease progression, there was little evidence of increased risk of death in the first 10 years after HCV infection for any of the groups studied. Also, as HCV treatments became more effective, the differences in mortality rates between groups were reduced.[47]

For Cohort 2 (HIV & HCV), we would expect that age at death is lower compared to Cohort 1, because individuals are suffering from two infections, and HIV treatment was ineffective in prolonging life until the mid-1990s. Leszczyszyn-Pynka et al. estimated median life expectancy at birth of 55, with an IQR of 43–59 years for a cohort of individuals with HIV/HCV co-infection who were followed from 1996 to 2014.[50] This is a more recent cohort than ours, and life expectancy may be higher because of the significant advances in treatment at the end of the 1990s. We assume that if HIV infected individuals in Cohort 2 died of their HIV

infection, they did so before the arrival of effective treatment. Gueler et al. in 2017 estimated remaining life expectancy (rLE) at age 20 for HIV mono-infected persons for different periods of the 1990s.[51] The estimates range widely between 12 and 51 years, explained by the significant clinical advances in treatment seen over the 1990s. Although these estimates do not reflect the added complication of HCV co-infection, we assume that Cohort 2 individuals in the 1990s most likely died of the complications of HIV infection because these would have developed earlier than those of HCV infection. We adopt the Gueler et al. remaining life expectancy (rLE) estimate of 12 years (at age 20) for HIV infected persons receiving monotherapy (1988-91) as lower bound estimate, and the rLE estimate of 21 years for dual therapy (1992-95) as upper bound estimate.[51] This means that for Cohort 2 (HIV & HCV), we assume an age at death of between 32 and 41 years for people without bleeding disorders using estimates from Gueler et al.[51]

For HIV & HCV infections in people with bleeding disorders, we use UKHCDO mortality trends in people with bleeding disorders (see **Figure A 3**). Following this evidence, while the progression of HIV seems to be similar for those with and without bleeding disorders, people with bleeding disorders were infected at an earlier age on average, which affects the progression of the disease and the impact on society. Based on assumptions on age and year of infection, we assume age at death values ranging between 20 and 40 years for people with bleeding disorders in Cohort 2 who are modelled as having died. This is a simplification for modelling which we recognise does not fully represent the experience of children who were co-infected and died before they reached adulthood.

The ***years from infection to death due to infection*** impacts on costs that are accrued during the lifetime of infected individuals. We use the values cited above for the age at death calculations to derive these values. For Cohort 1, we assume that both individuals with and without bleeding disorders have a mean survival time (from infection until death caused by the infection or associated conditions) varying between 6 and 18 years (inclusive) based on the evidence cited from Harris et al. and its update cited above.[44,96] For Cohort 2, we utilise published evidence from the study by Gueler et al. to determine a range for survival time between 8 and 20 years.[51] The survival for Cohort 1 is slightly shorter than for Cohort 2 because of the older age distribution of this cohort.

With respect to ***non-infection related mortality***, while one study shows that all-cause mortality in general was not higher for those infected with beta thalassaemia;[37] overall mortality of patients with haemophilia was found to be between two to five times higher than that of the general population by Plug et al.[47] After exclusion of deaths related to either HIV or HCV, mortality rate among patients with haemophilia was 20% higher than among the general population (SMR 1.2, CI 0.9–1.6), in patients with severe haemophilia this was 40% (SMR 1.4, CI 0.8–2.4). We therefore adjust the UK life tables for the general population with a multiplier of 1.24 for the group with bleeding disorders, to reflect the increased risk of all-cause mortality of this group. This value is the weighted average for non-infection-related mortality risk for individuals with haemophilia, assuming that 22% have severe disease. In sensitivity analyses, we evaluate the sensitivity of our findings to a higher background mortality risk by applying a 2 times higher risk for Cohort 1 HCV with bleeding disorders, compared to the general population. Those without bleeding disorders (transfusion patients) are generally older, with associated higher mortality risk. We do not adjust background mortality over and above that for the general (elderly) population. However, as explained above, transfusion patients may be of greater medical complexity than the general population, due to the reason they required a transfusion in the first place. We explore the sensitivity of our results when applying a background mortality risk of 2 times that of the general population for Cohort 1 HCV without bleeding disorders.

4.3 Modelling of impacts

A range of health, economic and social impacts were considered by the HEG for the purposes of these analyses. These are summarized in **Table 4** below. It is important to note that while best efforts were taken to identify data pertaining to each of these impacts in both the witness testimonies and published literature, we were not able to identify this data for each impact. Therefore, not all impacts are estimated in the cost of illness model. This section explains which impacts were included and excluded.

Table 4 presents an overall summary of types of impacts considered within the model, and those that were included within the final analysis. We consider losses arising up to 2021. **Table 4** also summarizes the measures we used to evaluate the impacts. Economic and social losses are reported in 2021 British pounds. This means that we inflate monetary losses that accrued in earlier years to the prices of the year 2021. Health losses due to excess mortality and morbidity are expressed in a unified metric, lost quality-adjusted life-years (QALYs). See section 4.3.4 for more details.

Table 4 also shows the perspective from which we evaluate the impacts in the model, i.e., answering the question who bears the impacts: the infected individuals themselves, their family, or UK society. We attempt to identify data for each of these types of impact, and to each group, to the best of our ability. However, it was not possible to identify data for all impacts or impacts for all groups. This is a limitation of the model and does not mean that there were no economic or health costs for specific groups. A discussion of impacts considered in the quantitative analysis is provided below.

4.3.1 Data collation

The following sections also explain in more detail how we collated data for the study, how we model each of the impacts, and which key existing studies have informed our model. We relied to a large extent on evidence from the secondary literature on the impacts of HCV and HIV infection in the United Kingdom and other high-income countries. This implicitly assumes that treatment costs are the same no matter the mode of infection, whether via IBBPs, sexually, from mother to child, or via shared needles. It also assumes that the experiences of infected individuals in other high-income countries are similar to the UK. The witness statements analysed in the qualitative study informed our choice of what were the most important impacts to model, but we did not directly use data from witnesses.

A hierarchy of evidence was applied such that primary data collected in the UK was considered the highest standard. National surveillance data was used wherever possible to inform epidemiological parameters. Peer-reviewed literature was used to inform the values for all other parameters. Where multiple peer-reviewed publications were available that met inclusion criteria (i.e. primary data from the UK) for a given parameter, quality appraisal was undertaken to determine the optimal information source. This considered the reputation for excellence of the journal in which the data was published, the methods used to collect and analyse the data, and the sample size/representativeness of the population. Data sources are transparently referenced for every value and assumption included within the model. We now discuss each impact in turn, and what data were collated to inform the magnitude of the impact.

Type of impact		Description	Unit of measurement	Perspective		
				Infected	Family	Society
Health- and social care	Primary care	Costs to the NHS, and non-monetary costs of accessing care to the infected persons (travel and waiting times)	£, and (weighted) average salary costs for time costs	x	x	x
	Hospital care	Costs to the NHS, and non-monetary costs of accessing care (travel and waiting times)	£, and (weighted) average salary costs for time costs	x	x	x
	Pharmaceuticals	Costs to the NHS, prescription charges to infected persons, and non-monetary costs of purchasing/obtaining pharmaceuticals (travel and waiting times)	£, and (weighted) average salary costs for time costs	x	x	x
	Rehabilitation	Costs to the NHS, monetary costs (user fees), and non-monetary costs of accessing care to infected persons (travel and waiting times)	£, and (weighted) average salary costs for time costs	x	x	x
	Social care	Costs to the governments, monetary costs (user fees), and non-monetary costs of accessing care to the infected persons (travel and waiting times)	£, and (weighted) average salary costs for time costs	x	x	x
	Informal care	Value of work provided by informal carers	£, evaluated at replacement costs of a homecare worker (HIV), and at average salaries (HCV)		x	x
	End-of-life care	Some costs from primary care, hospice, pharmaceuticals, and social care, and informal care	£ cost of end of life	x	x	x
	Private health care	Additional costs of private health care including private insurance are not included	Not assessed	na	na	na
Financial assistance and welfare payments	Support payments	Payments by the government and trusts to affected individuals and those close to them, including direct financial aid; not included in model but reported separately	£	na	na	na
	Welfare payments	Welfare payments including unemployment benefits, universal credit, pensions, and others; such payments are not included in model	£	na	na	na

Type of impact		Description	Unit of measurement	Perspective		
				Infected	Family	Society
Health and wellbeing	Excess mortality	Premature mortality impacts evaluated in quality-adjusted years of life lost compared to suited counterfactual	Estimates of remaining life expectancy at all ages, quality-adjusted life-years	x		
	Excess morbidity	Morbidity impacts due to infection, co-infection and associated comorbidities; for persons close to infected persons only attributable mental health impacts	Quality-adjusted life years	x		
	Stigma	Evaluated via mental health impacts	Quality-adjusted life years	x		
	Non-health related Quality of life	Impact on happiness and wellbeing because of altered life choices, housing quality, job satisfaction are not included	Not assessed	na	na	na
Productivity	Work productivity	Lost earnings due to absenteeism and presenteeism (HCV only)	Lost earnings, based on (weighted) average salaries	x		
	Home productivity	Lost earnings due to absenteeism and presenteeism not included in model	Not assessed	na	na	na
	Unemployment	Probability of unemployment (HCV only)	Lost earnings, based on (weighted) average salaries, and probability of unemployment	x		
	Low-skilled employment	Probability of low-skilled employment not included in model	Not assessed	na	na	na
Economic opportunity	Educational opportunities	Inability of accessing higher level of education not included	Not assessed	na	na	na
	Financial products	Inability of obtaining life- and travel insurance, mortgages, and related financial products not included	Not assessed	na	na	na

Table 4: Impacts included and not included in the model

4.3.2 Healthcare and social care costs

4.3.2.1 Healthcare costs borne by the NHS and society

Substantial healthcare costs are incurred in relation to treating and caring for those with infections over the estimated lifetime and at the end of life. We consider costs that occur in secondary (hospital) care in the treatment of the infection and associated conditions, and in primary care. The costs of rehabilitation, social care and community care, and pharmaceuticals are also considered in the model. Adjustments are made for changes in care over time due to changes in treatment protocols, drug regimes, inflation in prices of treatment, and other relevant factors. Healthcare costs are predominantly borne by the NHS, though we also consider certain health and social care costs borne by infected persons and their families. Healthcare and social costs vary across HCV and HIV & HCV infected persons, due to the nature of the diseases. Also, and because we heavily rely on previous studies, costs vary due to differences in study designs, approaches and methodologies.

4.3.2.2 Patient costs of accessing care

The infected persons and their families also bear costs in relation to accessing care. Patient costs are not well-published and we found that they were often difficult to obtain from the literature. Costs to the infected persons of accessing care include the monetary costs of care, including prescription charges for drugs and travel costs to healthcare facilities to receive treatments for included conditions. Costs that we include are also non-monetary, notably waiting times at healthcare facilities valued by average salaries. Family members often spend significant amounts of time providing 'informal' unpaid care. The hours spent caring can be considered important economic costs. We valued these costs for the years that care was provided, based on the evidence known to the HEG at the time of this study, both for HCV and HIV & HCV infected persons. Some infected persons may have sought private healthcare for their infections. The costs of accessing private care comprises out-of-pocket payments and/or regular insurance premium payments. We do not include costs arising from private care in our analysis.

4.3.2.3 Estimating costs of health and social care – HIV

Table 5 lists the costs and their data sources that we used to capture the economic impact of infection due to HIV. These are the costs applied to Cohort 2 (HIV & HCV co-infected individuals with or without bleeding disorders). As explained in section 4.2, in the early years of infection, we assume that for co-infected individuals, disease progression related to HIV infection dominates that of HCV. We had to make simplifying assumptions on the change in treatment availability and regime over the period of interest, relying on the secondary literature for the time period (see **Table 5** and **Table 6**).

It is important to note that costs presented within the model in relation to year and stage of disease reflect the average per person cost presented in the published literature. Average per person costs represent an amalgamation of all cost details from the patient sample, divided by the number of people within that sample. This means that, especially for the period 1987-1997, while aggregated cost estimates do encompass the cost of provision for zidovudine (AZT), we do not make any assumptions within the model regarding the proportion of people within the model on or off this antiretroviral therapy and instead assume a mean cost based on aggregated data. We recognise this as a crude approach to cost estimation, however, consider it the most pragmatic way in which to estimate healthcare costs over this broad period of time.

