

Note by Counsel to the Inquiry on the Mortality of People Infected with HIV, HCV or both

Introduction

1. This note draws together the available information about annual mortality from the Alliance House Organisations and subsequent national financial support/payment schemes, as well as other organisations.
2. This is not intended as a substitute for, but as a supplement to, the evidence already received from the Statistics Expert Panel. At the Inquiry's preliminary hearings David Lock KC (acting on behalf of the core participants represented by Leigh Day) proposed that this analysis be done.
3. Data had been obtained from the following organisations:
 - a. Macfarlane Trust, Eileen Trust and Skipton Fund.
 - b. The four devolved financial support/payment schemes, namely the English ("EIBSS"), Welsh ("WIBSS"), Scottish ("SIBSS") and Northern Irish ("NIIBPS") Infected Blood Support/Payment Schemes. These provided data from 2017 to mid 2022.
 - c. The National Haemophilia Database ("NHD"), which is run by the United Kingdom Haemophilia Doctors' Organisation ("UKHCDO"). The NHD data relate to people with bleeding disorders only.
 - d. HCV Research UK.
 - e. UK Health Security Agency ("UKHSA").
4. Where data are available, mortality rates have been calculated for the following infection types:
 - a. Coinfected, stratified by HCV stage if possible;
 - b. HCV mono-infected, stratified by HCV stage if possible;
 - c. HIV mono-infected.
5. Unless otherwise stated, all references are to both primary and secondary infections. Primary infections are those contracted by way of treatment with infected blood or blood products. Secondary infections are the result of viral transmission from someone else who was themselves infected as a result of receiving infected blood or blood products.
6. Annual mortality rates have been calculated using the following formula:

$$\text{Annual Mortality} = \frac{\text{Deaths in year}}{\text{Living at year end} + \text{Deaths in year}}$$

The figure for annual mortality is then multiplied by 1,000 to give an annual mortality per 1,000 persons:

$$\text{Annual Mortality per 1,000 persons} = \text{Annual Mortality} \times 1,000$$

The final figure is rounded to the nearest 10.

Limitations

7. The reliability of the analysis set out below is limited by the accuracy and consistency of source data which vary between organisations. Moreover, as the data contributing to the mortality analysis are often calculated from other information, the final figures may not always be accurate.
8. Some datasets have too small a sample size to allow for meaningful analysis. Where appropriate, we have combined small datasets into a summary table.
9. This Note reports on mortality of all causes, rather than infection mortality. It therefore takes into account deaths unrelated to the infections in question. Because of this, the mortality calculations contain a distortion effect caused by non-infection mortality which will increase due to ageing of the infected cohort.
10. The analyses were not conducted by age-group and therefore do not account for the age-dependent effects of infection progression.
11. There is a presumption that people with bleeding disorders who were infected with HIV were also coinfecting with HCV due to the extremely high prevalence of HCV infection in this population.
12. The rolling registration of new infectees/beneficiaries and deaths occurring during a year mean that the figure for those living at the start of the year is not the same as those living at the end of the year plus deaths in that year, causing a small overestimation of the at risk group and small underestimation of annual mortality. This effect is more notable where new infectees/beneficiaries are being registered at a high rate such as during the early years in the NHD datasets. The analyses do not account for this effect, but any adjustment would have only a limited impact.

Mortality in people coinfecting with HIV and HCV

NHD

13. Along with their report entitled “*Bleeding Disorders Statistics for the Infected Blood Inquiry 2022*” [WITN3826016], NHD provided spreadsheets containing information on the number of new HIV and HCV cases as well as deaths by year [WITN3826020; WITN3826021].¹
14. Using these spreadsheets, the annual mortality rates have been calculated for people in the ‘HIV positive’ group, which includes people with bleeding disorders “with positive HIV antibody results reported to the NHD or who had AIDS documented as their underlying cause of death on their death certificate”² and who were assumed to be “inevitably co-infected with hepatitis C” [WITN3826016 ep.44]. The figures are shown in **Table 1.1**. A graphical presentation of the data is shown in **Figure 1**.

Year	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
1979	4	0	0
1980	24	0	0
1981	55	1	20
1982	117	1	10
1983	221	4	20
1984	535	8	20
1985	1164	20	20
1986	1200	40	30
1987	1177	43	40
1988	1146	43	40
1989	1096	57	50
1990	1032	68	60
1991	959	74	70
1992	882	79	80
1993	794	90	100
1994	700	96	120
1995	611	89	130

¹ The unredacted versions of these spreadsheets were used, which include date of death information.