Type of costs	Explanation	Approach to estimation taken	Source
Medical costs	Medical costs are based on an amalgamation of costs borne by the health system in relation to interaction with the NHS and prescription of pharmacological treatment. These include primary care visits, hospital outpatient, day ward, and inpatient visits, and the cost of drugs to treat HIV and related complications	All medical costs were taken from published literature using primary costing studies. Where costs were unavailable for a given year, the most recent years' available cost data was used and then adjusted for inflation for the year in which the source data was presented to 2021	Beck et al. 1994 {1983-1989}[66], Petrou et al. 1995[54], Beck et al. 1996[9], Beck et al. 1998[63], Beck et al. 1999[10], Mandalia et al. 2010[65]
Social and community care	Social and community care costs represent an amalgamation of the wider costs to society for caring for a person with HIV. These include costs of informal caregiving, the use of social services, and foregone wages for the carers	All social and community care costs were taken from published literature using primary costing studies. Where costs were unavailable for a given year, the most recent years' available cost data was used and then adjusted for inflation for the year in which the source data was presented to 2021	Petrou et al. 1995[54]

Table 5: HIV cost definitions and data sources

From 1997 onwards, when multiple forms of highly active antiretroviral therapy (HAART) were available, we have taken estimates from those on triple therapy as the base case approach. This decision was informed by a review of the British HIV Association Guideline archive[53] which indicated that guidelines on treatment of HIV-infected adults with antiretroviral therapy all make broadly similar recommendations for a preferred first-line triple therapy, using either (2 x nucleoside reverse transcriptase inhibitors (NRTIs) + 1 x non-nucleoside reverse transcriptase inhibitors (NNRTI)), or (2 NRTIs + a boosted protease inhibitor (PI)). We recognise that drug generation, modality (multiple v single pill), and combinations changed over time. However, for the purposes of this model, 'treated' on HAART (i.e. 1997 and onwards) makes the assumption that all people treated with HAART are treated with triple therapy.

Estimates of social and community care for each stage of HIV disease are obtained from a single source.[54] These are then aggregated with the health and medical cost estimates obtained from the literature for each year of the model in order to present an aggregate health, medical, and social care cost per patient year. The costs are summarized in **Table 7**. The annual cost data used within the model for the 'asymptomatic', 'symptomatic' and 'AIDS' population sub-groups, corresponding respectively to 3+ years to death from AIDS, less than 3 years to death from AIDS, and year of death from AIDS in the model are presented in the appendix in **Table A 3**, **Table A 4**, and **Table A 5**. Costs are adjusted to 2021 prices using the Consumer Price Index.[55]

	1979-1984	1984-1987	1987-1997	1997-present
Treatment regimen				
Type of regimen	None	None	AZT	HAART
Treatment assumptions by group				
Asymptomatic	100% untreated	100% untreated	14-23% treated with AZT 77-86% untreated	100% treated
Symptomatic	100% untreated	100% untreated	32-45% treated with AZT 55-68% untreated	100% treated
AIDS	100% untreated	100% untreated	48-66% treated with AZT 34-52% untreated	100% treated
Key data source	Beck et al. 1994[66]	Beck et al. 1994[66]	Beck et al. 1994[66], Beck et al. 1996[9], Beck et al. 1998[63], Beck et al. 1999[10]	Beck et al. 1998[63], Beck et al. 1999[10], Mandalia et al. 2010[65]

Table 6: HIV Treatment regimen assumptions, disaggregated by time periods and proportion of people on various

	Asymptomatic	Symptomatic	AIDS
Community Care	974.24	1,537.31	2,059.07
Informal care	1,113.52	1,221.5	1,986.34
TOTAL	2,087.76	2,758.81	4,045.41
2021 adjustment*	3,626.97	4,793.09	8,767.63

Table 7: Per patient year community and Informal care costs per HIV disease stage

*Price source year = 1993. Source = Petrou et al., 1995[54]

4.3.2.4 Estimating costs of health and social care – HCV

The healthcare costs of HCV infection correspond to the average cost per person infected per year, in different stages of the disease. We rely on a set of assumptions to accommodate the complexities of the disease at different levels of severity. Determining healthcare costs for HCV was more complex than for HIV, for two main reasons: there is much less cost data from the UK on the management of HCV, as well as more stages of progression and possible outcomes that increase the level of uncertainty when estimating average costs. Cost definitions and sources of information are presented in **Table 8**.

Similar to healthcare costs for HIV, for HCV we also had to take into account technological innovations in available treatments over time, relying on existing literature. Treatment regimes and effectiveness rates are presented in **Table 9**. For simplification, HCV treatment periods are aggregated into three different periods of time with three main technologies: first, when interferon was used alone (1990-1998), second, when interferon was used together with other active substances (1999-2014), and third, after direct-acting antivirals (DAAs) started being used without interferon (2015-present). This simplification implies that, especially during the second period, not all the different therapies that were used over time are reflected in our cost estimates. This is due to the fact that we rely on previous studies, and published cost data are not available for every year. Nonetheless we believe that the distinction between these three periods captures the most relevant HCV treatment innovations (and respective changes in costs) up to today.

The non-end-stage liver disease (non-ESLD) category includes those with mild disease as well as those with compensated cirrhosis. To generate average costs across different patient groups, we weight the relative number of persons in these categories using proportions from national level data for the number of persons with HCV-related cirrhosis and the total number of persons infected with HCV (see **Table A 6**).[56] Similarly, for the end stage liver disease (ESLD) category, which includes those with decompensated cirrhosis and hepatocellular carcinoma (HCC), the proportions (or weights) are assumed to follow the national distribution and were taken from the latest publicly available UK Health Security Agency (UKHSA) HCV data and supporting documents for England and the UK.[56]

Type of costs	Explanation	Approach to estimation taken	Source
Disease management costs	Treatment costs are all healthcare costs excluding costs for antiviral drugs, end-of-life care, and advancing disease. These include initial investigations and follow-up, outpatient visits, inpatient days, necessary procedures, service use associated with chronic HCV infection and advanced disease costs for those who had treatment but no sustained virological response (or no treatment). These costs vary with time according to technological innovations	Disease management costs were taken from published literature using primary costing studies. Where costs were unavailable for a given year, the most recent years' available cost data was used and then adjusted for inflation for the year in which the source data was presented to 2021	Dusheiko and Roberts 1995[62], Wright et al. 2006[67], Hartwell et al. 2011[68]
HCV drug treatments	Costs exclusively associated with HCV drug treatments (namely interferon and DAAs). These costs vary with time according to technological innovations in treatment	All drug costs were taken from published literature using primary costing studies. Where costs were unavailable for a given year, the most recent years' available cost data was used and then adjusted for inflation for the year in which the source data was presented to 2021	NICE Technology appraisal guidance [TA363] 2015[16], NICE Technology appraisal guidance [TA365] 2015[75], NICE Technology appraisal guidance [TA330], 2015[76], NICE Technology appraisal guidance [TA413], 2016[77], NICE Technology appraisal guidance [TA430], 2017[78], NICE Technology appraisal guidance [TA499], 2018[79], NICE Technology appraisal guidance [TA507], 2018[80], Dusheiko and Roberts 1995[62], Wright et al. 2006[67], Hartwell et al. 2011[68]
End-of-life	Time invariant costs associated with end-of-life treatment in chronic HCV patients. These include nursing home, home health, hospice, and other services	End-of-life costs were taken from published literature and were added directly to the care costs of end stage liver disease	Menzin et al. 2012[81]

Type of costs	Explanation	Approach to estimation taken	Source
Cost of advancing disease	Costs for infected persons with chronic HCV who were not treated or were not treated successfully, excluding end-of-life-care	Advancing disease costs were taken from published literature. These costs were added proportionally to the treatment costs, applying a combination between treatment rate and effectiveness rate of the respective treatment period	Backx et al. 2014[57]

Table 8: HCV cost definitions and data sources

	1990 - 1998	1999 - 2014	2015 - pres.
Treatment regimen			
Type of regimen	Interferon	Interferon and ribavirin: pegylated interferon-α associated with ribavirin	Direct-acting antiviral (DAAs)
Effectiveness			
Proportion of those treated that have SVR[&] in this period	8-9%	38-80%*	95%
Key data source	Chen and Yu 2010[12]	Munir et al. 2010 13, NICE 2004[14]	NICE Technology appraisal guidance [TA363] 2015[16], NICE Technology appraisal guidance [TA365] 2015[75], NICE Technology appraisal guidance [TA330], 2015[76], NICE Technology appraisal guidance [TA413], 2016[77], NICE Technology appraisal guidance [TA430], 2017[78], NICE Technology appraisal guidance [TA499], 2018[79], NICE Technology appraisal guidance [TA507], 2018[80]

Table 9: HCV Treatment regimen assumptions, disaggregated by time periods and proportion of people on various available regimens

Note: *In the most recent years, treatment effectiveness went up to 80%, but we assume the middle point of 60% for the whole period; SVR[&]=sustained virological response.

Clearance treatments for HCV have been available since the 1990s.[12] However, the early treatments had severe side effect profiles with poor tolerability and low effectiveness. Advances in treatment for HCV mean that modern treatment regimens have high effectiveness (>95% chance of cure) with fewer side effects, but also higher costs (see **Table 9** for treatments and their effectiveness). For our simplified model, we make the assumption that after treatment, infected persons who achieved a sustained virological response and did not have cirrhosis, did not incur any further costs. Those who had cirrhosis continued to incur health care costs for cirrhosis. Infected persons who did not receive treatment, or who received treatment but did not achieve a sustained virological response, continued to incur health care costs, which we label here as 'costs of advancing disease'.[57] In addition, we apply DAA treatment costs to 90% of infected persons with ESLD in this last category to accommodate costs for those who refused or had contraindications to interferon but were able to receive treatment once DAAs became available.

DAAs are effective, but expensive. There is anecdotal evidence that the National Health Service (NHS) paid lower costs than those officially reported. Since NHS DAA treatment costs are confidential, there is some uncertainty around the real prices. Previous studies assumed costs of £10,000 for DAA treatment, and £15,000 for re-treatment.[58] We allow for a wide range in DAA treatment costs in our analysis, with a lower bound of £10,000 and upper bound of £43,263 for DAA treatment costs since 2015 (see **Table 10**).

Costs associated with informal care are added to NHS treatment costs. HCV informal care costs are taken from Federico et al. (2012),[59] a study that measures costs for 738 HCV outpatients in a Canadian tertiary-care clinic using a patient-completed questionnaire. Informal care costs are estimated by measuring the caregivers' time costs, costs for transportation, parking and childcare. Caregiver time is valued based on average hourly wages of employees by profession. Because the values in the reference paper do not correspond directly to our clinical disease stages, some adaptation is needed. The non-cirrhosis and cirrhosis non-ESLD are separate (to show the big difference in costs), and ESLD corresponds to the values of caregiver costs attached to hepatocellular carcinoma (HCC). In the model, costs are aggregated using the proportions as described for the medical costs. The values adopted for our estimations were converted from Canadian dollars (CAD) to British pounds (GBP) using the 2007 exchange rate, and are presented in **Table 11**.

The cost data used within the model for the 'non-ESLD', 'ESLD', and 'treated' sub-groups is presented in **Table A 6**, **Table A 7**, and **Table A 8** respectively. People with ESLD often have indications for a liver transplant. However, quantification is challenging as the number of liver transplants that were performed due to a HCV-related disease acquired through blood transfusion or blood products is uncertain. Whether a patient with HCV has a liver transplant depends on several factors including stage of HCV, as well as patient comorbidities, fitness for surgery and availability of a transplant. The high effectiveness of the newer DAA treatments has been associated with a significant fall in the number of transplants performed due to HCV since 2014. According to the UKHSA 2022 report,[56] the proportion of all first liver transplants performed in England due to HCV-related disease has halved from 12.1% in 2015 to about 6.1% in 2020. Similarly, in the literature, about 6% to 13% of HCV infected persons were estimated to have received transplants.[59,60] Using data from UKHCDO, Khan et al. reported that in Scotland, between 1970 and 1989, of a total of 440 infected persons identified as likely to have been infected with HCV through blood products, liver transplant was performed in 11 persons.[61]

Parameter Minimum Maximum			Values		Notes
Total Number of Persons Infected	Cohort 1 (HCV only)	Persons without BDs	17,300	31,900	G in Table 1
		Persons with BDs	2,400	5,000	E in Table 1
	Cohort 2 (HIV & HCV)	Persons without BDs	79	100	C in Table 1
		Persons with BDs	1,061	1,338	A in Table 1
Average value DAAs 2015-2019 at 2021 prices (£)			10,000	47,245.59	Anecdotal evidence of lower costs paid by the NHS
Proportion of persons living with non-ESLD HCV infection that are not in work			0	0.2	Evidence that there is no impediment to work productivity for asymptomatic HCV infection in the initial years past infection
Decrement in QALY weight for person living with non-ESLD HCV infection			0	0.12	Evidence that there is no quality-of-life impact for asymptomatic HCV infection in the initial years past infection

Table 10: Parameters varied to induce the uncertainty ranges.

	Non-ESLD: Non-cirrhosis	Non-ESLD: Cirrhosis	ESLD	Reference
Informal care	£296	£1,491	£2,043	Federico et al. (2012)[59]
2021 adjustment*	£355	£1,789	£2,453	

Table 11: Per patient year community and Informal care costs per HCV disease stage

*Price source year = 2007

To include these costs in the model, we multiply the cost of transplant (before DAAs) by the proportion of people in the ESLD group that had a transplant. Because this proportion is unknown, as before, we use the national level data from UKHSA reports[56] to calculate the ratio between the number of HCV-related transplants and the number of HCV-related ESLD. **Table 12** shows the average cost of liver transplant per patient for each treatment period based on the literature. These costs include cost of treatment, i.e. all medical costs involved, and informal care, measured by the caregiver's cost of time. Trends in the costs collected indicate a potential slight decrease in liver transplant costs over time. Studies in the UK and Europe have acknowledged this potential decline since the 1990s, which has been associated with changes in protocols and technology, increased experience and higher efficacy of transplant-related procedures.[94,95]

Type of costs	Period	Costs	2021 adjustment	Source year	Reference
Treatment	1990 - 1998	£28,077	£49,344.46	1993	Dusheiko and Roberts 1995[62]
	1998 - 2014	£27,330	£39,764.30	2003	Wright et al. 2006[67]
	2015 - pres.	£10,000 (min), £43,263 (max)	£11,923.21 (min) £51,583.40 (max)	2011	Hartwell et al. 2011[68], Williams et al. 2020[58]
Informal care	Invariant	£4,787	£5,747	2007	Federico et al. 2012[59]

Table 12: Per patient year liver transplant costs - Medical costs and informal care

Note: Hartwell et al. (2011)[68] was the most recent study found to include HCV related transplant costs.

4.3.3 Financial assistance and welfare payments

The government made financial payments to infected individuals and some family members through trusts and schemes. These payments include support for the adverse effects of infections caused by infected blood and blood products and help for individuals and their households to meet day-to-day living needs. Financial assistance payments were not meant to compensate for loss of earnings. However, the need for financial assistance is likely related to low earnings, reduced household income and poor health that are caused by the infection. The assistance payments are briefly summarized below, and explained in greater detail in the Infected Blood Compensation Study.[83]

In addition to this specific assistance, infected individuals and their families could (and can) apply for any of the following means-tested welfare benefits (and the predecessors of these benefits) from the Department for Work and Pensions: Income support, Jobseeker's Allowance, State Pension Credit, Housing Benefit, Employment and Support Allowance, and Universal Credit. Some of the infected individuals could not work, and therefore were eligible for the standard universal credit, housing benefits, child tax credit, winter fuel payments or pensions provided by the UK welfare system. On the other hand, and perversely, premature deaths may have resulted in 'savings' in these payments to the UK welfare system, when compared to a no-infection counterfactual. There is no data on what proportion of infected individuals and their families received these benefits, and at what levels. Also, the net impact of infections on the welfare system crucially depends on age and year at death, for which our data are incomplete. Lastly, many benefits are replacing lost income due to reduced or total loss of work productivity, which is an impact we calculate. Adding welfare payments to our analysis may therefore result in double counting. For these reasons, we exclude welfare payments from the analysis.

Organisation	Disease stage	Lump-sum transfer	On-going payments until 2016
Skipton Fund	Stage 1 HCV	£20,000 (2004-2016)	No ongoing payments
	Stage 2 HCV	£50,000 on top of the £20,000 above (2004-2016)	£14,574 (value in 2015-16)
	Family	Entitled to claim payments[1*]	na
Macfarlane and Eileen Trusts, or predecessors	Infected person	£20,000 in 1991 + £21,500-£60,500 in 1992 dependant on individual family circumstance at that date[2*]	£14,574
	Family of an infected person who died before scheme established	£43,500	Not entitled to ongoing payments
Both	Co-infected persons	Both payments	HIV & Stage 1 HCV: £14,574, MFET; HIV & Stage 2 HCV: £29,148

Table 13: Non-discretionary payments from 1990 until 2016

Notes:

[1*] Family of an infected person who died after the schemes were established but who never made a Skipton claim could claim at any time; Family of an infected person who died before the schemes were established (29 August 2003) could claim until March 2011

[2*] In 1993, people without bleeding disorders became eligible to claim the same lump sum payments at the time of registration.

Reference: The All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood Inquiry into the current support for those affected by the contaminated blood scandal in the UK - Executive Summary, (Figure 1 and 2, APPG Inquiry 2015[8])

4.3.3.1 Historical evolution of financial assistance

This section summarizes briefly how the support schemes evolved over time since the 1990s, the main organizations providing support, and the monetary sums that infected and affected persons could apply for, depending on the disease and disease stage. Financial support for people affected by HIV and/or HCV through treatment with NHS-supplied blood or blood products started for some in 1989. Between 1989 and 2016, five different organisations funded by the UK Health Departments developed which were registered as trusts or private companies and gave non-discretionary continuous and one-off lump sum payments to eligible beneficiaries and their families. **Table 13** presents a summary of the amounts that were distributed by each organization, and by disease and disease stage.

Three charities (Macfarlane Trust, Eileen Trust and Caxton Foundation) provided support to infected individuals and their families on a discretionary basis according to their own policies. For this reason and because the charities provided support in various forms, it is challenging to summarise payments. Support to affected individuals was provided in grants (to pay for living expenses ranging from daily necessities to home renovations, property and holidays) or one-off and ongoing lump sum payments (e.g. winter fuel allowances). These payments could be granted on top of the previously described non-discretionary payments. These five organisations together were known as the 'Alliance House Organisations'.

In 2016, the Department of Health estimated that over £390 million had been paid out through the trusts and funds in the UK.[97] The system was subject to strong criticisms by those who were directly or indirectly affected, claiming that it had become complex and confusing. In reply to these concerns, it was substantially reformed. At that point, another £570 million was projected to be spent, amounting to a total of £970 million spent in support schemes for infected persons from 1988 until mid-2023. The outcome of this reform was the establishment of four new support schemes: the Scottish Infected Blood Support Scheme (SIBSS) (effective as of April 2017); the Wales Infected Blood Support Scheme (WIBSS) (October 2017), the England Infected Blood Support Scheme (EIBSS), and the Infected Blood Payment Scheme for Northern Ireland (IBPSNI) (from November 2017). A summary of the main discretionary payments in place until 2022 is provided in **Table 14**. Discretionary income top-ups and one-off grants were available to some beneficiaries and/or affected partners, as well as psychological support and further cost of living or winter fuel payments.

4.3.4 Health-related quality-of-life

The qualitative analysis has demonstrated that substantial costs are incurred due to excess mortality and morbidity caused by infection. We have endeavoured to estimate adverse health impacts of infections, and associated conditions including mental health impacts, focusing on lost health due to premature mortality and ill health experienced during the infected persons' shortened lives. Mortality and morbidity impacts are expressed in terms of a generic measure of lost health, aggregate lost Quality-Adjusted Life Years (QALYs). This section describes the methods and data used to measure morbidity and mortality due to HCV infection and HIV & HCV co-infection.

We do not assess directly the impact of IBBPs on non-health related quality-of-life. For example, infection resulted in altered life choices with respect to education, employment, or family size, poorer housing quality or job satisfaction. Some of these impacts are likely to be captured in the lost earnings, or in the mental health component of Health-related Quality of Life (HQoL), particularly if they would apply to HCV and HIV infected persons from all causes.

Organisation	Type of support	Lump-sum transfer	Annual payments 2022
SIBSS, WIBSS, EIBSS, IBPSNI	Hepatitis C (stage 1)	£50,000	£18,912
	Hepatitis C (stage 1) with SCM*		£28,680
	Hepatitis C (stage 2)	£20,000	£28,680
	HIV	£80,500	£28,680
	Co-infected persons with HIV and Hepatitis C (stage 1)		£38,928
	Co-infected persons with HIV and Hepatitis C (stage 1) with SCM		£45,072
	Co-infected persons with HIV and Hepatitis C (stage 2)		£45,072
	Bereaved Partner	£10,000	100% / 75%
	Winter Fuel Payment (December)		£544

Table 14: Non-discretionary payments 2022

Notes: *SCM – Special category mechanism that assesses whether an applicant has a substantial and long-term adverse impact on ability to go about routine daily activities.

Reference: Infected Blood Compensation Study, Francis (2022).[83]

This section describes the methods and data used to measure morbidity and mortality due to HCV infection and HIV & HCV co-infection. Excess mortality and morbidity impacts reflect that infected persons may have died earlier and experienced more ill health compared to the life they would have lived had they not been infected. Both impacts are expressed in terms of aggregate lost Quality-Adjusted Life Years (QALYs). Generally, QALYs value each life year with a so-called QALY weight. QALY weights are measured on a 0 to 1 scale representing health states ranging between death (0) to perfect health (1). A QALY weight of 0.8, for example, values a life year lived in pretty good health but with some morbidities. QALYs are measured across several dimensions of health, including a person's ability to carry out the activities of daily life, being mobile and free from pain and mental disturbance. QALY weights are obtained from survey data for many different conditions and populations. QALYs are additive across individuals, and across years.

Lost QALYs due to morbidity can be calculated by comparing to counterfactual QALYs accrued in the absence of infection. An infected individual may have experienced a reduction in their health of, say, 0.2 due to infection, compared to the counterfactual year of life lived without infection which may have accrued 0.8 (a year of life lived in slightly less than perfect health even in absence of the infection); the QALY weight for one year would be therefore 0.8 - 0.2 = 0.6, and the loss in QALY due to the morbidity impacts of infection 0.2. Lost QALYs due to premature mortality can be calculated based on expected remaining life expectancy in the year of premature death, adjusted for the QALY reductions due to morbidity during these remaining life years. For example, if an infected individual's remaining life expectancy would have been 6 years, with each of these years lived in less than perfect health valued with a

QALY weight of 0.6, then the quality-adjusted life-expectancy (QALE) would have been 6 x 0.6 = 3.6. We calculate QALYs for infected persons only; although family members may have also suffered reductions in HQoL, they are not considered in the quantitative analysis.

Usually, economic evaluations project impacts into the future. People prefer to receive health benefits now rather than in the future and so QALYs for future years are usually discounted. However, this analysis faces the unusual challenge of conducting a retrospective analysis where all losses are certain because they have already occurred. Financial costs that have occurred in the past need to be inflation adjusted to the present day; however, QALYs are not subjected to inflation; they can be interpreted as the utility individuals obtain from their health. We have therefore decided that the concept of time preference and inflation is not relevant and do not adjust past QALY losses to the end of our projection horizon.

4.3.4.1 Excess mortality

Substantial costs are incurred due to the lost life years caused by infection. The costs of infection in terms of quality-adjusted lost life years due to early death have been determined. Lost QALYs are calculated based on the population Quality-Adjusted Life Expectancies (QALEs), assuming those remaining life years would have been lived in average health of the UK population. The lost QALYs are aggregated over all individuals who have died up until the end of our projection horizon.

We estimate an average age at death for Cohort 1 (HCV) of between 66 and 79, see section 4.2.3. We use recent estimates of QALE for the general population to estimate lost QALYs due to infection for both cohorts.[98] These estimates likely overestimate QALEs for the 1990s, resulting in a possible upward bias of QALYs lost due to early deaths, but these were the only QALE estimates obtainable. We acknowledge that our assumptions on age at death in the model do not allow us to reflect differences in disease progression by types of patients, but we believe we have captured most by assuming relatively wide ranges for age at death.

4.3.4.2 Excess morbidity

Losses in QALYs are also incurred by the considerable ill-health caused by living with the infections. This is measured in lost QALYs for each disease state, assuming that each state lasts at least one year. The HQoL for each life year is calculated by determining the QALY weight for each patient considering cohort and disease stage, using data from the literature. The QALY weights vary with the level of ill-health experienced as infected persons move through disease stages. To calculate QALY loss, the reductions in QALY weight for infected persons in Cohorts 1 and 2 are determined by subtracting their QALY weight from the average estimated QALY weight of the general population at the time. Total QALY loss is obtained by summing the product of QALY weight reductions and the number of persons infected who are alive in each disease stage, and then aggregated over the full time period.

QALYs are complex to measure, and the methods used for their assessment have changed over time. While there are several references in the literature that could provide estimated QALY weights for HCV and HIV at different points in time, for the sake of consistency, our analysis uses weights from two studies with strong and well recognized results for the time period, though the study cohorts will not entirely match the experiences of people infected through IBBPs.[60,69] The values for both cohorts and disease stages are summarized in **Table 15**.