² Not all these individuals have been infected in the UK: NHD & UKHCDO report that “[w]hen a newly immigrated PwBD [person with bleeding disorder] with HIV infection was registered on the database, the NDH did not record the country where the infection was potentially acquired” [WITN3826016 ep.41].

Year	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
1996	561	51	80
1997	528	34	60
1998	506	22	40
1999	487	19	40
2000	463	25	50
2001	450	13	30
2002	435	15	30
2003	426	9	20
2004	416	10	20
2005	407	9	20
2006	400	7	20
2007	394	6	20
2008	383	11	30
2009	374	9	20
2010	362	12	30
2011	355	7	20
2012	347	8	20
2013	342	5	10
2014	339	3	10
2015	332	7	20
2016	328	4	10
2017	325	3	10
2018	320	5	20
2019	315	5	20
2020	311	4	10

Table 1.1 Annual mortality rates for people with bleeding disorders who were infected with HIV and presumed to be coinfecting with HCV, calculated using NHD data, 1979-2020.

Mortality in PwBD coinfected with HIV and HCV (NHD)

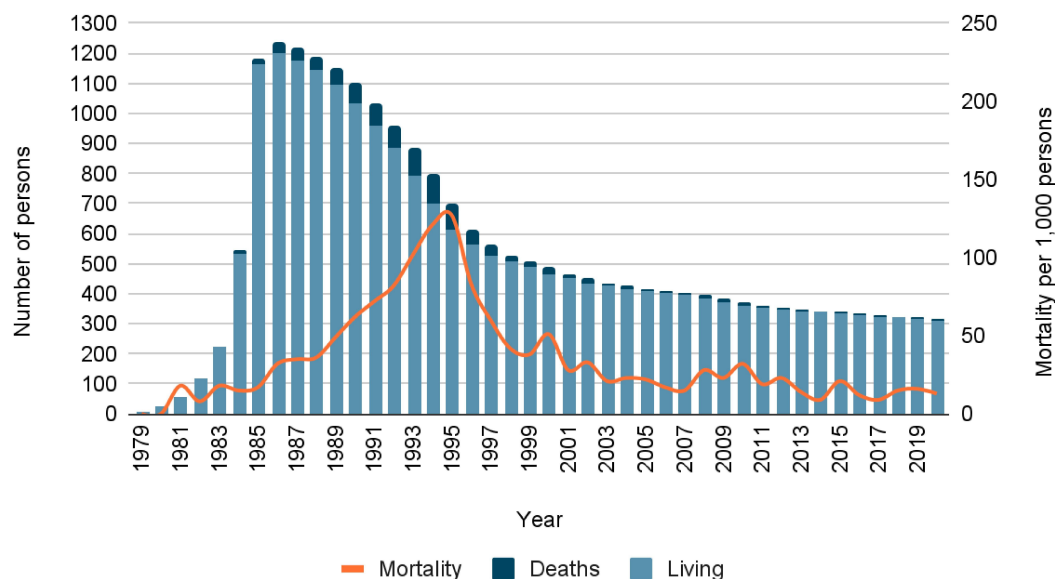


Figure 1 Annual mortality rates for people with bleeding disorders (“PwBD”) who were infected with HIV and presumed to be coinfected with HCV, calculated using NHD data, 1979-2020.

UKHSA

15. Using a spreadsheet provided by UKHSA [PHEN0002472], mortality rates for people infected with HIV via treatment for haemophilia in the UK have been calculated, shown in **Table 1.2**.³ A graphical presentation of the data is shown in **Figure 2**.

16. As can be seen when compared with the NHD data above, UKHSA recorded fewer people with bleeding disorders who were infected with HIV. This results in greater uncertainty in the mortality rate estimates.

Year	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
1984	81	3	40
1985	352	7	20
1986	388	13	30
1987	390	16	40
1988	381	20	50

³ See PHEN0002471 for a description of the exposure categories used in PHEN0002472. In the analysis in this note, the ‘Haemophilia’ and ‘Other blood products’ categories were used but not the ‘Blood products (undetermined)’ category, and data were analysed for those where the infection was acquired in the UK.