Cohort	Disease stage			QALY weight reduction
Cohort 1 (HCV)	Non-ESLD*	Infected persons with more than 2 years to live		0.12
	ESLD*	infected persons with less than 2 years to live		0.41
	HCV treated*	individuals infected 20 years before date of first treatment		0.2
Cohort 2 (HIV & HCV)	early years of infection**	Asymptomatic HIV[$]	infected persons with more than 3 years to live	0.05
		Symptomatic HIV[$]	infected persons with less than 3 years to live	0.1
		AIDS[$]	infected persons who die in the same year of AIDS	0.15
	later years of infection for those surviving HIV infection***	Non-ESLD* and asymptomatic HIV[$]	infected persons with more than 2 years to live	0.17 (0.12 + 0.05)
		ESLD* and asymptomatic HIV[$]	infected persons with less than 2 years to live	0.46 (0.41 + 0.05)
		HCV treated* and asymptomatic HIV[$]	individuals infected 20 years ago	0.25 (0.2 + 0.05)

Table 15: Quality-of-life weight reductions for every year lived by infected persons

Note: *QALY reductions for HCV are adapted from Grieve, 2006, Cost effectiveness of interferon alpha or peginterferon alpha with ribavirin for histologically mild chronic hepatitis C [60]; [$]QALY reductions for HIV are adapted from Miners, 2014, Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: a cross-sectional comparison with the general population[69]; **years from 0 to between 8 and 20 years after infection; ***years from between 8 and 20 years until death from HCV infection or other causes, or end of projection horizon, whichever is earlier. See Table 3 for cohort construction. All QALY reductions are calculated assuming average general population QALY weight of 0.86 as counterfactual following Kind et al. 1998[85].

For Cohort 1 (HCV only) the estimates of reductions in QALY weight are obtained from a study by Grieve et al. (2006) evaluating the cost-effectiveness of antiviral therapy for HCV.[60] This study is a national reference for HCV cost analysis in the UK. Each participant included in the study was asked to complete an EQ-5D questionnaire (a specifically developed survey to derive QALY weights) at each visit during the trial. The answers resulted in estimated HQoL at different stages of HCV disease. The study was conducted before the introduction of DAA medications. In the 1990s, interferon was used for treatment but it was less effective and associated with more severe side effects.[12]

Grieve et al. (2006) presented QALY weights, and to obtain QALY weight reductions,[60] we subtract the Grieve et al. weights from the average QALY of the general population in the 1990s, which has been estimated by Kind et al.[85] We use the weighted health state index, averaged across all ages. We map Grieve et al.'s (2006) disease stages to the ones defined in our study, as follows: For non-ESLD, we use Grieve's QALY weights for HCV-infected persons suffering either no cirrhosis, or compensated cirrhosis.[60] For ESLD, we use the QALY weights estimated for HCV-infected persons suffering from decompensated cirrhosis, hepatocellular carcinoma (HCC) or who have a liver transplant. We generate weighted averages for ESDL and non-ESLD by using data on proportions of HCV infected persons in each disease stage from England (UKHSA 2022),[56] see also section 4.2. The weights used

for the non-ESLD group are the most influential to our model as this is the largest group in our sample. The sample in the study (185 patients with mild disease and 71 patients with moderate disease) is much smaller than the evidence received by the Inquiry and the study's results of no to very mild symptoms for sometimes many years after infection do not match the observations in our qualitative study. We allow for a zero QALY decrement (reduction) for non-ESLD as a lower bound estimate, to capture asymptomatic HCV infection in the overall results (see **Table 10**).

Lastly, for HCV treatment, we assume the QALY weight for infected persons undergoing treatment applies. This last value corresponds to the category of "treatment in patients with mild disease" in Grieve et al. (2006).[60] From the qualitative analysis we understand that HCV treatment (before DAAs) was experienced by many patients as a very aggressive and difficult process, which may not be completely reflected in this QALY weight.

For Cohort 2 (HCV & HIV), we assume that QALY weights for HIV disease stages apply in the early years of infection (see section 4.2). This simplification is justified because in the 1990s, the symptoms of HIV disease would generally have manifested before those of HCV disease. In our model, we assume that those who survive HIV infection join the HCV cohort if they do not die from causes relating to being HIV-positive, from which point on both HIV and HCV QALY weight reductions apply. By adding HIV and HCV reductions without an adjustment, we attempt to capture the more severe quality of life reductions for HIV infected persons who survived poor treatments in the 1980s/90s and then experienced co-infection with HCV for the remainder of their lives.

The HIV QALY weights are obtained from Miners et al. (2014).[69] This study compared HQoL between 3,151 people with HIV and 7,424 people from the general population by merging two cross-sectional surveys that collected data on HQoL using the same survey. While this study was conducted in the era of HAART, it includes information on HQoL for individuals at all stages of the disease, though duration of infection was not recorded and some infections analysed by Miners et al. will be more recent than the 1979-1986 window used in our analysis for IBBPs. For asymptomatic HIV infected persons, we assume weights for Miners' category "HIV+ never started anti-retroviral treatment (ART)". For symptomatic HIV infected persons, we assume weights for category "CD4 count > 200 per uL", and for AIDS infected persons weights for category "CD4 count <= 200 per uL".

For aggregation of QALYs for Cohort 1, QALY losses for non-ESLD and ESLD infected persons can be added as these stages are mutually exclusive. With respect to HCV treatment, there is double counting of QALY loss in the treatment year with non-ESLD infected persons (ESLD was contra-indication to interferon). We therefore subtract QALY loss for non-ESLD from QALY loss for HCV Treatment. For Cohort 2, to avoid double counting, only the QALY loss for AIDS is counted in the year of death, not the loss for symptomatic infection. **Table 15** shows quality-of-life weight reductions for every disease stage.

While HIV related stigma has been widely reported in the literature, there is much less evidence on HCV-related stigma. HCV-related stigma is generally associated with drug use and fear of infection reinforcing stigmatising attitudes.[73] Literature on how to measure the health and economic impact of stigma has shown that HQol is able to capture mental health and quality of life perceptions, at least partly. As expected, stigma is negatively associated with reported QALY values.[101-105] This implies that the impact of stigma due to HIV and HCV infection and HIV & HCV co-infection is (partly) captured by the QALY reductions for both cohorts in our study.

The health loss could be converted into monetary terms, based on monetary valuations of a QALY.** There is no universally agreed and acknowledged estimate of the value of a QALY, but a recent scoping review of existing evidence and studies on the monetary value of a life year cited values between £30,000 to £60,000.[71] While the scoping review emphasized that methodologies differed across the reviewed studies, and there is no consensus, we use this lower and upper bound to suggest an approximate valued loss of health.

4.3.5 Productivity costs

Productivity costs occur when individuals are unable to engage in economic activities that they potentially would have been able to in the absence of illness. While the range of such activities is wide, most cost of illness studies focus on the productivity costs through reduced time spent in work. This includes lost years of work due to premature mortality. The relevance of such costs is rarely disputed, but their magnitude, measurement, and valuation is. A thorough examination of the alternative approaches is provided by Pritchard and Sculpher (2000).[64] In this report we adopt the most widely used human capital approach where it is assumed that if work is lost due to illness then that represents a loss of production to the economy. The approach values production using national average wages. This again is conventional and assumes that wages reflect productivity.

In the analyses we consider the fact that due to underlying societal and personal circumstances not everyone who is of working age will be in work even in the absence of illness. The employment rate of those of working age over the period of interest was 69.1%.[41] We also assume that work loss only applies to those under the age of 65 years. We do not apply gender differences to age of retirement nor do we account for the fact that some would remain in paid employment beyond the age of 65. The approach also does not involve attaching costs to lost unpaid production (including in the home). Informal care provided by family members is considered under healthcare costs.

A summary of values used in the modelling of productivity costs is shown in**Table 16**.

Measure	Value	Source
Population work participation rate	69.1%	ONS[41]
Retirement age	65 years	
HCV employment rate (except last two years of life)	80% of those otherwise employed	Rand Europe[70]
HCV productivity loss for those in work	7.5%	Su et al.[72]
HCV productivity loss in final two years of life	100%	Rand Europe[70]
HIV non-symptomatic lost work	25.4 days per year	Mullins et al.[52]
HIV symptomatic lost work	70.7 days per year	Mullins et al.[52]
AIDS lost work	176.4 days per year	Mullins et al.[52]

Table 16: Parameter values for productivity costs and their sources

** Note that such valuations are used to determine willingness-to-pay threshold for the acceptance of health technology, and not usually to place monetary values on health impacts in cost-of-illness studies. However, we adopt this approach here to provide some ballpark approximate assessments of lost health.

4.3.5.1 Estimating productivity costs associated with HCV infection

A small number of studies have estimated the economic costs of lost production as a result of HCV. In the USA, Su et al. (2010) found that employees with HCV were 7.5% less productive than those without the condition.[72] They also indicated that those with cirrhosis or cancer were completely absent from the labour market. Vietri et al. (2013) published an international study on HCV and work impairment using 2010 European Survey among adults from France, Germany, Italy, Spain and the UK.[73] Participants with HCV reported to have 12 percentage points more work impairment related to health compared to other respondents and more impairment in non-work activities (34% vs. 28%).[73]

Earlier studies have also associated HCV with a significant work-related burden. A study by Dusheiko and Roberts (1995) analysed a sample of patients with liver disease in clinics in North America or Europe.[62] The study assumed an episode requiring an inpatient admission for illness or an assessment before or after a transplant corresponded to one month away from work. Those undergoing a transplant would take at least one year off work or normal activity.

While useful, the above studies have their limitations for the purposes of this report. As described earlier, our approach is to estimate the productivity costs for each year while people have HCV and also the productivity costs associated with premature death. The best source of information to inform this for HCV was a report by RAND Europe.[70] This made some key assumptions that are useful for our subsequent modelling:

- Those with cirrhosis or liver cancer do not participate in work
- Employment rates for people with chronic HCV is 80%
- Those who are in work are 7.5% less productive than if they did not have HCV

In our analyses, the second of these assumptions is applied to the proportion of the working age population who on average would be in the workforce (which was on average 69.1%). We recognise the limitations of using single data points for a progressive disease.

4.3.5.1.1 Productivity costs for non-ESLD

We assume that persons with HCV disease in non-end-stage liver disease have more than two years to live. We further assume that in the absence of HCV infection an individual in this category would have a 69.1% likelihood of working, which is based on national workforce participation rates during the period of interest. With HCV infection (except in the final two years of life) the 80% are assumed to be in work and 20% not, though we recognise that the qualitative study describes a more complex picture. The work loss for these 20% is assumed to be equivalent to the average annual salary (in 2021 prices) over the period, which is £27,384, giving an expected productivity loss of £3,784 (the product of 0.691, 0.2 and £27,384). For the 80% in work, there is assumed to be a productivity loss of 7.5% and so the expected productivity loss is £1,135 (the product of 0.691, 0.8, 0.075 and £27,384). Therefore, the overall expected annual productivity loss in this category is £4,919 (the sum of £3,784 and £1,135). The productivity costs due to HCV treatment are not separately added to the analysis, but we assume that they are included in the costs of non-ESLD, though we recognise that the side-effects of interferon and ribavirin treatments were often severe. We consider that there is uncertainty surrounding the number of individuals with non-ESLD who are unable to work; many in this disease stage may be asymptomatic for many years, and therefore we allow for no impediment to work productivity for a lower bound estimate of productivity costs (see **Table 10**).

4.3.5.1.2 Productivity costs for ESLD

We assume that persons infected with HCV and with less than two years to live can be typically classified as having ESLD. We further assume that individuals in this category will have severe symptoms and will not be in work. The expected annual productivity loss is therefore £18,922 (the product of 0.691 and £27,384).

4.3.5.1.3 Productivity costs due to death from HCV infection

It is assumed that (the minority of) individuals who die due to HCV will lose work years up to when they would have been 65. The age of death is a parameter in our overall model and is varied in sensitivity analyses. If we assume someone dies at, say, age 55 then the expected mortality-related productivity loss would be £189,223 (the product of 10 years, 0.691, and £27,384). We have not discounted this amount due to reasons discussed earlier.

4.3.5.2 Estimating productivity costs associated with HIV & HCV co-infection

As with other aspects of the analyses presented in this report we are assuming that those with HIV infection will also have HCV and that the impacts are dominated by HIV disease in the early years of infection. The model uses a simplified assumption that those who survive HIV infection experience the same productivity loss as those with HCV mono-infection (see section 4.2), and in addition those associated with asymptomatic HIV infection.

Regarding productivity losses associated with HIV infection, we were able to find one study in the UK. Mullins et al. (2000) use the Positive Lives Employment Survey from 1997 to estimate the indirect costs of care for HIV infection in England,[52] by stage of infection at a population level. The survey includes information on the health and employment status of HIV-positive homosexual men living in the UK, including type and number of benefits they received, such as disability living, mobility, and severe disablement allowances, housing benefits, and income support. The loss in economic productivity due to disability was estimated by multiplying the average gross wage rate by the estimated differences in disability days across stages of disease. The results in days lost in a year were 25.4 days/year for asymptomatic cases, 70.7 days/year for symptomatic cases and 176.4 days/year for AIDS. The total population estimates were calculated by multiplying individual estimates of indirect costs times the actual number of HIV-infected persons, by stage of infection, reported to the Communicable Disease Surveillance Centre (CDSC) in 1997 (IBI SEG 2022).[6] The source of the reduction in productivity found comes both from short-term absenteeism and lower performance indicators. The authors differentiate these indirect costs from costs associated with disability-related benefits (not included) since the indirect costs are paid by the employer.

The approach used here is to follow the approach of Mullins et al. and to assume that the work loss amounts to 25.4 days each year for people prior to the last 3 years of life, 70.7 days in the third and second year prior to death, and 176.4 days in the final year. It is assumed that in a year there are 250 working days, and the annual average salary is divided by this amount to produce a cost per day of £109.54. This results in annual work loss costs of £2,782, £7,744 and £19,322 for the three severity levels. Death before the age of 65 is assumed to result in complete work loss but with adjustment made for employment rates.

4.3.5.2.1 Productivity costs for asymptomatic HIV

We assume that persons in this stage of HIV infection have more than three years to live, and are largely asymptomatic. Their work loss amounts to £2,782 per year.

4.3.5.2.2 Productivity costs for symptomatic HIV

We assume that persons in this stage of HIV infection have less than three years to live. In these final three years of life, i.e., for those who die, there are two costs applied. In the first of these two years it is assumed that they have symptomatic HIV, and this results in a work loss cost of £7,744 for each of these years. In the final year of life, it is assumed that the person has AIDS and the work loss cost is £19,322.

4.3.5.2.3 Productivity costs for AIDS

We assume that persons with AIDS die within a year. For those who die there is a cost of lost productivity up to retirement age. As with HCV, we assume that this applies to 69.1% of people (reflecting employment rates) and we also assume that the average salary of £27,384 reflects the value of lost productivity.

4.3.6 Economic opportunity

The qualitative analysis demonstrates that many infected individuals and their families have had reduced opportunities to lead a fulfilled and prosperous life. For example, they could not choose the education or employment they would have done if not infected. Reduced education opportunities can have a long-term impact on employment prospects and life-time earnings. Infected individuals may have been more likely to be employed in a low-skilled occupation. Those affected by life-threatening illness are frequently prevented from accessing financial products such as home insurance and a mortgage, health insurance, or travel insurance at a similar cost to others, affecting household income.

We regret that we cannot evaluate losses related to economic opportunity due to lack of data for infected persons, but also because we are unable to establish a reliable counterfactual impact, i.e., what economic opportunities would have been in the absence of infection. However, some of these impacts may be captured in other impact estimates, most notably lost productivity.

4.3.7 Modelling of costs considering disease progression and uncertainty

Our set of estimates for the total costs is computed in the following steps:

1) Cohort 1 for those with bleeding disorders is constructed, with individuals in this group varying in respect of the following parameters: the year of infection, the probability they will die of the infection, and, for those that do die of the infection, the number of years to death and the age at death. The parameter values for each individual[3*] are realised by simulated draws from statistical distributions (**Table 3**).

2) The other groups (Cohort 2 for those with bleeding disorders, Cohort 1 for those without bleeding disorders and Cohort 2 for those without bleeding disorders) are constructed similarly using parameters specific to those groups.

3) In each year and for each cohort, counts are computed of the number of individuals in each disease stage and experiencing each event. This computation allows for the assumptions made about the disease progression and the reduction in size of the cohort in successive years due to deaths from other causes.

[3*] For a computational convenience, exactly 1,000 individual trajectories are constructed in this manner, which are thus "shared" by small sets (up to 5) of modelled individuals.

4) From these counts, estimates of the costs are computed.

5) The costs from across all the cohorts and all the years are summed to give a total estimate of each type of cost.

To create the range of results, this process is repeated under alternative assumptions for specific parameters that have a strong influence on the results. To create the lower bound estimate, the lowest credible value for each of the following parameters is used: the numbers of persons infected (in each cohort and according to whether the persons have bleeding disorders or not), the cost of DAAs, the proportion of those living with non-ESLD HCV infection who cannot work, and the quality-of-life decrement for those living with non-ESLD HCV infection (see **Table 10**). To create the upper bound estimate, the highest credible values for each of these parameters is used (**Table 10**).

4.4 Results

This report calculates economic and health costs of infected blood and blood products (IBBPs) to the United Kingdom over a period from 1970 to 2021. We employed a cost-of-illness model to quantitatively estimate three types of economic costs: healthcare, productivity and health-related quality of life costs. The analysis generates estimates of the aggregate economic impact of IBBPs to UK society by modelling the life trajectory from infection for cohorts of persons infected with HCV and co-infected with HIV & HCV. The model considers only the most salient drivers of cost in aggregate for which there were published data and does not simulate the actual experience of every individual infected or affected by IBBPs.

The analysis recognises that healthcare costs arise from the medical treatment of the infected, and are borne by the NHS, patients and their families. Productivity costs are the lost earnings due to inability to work (fully or partially). Health-related quality of life costs recognise that many infected individuals died earlier than they would normally have, and that they spent sometimes many years in ill-health. We express lost health, both in terms of excess mortality and morbidity, in lost quality-adjusted life-years (QALYs). The model was run using the parameter values noted in the foregoing sections and under alternative scenarios in which certain parameters related to the disease progression and costs were varied. The range of results produced are reported as the 'uncertainty interval' for the model results.

The SEG summary of existing evidence and SEG modelling suggests that there were 25,700 (uncertainty range 19,700 - 36,900) HCV infections, and 1,290 (1,140 - 1,438) HIV & HCV co-infections.[6] This is a total of 26,990 (20,840 - 38,338) infected persons. In addition, there are the families of the infected persons who are indirectly affected by the infections.

We estimate that the economic costs due to healthcare and productivity losses ranged from £1.9bn to £4.2bn between 1970 and 2021, calculated at 2021 prices (see **Table 17**). These costs consist of healthcare costs, mainly borne by the NHS, and of lost earnings, mainly borne by the infected persons and indirectly, their families.

The health and social care costs range between £900mn and £1.6bn. These are costs covered by the NHS for primary and hospital care over the lifetime of the infected persons, costs of pharmaceuticals and costs for end-of-life care for those who died due the infections. They also include costs of rehabilitation and social care. Some of the healthcare costs borne by infected persons are also included, in the form of prescription charges, and travel costs. The non-monetary costs of time taken to travel to and waiting for appointments at care providers is included, as is the value of work provided by informal carers. The lower bound estimates of healthcare costs are influenced by patient trajectories in the model that, for example,

are dominated by asymptomatic disease that require little intervention, and do not progress to HCV treatment or treatment for symptomatic HIV. Low estimates are also influenced by patient trajectories where death occurs soon after infection, but of causes unrelated to infection, for example, HCV infected people who die of causes related to the transfusions they received, but not related to the infection. The upper bound estimates of healthcare costs are influenced by trajectories that, for example, comprise symptomatic disease, and treatments for symptomatic HIV and/or HCV, possibly two rounds of treatment for HCV, treatment for ESLD, and end-of-life care for death from either HIV- or HCV-related infection.

		Units	Estimated Range
Costs	Healthcare costs	GBP [Millions] to nearest £100M	£ 900 - 1,600
	Productivity costs		£ 900 - 2,600
	Total Costs		£ 1,900 - 4,200
Health Losses	Mortality	Lost Quality-adjusted Life-Years to nearest 10,000	60,000 - 100,000
	Morbidity		10,000 - 90,000
	Total Health Losses		70,000 - 200,000
	Total valued health losses (at £30,000)	GBP [Millions] to nearest £100M	£ 2,000 - 5,900
	Total valued health losses (at £60,000)	GBP [Millions] to nearest £100M	£ 4,100 - 11,800

Table 17: Healthcare, productivity and health costs due to infected blood and blood products.

Notes: Costs over all infected individuals through to end 2021; upper and lower bound estimates generated by varying key parameters between lowest and highest values; Health costs are measured in quality-adjusted life-years (QALYs); inconsistencies in summations are due to rounding errors; valued health losses are obtained by multiplying total lost QALYs with alternative valuations of £30,000 and £60,000 per QALY.

The infected persons lost income because they could not work, became unemployed, or were less productive when at work. We consider the lost earnings due to productivity losses, based on average salaries over the decades. This is also a loss of the contribution the infected persons could have made to the UK economy. The productivity costs for the infections vary between £900mn and £2.6bn. Generally, the lower bound estimates of productivity loss are influenced by trajectories in the model with infections at an advanced age, i.e. close to or in retirement age, or where deaths occur (at any age) due to causes unrelated to the infection. The upper bound estimates of productivity costs are influenced, for example, by disease trajectories with infection-related deaths in young individuals, which implies that the total income over the expected remaining life-years is lost. Also, upper estimates are influenced by trajectories of those that survive but experience symptomatic disease and treatments that adversely impact ability to work productively.

Many infected persons died earlier than they would normally have, and they lived sometimes many years in ill-health. Lost health, both in terms of excess mortality and morbidity, can be converted into lost quality-adjusted life-years (QALYs). The total health loss measured in QALYs for the infections ranges between 70,000 and 200,000 QALYs (rounded to the nearest 10,000). There are slightly more QALYs lost due to excess mortality compared to excess morbidity in our simplified model, at a range of 60,000 – 100,000 QALYs for mortality and 10,000 – 90,000 QALYs for morbidity. The wide range in mortality estimates is partly due to the high uncertainty in the HCV-related mortality rate for both persons with and

without bleeding disorders, and uncertainty in the age at death. The lower bound estimates in mortality are influenced by trajectories where age at death is quite high and close to counterfactual age at death without infection, or for trajectories with deaths unrelated to the infection. The upper bound estimates in mortality are influenced by trajectories with low age at infection-related death, which means many QALYs are lost due to premature mortality when compared to (higher) counterfactual age at death. The lower bound estimates in morbidity are influenced by trajectories where death occurs soon after infection (irrespective of whether infection-related or not), because there are few years over which morbidity-related QALY loss can accrue. Lower bound estimates are also influenced by trajectories dominated by asymptomatic disease with little adverse impact on quality-of-life. Upper bound estimates are influenced by trajectories with many years lived, first in asymptomatic then symptomatic disease stages, and requiring treatments associated with severe side effects, for example, two rounds of HCV treatment, and ESLD or symptomatic HIV infection followed by end-of-life care.

The total loss in health due to IBBPs can be expressed in monetary terms, if we make the assumption that commonly cited willingness to pay thresholds for health technologies are applied and assume that these values are placed on a QALY. The total valued health losses would range between £2bn and £5.9bn (for £30,000 valuation), and £4.1bn and £11.8bn (for £60,000 valuation). These health costs may be added to the healthcare and productivity costs.

The costs and health loss per person can be calculated by dividing estimated values by the total number of infected individuals (see **Table 18**). The average healthcare and productivity costs per infected person range between about £48,000 and £202,000 over the period 1970 – 2021. Average lost QALYs range between 1.8 and 9.5 per person, that is between £53,000 – £284,000 (for a £30,000 valuation) and £107,000 – £568,000 (for a £60,000 valuation).

	Units	lower bound	upper bound
Average costs per infected person	GBP to nearest £5000	£48,000	£202,000
Average QALYs lost per infected person	Quality-adjusted Life-years	1.8	9.5
Average valued QALYs lost per infected person (£30,000 per QALY)	GBP to nearest £5000	£53,000	£284,000
Average valued QALYs lost per infected person (£60,000 per QALY)	GBP to nearest £5000	£107,000	£568,000

Table 18: Healthcare, productivity and health cost per infected person, 1979 – 2021

While welfare benefits are not included in the overall costs, they are of interest from a financial point of view. Based on the work of Connolly et al. (2018) we estimate that the value of benefits per year for chronic HCV prior to the final two years of life is £2,211.[74] During each of the final two years we estimate it at £16,782 per person per year. Although HCV and HIV are very different conditions, we felt it was not inappropriate to use these values for benefits provided to HIV patients (although using the three years prior to death for the higher amount). This results in a total over the period of interest of £2.2 billion for the cohort of HCV infected persons. It is not, though, valid to add this to the costs of treatments and lost work, due to concerns of double counting.

4.4.1 Sensitivity analyses

We conducted sensitivity analyses to determine how our assumptions on background mortality risk for non-infection related causes affects overall findings. For the main results we assume that persons without bleeding disorders had the same mortality risk as the general population, and persons with bleeding disorders a 24% higher mortality risk. In the sensitivity analysis, we assume a multiplier of value 2.0 for both groups, i.e. double the background mortality risk. The value of the multiplier is deliberately chosen to be large in order to estimate the greatest possible effect that this parameter could have on model results. We find that for the 2.0 multiplier, total costs and health losses are about 10% lower. This implies that even if we were to assume a very high background mortality, this would not have a very marked impact on results. The costs attributable to the infections are lower if background mortality for non-infection related causes is higher; first, individuals die earlier, and stop accruing healthcare costs, and losses due to reduced productivity and increased morbidity, and second, the health and productivity losses associated with deaths do not count towards the infection-related costs if these deaths are not caused by the infections.

4.5 Limitations of the quantitative analysis

The estimates of economic and health losses are uncertain. Overall, the members of the HEG believe that the costs are likely to be underestimated rather than overestimated. If assumptions or judgements had to be made, we usually erred on the conservative side. The modelling has many limitations, most of them due to the availability of data. In no particular order, limitations and assumptions include:

1. We do not calculate cost impacts for those infected with hepatitis B virus, because it is not possible to ascertain with any reasonable accuracy how many people were infected with hepatitis B virus between 1970 and 1991 through IBBPs, as also concluded by the SEG.[6]

2. We do not calculate cost impacts for onward transmission to partners, children or others since SEG were not able to estimate this.[6]

3. We do not calculate cost impacts for the five individuals infected with variant Creutzfeldt-Jakob Disease (vCJD) via IBBPs. Costs for those individuals would likely be high, because all five died of the infection. However, due to the small number of infected persons,[6] the impact on our total cost estimate would constitute a small additional fraction of the total costs reported here.

4. Uncertainty in estimates from the SEG report carries through to our estimates. The numbers of cases of infection are best estimates from the SEG report.[6]

5. Various costs are excluded due to lack of data or difficulty in measuring them in monetary terms, including lost unpaid work, inability to obtain financial products such as mortgages or insurance, reduced economic and educational opportunities, disengagement from formal learning, altered life courses, costs of private healthcare, and others.

6. Most costs that were borne by loved ones are not included, for example adverse health impacts and stigma, reduced work productivity (except for lost work due to informal care provision, which is partially included), unemployment, and all costs that are excluded for the infected individuals themselves. The qualitative analysis in section 3 helps to identify some of these impacts.

7. The availability of robust cost estimates to attach to the case numbers is limited. We rely on a small number of studies which themselves were based on various assumptions. Some studies provide conflicting estimates, and we have to accept the resulting discrepancies. For example, the method for costing informal care varies across the two cohorts because of differences in existing literature.

8. We do not analyse the impact of IBBPs on welfare payments, due to potential double counting.

9. Most estimates of costs and health impacts are taken from studies of the general HCV and HIV infected population, which may not be representative of the specific cohorts of individuals infected by IBBPs. Further, for individuals infected via IBBPs, we do not differentiate impacts by route of transmission, i.e. we do not consider whether infection occurred via blood or blood products.

10. We had to simplify disease trajectories. For example, we assume that individuals with HIV & HCV co-infection experience symptoms due to HIV first, and those who survive, go on to experience impacts related to asymptomatic HIV and the full clinical disease course of HCV. This is a simplification that will not reflect the life trajectories of many infected individuals.

11. However, many simplifications in disease trajectories have little impact on our overall cost estimates because we express all monetary costs in 2021 prices; this implies that, for the purposes of our model, it is irrelevant in which calendar year specific disease stages occur, as long as they occur with a certain probability during the 51-year projection horizon.

12. We have no data on year of infection and death, age at death, and disease progression including year of HCV treatment for the cohorts of infected persons. This is a major limitation, which means we cannot attach costs to specific years in which infections, treatments, and deaths occurred. We therefore have to treat year of infection, treatment and death for the cohorts as random variables, and draw their values from statistical distributions to determine the impact of uncertainty on our estimates.

13. We assume that the key parameters are statistically independently distributed. This is unlikely to be true for some parameters. For example, there may be an association between age of death and probability of infection-related death for HCV infected persons via transfusions, who in the first 10 or so years post transfusion are not expected to die on account of the chronic HCV but for transfusion-related reasons.

14. We do differentiate impacts for individuals with and without bleeding disorders, however, we do not differentiate impacts by type of bleeding disorder, e.g., haemophilia A or B, or other bleeding disorders. We do not consider other pre-existing conditions. However, our counterfactual disease trajectories are adjusted for age, and therefore, implicitly conditions that are typically associated with age.

15. We assume that individuals infected with HIV were co-infected with HCV. This is appropriate for those with bleeding disorders but may not hold for the estimated 79 - 100 individuals infected with HIV through blood transfusions between 1979 and 1991[6]. This may result in a slight overestimate of costs for HIV mono-infected, however, as this is such a small group our overall cost estimates are unlikely to be impacted substantially.

16. Healthcare costs are derived from studies that may not reflect treatment practices in all years of the time period. When we use more than one study for different periods, their approaches may not be comparable resulting in cost differences that are driven by methodology rather than reality.

17. The productivity costs are calculated using the human capital approach. While this is the most commonly used method, we do recognise that there has been ongoing debate among health economists on this and other approaches have been suggested (such as the friction cost approach which tends to result in lower costs).

18. The QALY losses are calculated based on studies that may not have been representative of the cohort of infected individuals, or of the actual treatment regimes and time periods.

19. Costs over time are usually subjected to discounting. This generally applies to (uncertain) future costs which are valued less than current costs due to time preferences. In these analyses we are using historic costs and so a form of inverse discounting might be applicable. We are unaware of precedents for this especially when calculating QALYs over time, therefore we are not applying any discounting.

20. We do not account for potential differences across men and women in disease progression and impact estimates.

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Appendix

Additional tables

Description	Proportions	Range	Description
Infected in Non-ESLD group that develop (compensated) cirrhosis	0.115	(0.11-0.12)	Compensated cirrhosis as a percentage of estimated chronic prevalence of HCV in England (2015-2020)
Infected in ESLD group that develop Liver cancer (HCC)	0.285	(0.23-0.34)	Number of first episodes of HCV-related HCC as a percentage of Number of first episodes of HCV-related ESLD/HCC in England (2010-2020)

Table A 1: Proportions in HCV disease stages used for generating weighted average costs

Source: UKHSA 2022: Hepatitis C in England and the UK[56]; Note: The time periods used depend on data availability. As of 2015, UKHSA updated estimation methods of the total number of people infected with HCV and updated values from 2010 onward.

@1992	HaemA <=5 IU/dl	HaemA other	HaemB <=5 IU/dl	HaemB other	Von Willebrand	Any Acquired	Other	Weighted average
N	2164.0	1255.0	489.0	285.0	781.0	24.0	308.0	
Mean age at 1st exposure to pooled plasma	16.6	27.2	16.6	23.0	35.0	56.1	30.3	**23.1**

Table A 2: sNHD3 Report table 3.2.2 - Mean age at 1st exposure to pooled plasma PwBD

Note: Bird, S, et al. 2022: Status report on the slim-National Haemophilia Database, version 3 (sNHD3)[49]

Year	Descriptor	Cost (GBP)	Source	Price year	2021_CPI adjusted	TOTAL (with social care) in GBP
Pre 1983	n/a	n/a	n/a	n/a	n/a	0
1983	IPD/OPD/tests/drugs	531.60	Beck et al., 1994[66]	1993	922.82	4549.79
1984	IPD/OPD/tests/drugs	864.20	Beck et al., 1994[66]	1993	1501.53	5128.5
1985	IPD/OPD/tests/drugs	994.20	Beck et al., 1994[66]	1993	1727.46	5354.43
1986	IPD/OPD/tests/drugs	883.80	Beck et al., 1994[66]	1993	1534.55	5161.52
1987	IPD/OPD/tests/drugs	810.40	Beck et al., 1994[66]	1993	1407.69	5034.66
1988	IPD/OPD/tests/drugs	791.10	Beck et al., 1994[66]	1993	1374.67	5001.64
1989	IPD/OPD/tests/drugs	937.90	Beck et al., 1994[66]	1993	1630.14	5257.11
1990-1995	IPD/OPD/tests/drugs	856.30	Beck et al., 1994[66]	1993	1487.63	5114.6
1996	IPD/OPD/dayward +AZT+ PI	12,592	Beck, 1998[63]	1998	19737.71	24037.82
1997	IPD/OPD/Dayward +triple HAART therapy	16,347	Mandalia, 2010[65]	2006	22813.67	26440.64
1998	IPD/OPD/Dayward +triple HAART therapy	16,542	Mandalia, 2010[66]	2006	23085.81	26712.78
1999	IPD/OPD/Dayward +triple HAART therapy	16,506	Mandalia, 2010[65]	2006	23035.57	26662.54
2000	IPD/OPD/Dayward +triple HAART therapy	15,941	Mandalia, 2010[65]	2006	22247.07	25874.04
2001	IPD/OPD/Dayward +triple HAART therapy	15,827	Mandalia, 2010[65]	2006	22087.97	22087.97
2002	IPD/OPD/Dayward +triple HAART therapy	16,257	Mandalia, 2010[65]	2006	22688.07	26315.04
2003	IPD/OPD/Dayward +triple HAART therapy	16,422	Mandalia, 2010[66]	2006	22918.34	26545.31

Year	Descriptor	Cost (GBP)	Source	Price year	2021_CPI adjusted	TOTAL (with social care) in GBP
2004	IPD/OPD/Dayward +triple HAART therapy	17,254	Mandalia, 2010[65]	2006	24079.47	27706.44
2005	IPD/OPD/Dayward +triple HAART therapy	16,930	Mandalia, 2010[65]	2006	23627.3	27254.27
2006-present	IPD/OPD/Dayward +triple HAART therapy	18,280	Mandalia, 2010[65]	2006	25511	29137.97

Table A 3: Per patient year health and medical costs for 'asymptomatic / 3+ years to death' HIV disease stage

key: IPD - Inpatient department; OPD - Outpatient department; 'drugs' - refers to any pharmacological treatment given to infected for the treatment of their symptoms; AZT - Zidovudine; PI - protease inhibitor; HAART - highly active antiretroviral therapy

Year	Descriptor	Cost (GBP)	Source	Price year	2021_CPI adjusted	TOTAL (with social and community care costs) in GBP
1979-1983	IPD/OPD/tests/drugs	5,317.80	Beck et al., 1994[66]	1993	9240.34	14033.43
1984	IPD/OPD/tests/drugs	2,838.70	Beck et al., 1994[66]	1993	4932.12	9725.21
1985	IPD/OPD/tests/drugs	4,743.30	Beck et al., 1994[66]	1993	8242.79	13035.88
1986	IPD/OPD/tests/drugs	2,272.20	Beck et al., 1994[66]	1993	3948.47	8741.56
1987	IPD/OPD/tests/drugs	3,407.10	Beck et al., 1994[66]	1993	5920	10713.09
1988	IPD/OPD/tests/drugs	3,194.10	Beck et al., 1994[66]	1993	5550.81	10343.9
1989	IPD/OPD/tests/drugs	3,069.90	Beck et al., 1994[66]	1993	5333.57	10126.66
1990-1995	IPD/OPD/tests/drugs	3,174.40	Beck et al., 1994[66]	1993	5516.05	10309.14
1996	IPD/OPD/dayward +AZT+ PI	13,446	Beck, 1999[10]	1998	21076.34	26588.22
1997	IPD/OPD/Com care +triple HAART therapy	19,806	Mandalia, 2010[65]	2006	27641.01	32434.1
1998	IPD/OPD/Com care +triple HAART therapy	21,006	Mandalia, 2010[65]	2006	29315.42	34108.81
1999	IPD/OPD/Com care +triple HAART therapy	21,980	Mandalia, 2010[65]	2006	30675.02	35468.11
2000	IPD/OPD/Com care +triple HAART therapy	19,683	Mandalia, 2010[65]	2006	27469.36	32262.45
2001	IPD/OPD/Com care +triple HAART therapy	19,521	Mandalia, 2010[65]	2006	27243.27	32036.36
2002	IPD/OPD/Com care +triple HAART therapy	19,954	Mandalia, 2010[65]	2006	27847.56	32138.24
2003	IPD/OPD/Com care +triple HAART therapy	21,474	Mandalia, 2010[65]	2006	29968.85	34761.94

Year	Descriptor	Cost (GBP)	Source	Price year	2021_CPI adjusted	TOTAL (with social and community care costs) in GBP
2004	IPD/OPD/Com care +triple HAART therapy	21,621	Mandalia, 2010[65]	2006	30174.0	34967.09
2005	IPD/OPD/Com care +triple HAART therapy	22,713	Mandalia, 2010[65]	2006	31697.99	36491.08
2006-present	IPD/OPD/Com care +triple HAART therapy	21,597	Mandalia, 2010[65]	2006	30140.51	34933.6

Table A 4: Per patient year health and medical costs for 'symptomatic / 2 years to death' HIV disease stage

key: IPD - Inpatient department; OPD - Outpatient department; 'drugs' - refers to any pharmacological treatment given to infected for the treatment of their symptoms; AZT - Zidovudine; PI - protease inhibitor; HAART - highly active antiretroviral therapy

Year	Descriptor	Cost (GBP)	Source	Price year	2021_CPI adjusted	TOTAL (with social and community care costs) in GBP
1979 -1982	IPD/OPD/Com care + no AZT	10,434	Beck, 1996[9]	1996	16912	25679.63
1983	IPD/OPD/tests/drugs	23,567	Beck et al., 1994[66]	1993	40956	49723.63
1984	IPD/OPD/tests/drugs	15,140	Beck et al., 1994[66]	1993	25311.58	34079.21
1985	IPD/OPD/tests/drugs	13,988	Beck et al., 1994[66]	1993	24309.54	33077.17
1986	IPD/OPD/Com care +AZT	17,880	Beck et al., 1994[66]	1996	28982.37	37750
1987	IPD/OPD/tests/drugs	12,747	Beck et al., 1994[66]	1993	22152.82	30920.45
1988	IPD/OPD/tests/drugs	13,225	Beck et al., 1994[66]	1993	22983.53	31751.16
1989	IPD/OPD/tests/drugs	14,029	Beck et al., 1994[66]	1993	24380.79	33148.42
1990-1995	IPD/OPD/tests/drugs				29976.38	38744.01
1996	IPD/OPD/dayward +AZT+ PI	22,988	Beck, 1999[10]	1998	36033.23	44800.86
1997	IPD/OPD/Com care +triple HAART therapy	38,887	Mandalia, 2010[65]	2006	54270.22	63037.85
1998	IPD/OPD/Com care +triple HAART therapy	37,626	Mandalia, 2010[65]	2006	52510.39	61278.02
1999	IPD/OPD/Com care +triple HAART therapy	38,483	Mandalia, 2010[65]	2006	53705.21	62474.04
2000	IPD/OPD/Com care +triple HAART therapy	37,242	Mandalia, 2010[65]	2006	51974.48	60742.11
2001	IPD/OPD/Com care +triple HAART therapy	39,981	Mandalia, 2010[65]	2006	55797.0	64564.63
2002	IPD/OPD/Com care +triple HAART therapy	36,978	Mandalia, 2010[65]	2006	51606.38	60373.68

Year	Descriptor	Cost (GBP)	Source	Price year	2021_CPI adjusted	TOTAL (with social and community care costs) in GBP
2003	IPD/OPD/Com care +triple HAART therapy	40,221	Mandalia, 2010[65]	2006	56131.94	64899.57
2004	IPD/OPD/Com care +triple HAART therapy	37,311	Mandalia, 2010[65]	2006	52070.38	60838.41
2005	IPD/OPD/Com care +triple HAART therapy	39,045	Mandalia, 2010[65]	2006	54490.73	63258.36
2006	IPD/OPD/Com care +triple HAART therapy	41,747	Mandalia, 2010[65]	2006	58261.61	67029.24

Table A 5: Per patient year health and medical costs for 'AIDS / year of death' HIV disease stage

key: IPD - Inpatient department; OPD - Outpatient department; 'drugs' - refers to any pharmacological treatment given to infected for the treatment of their symptoms; AZT - Zidovudine; PI - protease inhibitor; HAART - highly active antiretroviral therapy

Year	Descriptor	Cost (GBP)	Source	Price year	2021_CPI adjusted	TOTAL (with social care) in GBP
1990 - 1998	Non-cirrhosis	324.90	Dusheiko G.M, Roberts J.A., 1995[62]	1993	571.00	803.89
1999 - 2004	Non-cirrhosis	727.14	Wright and Grieve et al., 2006[67]	2003	1057.96	1290.86
2005 - 2014	Non-cirrhosis and cirrhosis	771.12	Wright and Grieve et al., 2006[67]	2003	1121.96	1463.09
2015-Pres.	Non-cirrhosis and cirrhosis	892.39	Hartwell, Jones, Baxter and Shepherd, 2011[68]	2011	1064.01	1405.14

Table A 6: Per patient year health and medical costs for 'Non-ESLD' HCV disease stage

key: IPD - Inpatient department; OPD - Outpatient department; 'drugs' - refers to any pharmacological treatment given to infected for the treatment of their symptoms; AZT - Zidovudine; PI - protease inhibitor; HAART - highly active antiretroviral therapy

Year	Descriptor	Cost	Source	Price year	2021_CPI adjusted	TOTAL (with social care) in GBP
1990	Decompensated cirrhosis and HCC	5130	Dusheiko G.M, Roberts J.A., 1995[62]	1993	9016	10626
1999	Decompensated cirrhosis and HCC	11409	Wright and Grieve et al., 2006[67]	2003	16599	18209
2015-Pres.	Decompensated cirrhosis and HCC	14459	Hartwell, Jones, Baxter and Shepherd, 2011[68]	2011	13603	13604

Table A 7: Per patient year health and medical costs for 'ESLD' HCV disease stage

Year	Descriptor	Cost (GBP)	Source	Price year	2021_CPI adjusted
1983 - 1999	Interferon	837	Dusheiko G.M, Roberts J.A., 1995[62]	1993	1471.00
1999-2014	RBV and interferon alpha	6514	Wright and Grieve et al., 2006[67]	2003	9477.67
2014	RBV and interferon alpha	6514	Hartwell, Jones, Baxter and Shepherd, 2011[68]	2011	7766.78
2015	DAA	69966	NICE - February 2015[76]	2015	78072.24
2016	DAA	36500	NICE - October 2016[77]	2016	40331.49
2017	DAA	38980	NICE - January 2017[78]	2017	41990.74
2018	DAA	44827	NICE - February 2018[80]	2018	47196.25
2019	DAA	38981	NICE - Jan 2018[79]	2019	40357.18

Table A 8: Per patient year health and medical costs for antiviral medical treatment of HCV

HCV costs calculations per disease group

To build estimates that incorporate the different HCV disease stages, within each group of Non-ESLD and ESLD, people infected are further divided into different conditions (see **Table A7** with proportions used for weighted average costs per group). In the Non-ESLD group, cirrhosis can appear 20 years after infection. This means that after 2000, a fraction of those that got HCV through transfusions or blood products will need treatment for HCV-related cirrhosis. We incorporate these costs by adding cirrhosis treatment costs to a fraction of those in the Non-ESLD group. In the same way, the ESLD group includes people infected with decompensated cirrhosis and HCC. We incorporate these costs by adding HCC treatment costs to a fraction of those in the ESLD group, and decompensated cirrhosis treatment costs to the remaining.

Because these fractions are unknown, we adopt proportions from national level data. The average cost per person per year for each group is thus a weighted average of different costs, where weights are the proportions of infected individuals in each stage of the disease. These proportions (or weights) are assumed to follow the national distribution and were taken from the latest publicly available UKHSA HCV data and supporting documents for England and the UK. For simplicity, we assume these proportions to be invariant over time. Table A7 shows the proportions values used for the different groups to compute weighted averages and their description.

Within the 'treatment group' we account for treatment costs for those who got treated successfully using the effectiveness rates reported in the literature for the different time periods. To those who either did not get treatment or got treatment but were not cured, we first apply costs of advancing disease (excluding end-of-life-care) and at the end of the period we apply DAAs costs to 90% of patients in this group.[57]

Additional figures

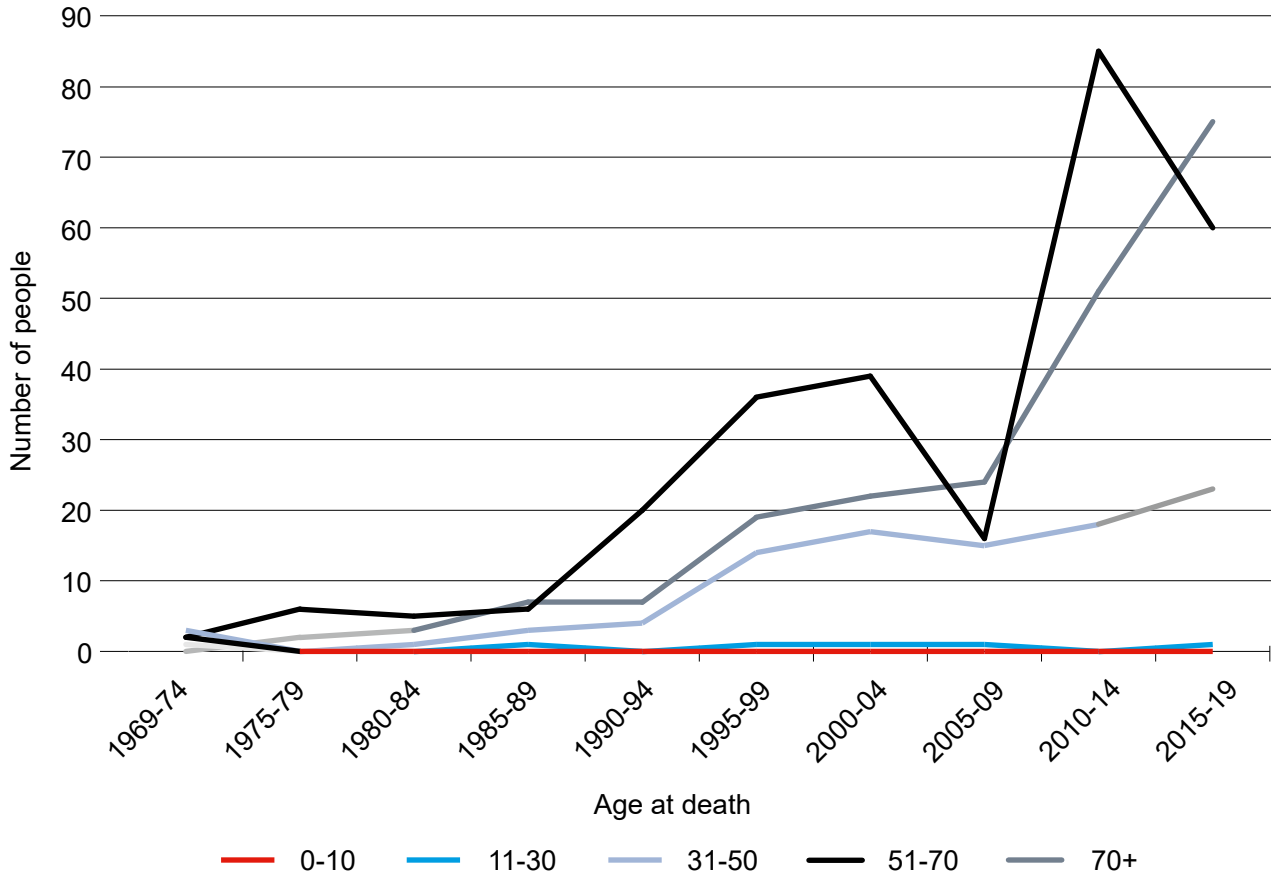

Figure A 1: PwBD HCV positives and presumed positives age groups at deaths - NHD & UKHCDO, Pivot Tables 12.3.1, Mortality trends in PwBD over time [WITN3826027][99]

Note:* UKHCDO defines: a) Tested HCV antibody positive: people with bleeding disorders with a HCV antibody positive test result reported to the NHD or HCV documented on the death certificate; b) HCV presumed positive: This group includes people with bleeding disorders born before 1992 with HCV-related liver disease or hepatocellular carcinoma (HCC) reported as the underlying cause of death or documented as significant co-morbidity in the absence of any HCV positive antibody result.[6]

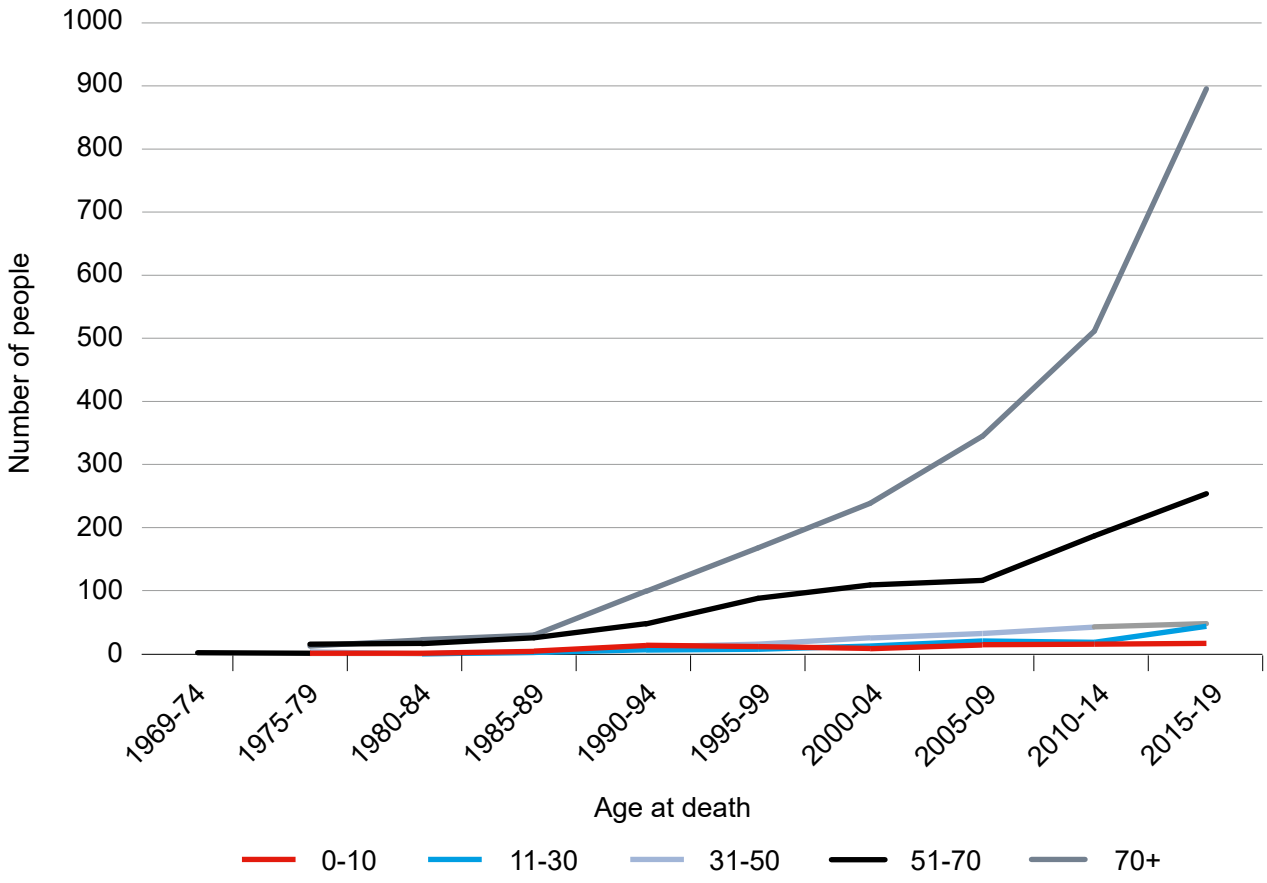

Figure A 2: Age groups at deaths of PwBD not known to be at risk HCV – NHD & UKHCDO, Pivot Tables 12.3.1, Mortality trends in PwBD over time [WITN3826027][99]

Note:* UKHCDO defines: c) Not known to be at-risk as people with bleeding disorders with no records of exposure to at-risk pooled concentrates or blood components on the NHD. Some of these people may have been exposed to an at-risk blood product without the NHD being aware.[6]

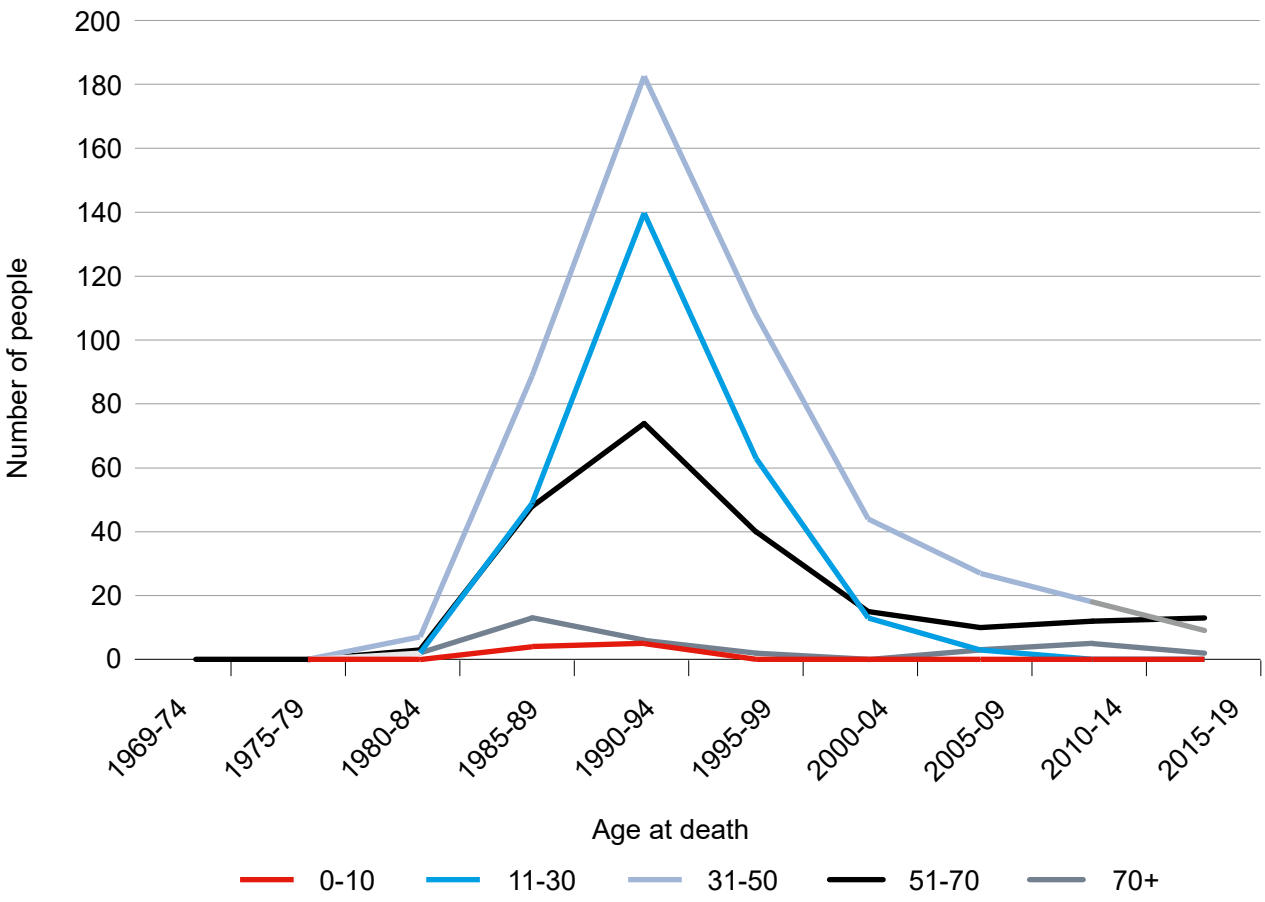

Figure A 3: HIV positives age groups at deaths - NHD & UKHCDO, Pivot Tables 12.3.1, Mortality trends in PwBD over time [WITN3826027][99]

Verifying Statements

Each contributing group member confirms that he or she understands his or her duty to provide independent evidence and has complied with that duty.

All contributing group members confirm that in respect of those parts of the report to which they have contributed:

(i) They have made clear which facts and matters referred to in this report are within their knowledge and which are not.

(ii) Those that are within their knowledge they confirm to be true.

(iii) The opinions they have expressed represent their true and complete professional opinions on the matters to which they refer.

Authors

Professor Katharina Hauck (Co-convenor)

Katharina Hauck is a professor in health economics and deputy director of the Abdul Latif Jameel Institute for Disease and Emergency Analytics (J-IDEA) at the School of Public Health, Imperial College London. She is specialized in the economics of infectious diseases and the economic evaluation of complex public health interventions. Katharina holds a PhD in Economics from the University of York. Her previous appointments were at Monash University (Australia), University of York (UK), and the World Health Organization in Geneva (Switzerland). Katharina is leading several large international collaborative studies on the economics of pandemic preparedness, medicine quality and the economics of malaria elimination. Katharina is a member of several national and international expert advisory groups on the economics of infectious diseases, and COVID-19.

Professor Paul McCrone (Co-convenor)

Paul McCrone is a health economist at the University of Greenwich. He was previously at the Institute of Psychiatry, Psychology and Neuroscience at King's College London, where he worked for 27 years after having previously worked at the University of Kent. He has worked on many economic studies in health and social care. He also teaches health economics to Masters level students, supervises PhD students, and has published widely in peer-reviewed journals. He is involved in policy discussions around health funding and is part of the NIHR-funded Mental Health Policy Research Unit.

Dr Laura Downey

Laura Downey is a senior research fellow in health systems science and economics at the George Institute for Global Health, a senior lecturer in the school of population health at the University of New South Wales Australia, and an honorary fellow at the School of Public Health at Imperial College London. Her research is focused broadly on evaluating health system performance in relation to Universal Health Coverage goals and developing innovative solutions to support equitable access to high quality, affordable care for the world's most vulnerable populations. Previously, Dr Downey was a technical advisor in global health at the International Decision Support Initiative (iDSI) based at the Centre for Global Development, where she worked with governments in low and middle income countries to support improvements in evidence-based health policy in relation to value for money of healthcare investment and quality of care delivery. She has held research and policy positions at the National Institute of Health and Care Excellence (NICE) UK, University College London (UCL) UK, and the University of New South Wales, Australia. Dr Downey has been closely involved in numerous health system reforms in India between 2015 and 2020, and remains a health policy mentor for the Indian Council of Medical Research and a distinguished fellow of the Indian Institute of Public Health. She has worked with country partners across Asia, Africa, and Europe in partnership with global institutions such as the World Health Organisation (WHO), and the World Bank.

Professor Timothy Hallett

Timothy Hallett is Professor of Global Health at Imperial College London, an Associate Director of the MRC Centre for Global Infectious Disease Analysis and a lead investigator at the Jameel Institute. His main research interests are characterising the epidemiology of, and the potential impact of interventions for, some of the most high burden infectious diseases globally (e.g. for HIV, HBV, HCV, TB); and, understanding how resources available for healthcare systems can be used to generate the greatest health gains for the population they serve (see tlomodel.org). He founded and directed the HIV Modelling Consortium (a network of epidemiologists, statisticians and health-economists focussed on HIV in the highest burden settings) and chaired the UNAIDS Reference Group on Estimates, Modelling and Projections (which reviews and develops the official methods for calculating AIDS statistics). He is an Affiliate Professor at the University of Washington, Department of Global Health, chair of the Modelling Guidance Group of The Global Fund and a Fellow of the Academy of Medical Sciences.

Professor Myfanwy Morgan

Myfanwy Morgan is Emeritus Professor at King's College London. Her research has contributed to the effective management of chronic conditions through studies at all stages of the patient pathway from the uptake of services to the use of prescribed treatments and issues of effective implementation and configuration of services. She currently collaborates with European research groups, and she led the King's College delegations to the Rollins School of Public Health, Emory University, and Witwatersrand University, South Africa, on Access to health care (editor Access to Health Care, Routledge). She has worked with multi-disciplinary groups across many clinical specialties and was a Research Adviser to studies undertaken by the Royal College of Surgeons and Royal College of Physicians. She has also been a member of DHSS Taskforce Implementation Groups and gave oral evidence to the All-Party Parliamentary Committees on organ and stem cell donation and transplantation. She was a member of MRC and NIHR grant awarding panels and was awarded Honorary Fellow of the Faculty of Public Health.

Dr Shevanthi Nayagam

Shevanthi Nayagam is a clinical academic and honorary consultant hepatologist at Imperial College London. Her research interests combine clinical research, epidemiology, applied modelling and health economics in guiding public health policy towards the elimination of viral hepatitis, with a focus on low-and middle-income countries. She co-leads the Imperial College Viral Hepatitis Applied Modelling group, is a research member of the PROLIFICA team (Prevention of Liver Disease and Cancer in Africa) and has worked with many countries to support their national hepatitis strategies. Since 2012 she has also worked with WHO in various advisory roles (including guidelines development) and is a member of the Vaccine Impact Modelling Consortium.

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Letter of Instruction

This report was produced in response to the following questions, extracted from the letter of instruction to the health economics expert group.

10. So as to inform his analysis and consideration of that evidence, the Chair would be assisted at this stage by receiving a report addressing the following topics, insofar as they are within your area of expertise and it is possible to address them on the evidence and data available to you:

    a. A cost-of illness study from a societal perspective of the impact to the United Kingdom, to the extent that it can be estimated, of infection from blood or blood products and its consequences.

    b. An historic cost-effectiveness analysis of the societal value of introducing surrogate testing of blood donations before HCV screening became available and also of introducing earlier HCV screening.