Year	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
1989	352	35	90
1990	314	40	110
1991	258	58	190
1992	212	49	190
1993	166	47	220
1994	152	16	100
1995	144	9	60
1996	142	2	10
1997	140	3	20
1998	139	1	10
1999	139	0	0
2000	136	3	20
2001	135	1	10
2002	133	2	20
2003	130	3	20
2004	126	4	30
2005	125	1	10
2006	125	0	0
2007	124	1	10
2008	119	5	40
2009	118	1	10
2010	116	2	20
2011	115	1	10
2012	115	0	0
2013	114	1	10
2014	114	0	0
2015	111	3	30
2016	110	1	10
2017	108	2	20
2018	105	3	30
2019	103	2	20
2020	102	1	10

Table 1.2 Annual mortality rates for people infected with HIV via treatment for haemophilia in the UK and presumed to be coinfecting with HCV, calculated using UKHSA data, 1984-2020.

Mortality in PwBD coinfected with HIV and HCV (UKHSA)

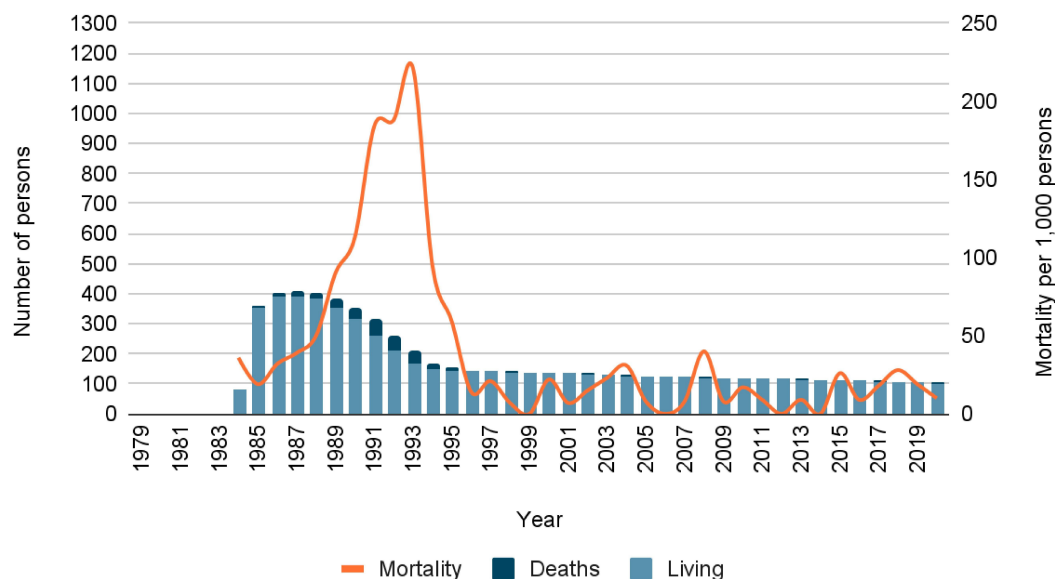


Figure 2 Annual mortality rates for people infected with HIV via treatment for haemophilia in the UK and presumed to be coinfected with HCV, calculated using UKHSA data, 1984-2020.

Macfarlane Trust

17. In total, 1,243 people with haemophilia were registered with the Macfarlane Trust as having been infected with HIV. 256 of them had died by March 1991, and by 31 March 2017 the number of survivors had reduced to 295. **Table 1.3** shows the annual figures from 1992 to 2017. The reported annual deceased figures may be a reflection of the year in which the Macfarlane Trust was notified of a beneficiary's death rather than actual year of death. A graphical presentation is shown in **Figure 3**.⁴

Source URN	Year (ending 31 March)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
MACF0000045_027, ep.5	1992	894	76	80
MACF0000045_026, ep.5	1993	817	81	90
MACF0000045_024, ep.4	1994	727	90	110

⁴ Data for the Macfarlane Trust were compiled primarily from the Trust's Annual Reports, which included some primary beneficiary and mortality data, up to date as of 31 March of each year, for the years 1991-2017. In a minority of years in which the Annual Report did not contain complete or reliable data, the Trust's Monthly Statistics have been used to supplement or substitute data obtained from the Annual Report. While the Monthly Statistics often provide more detailed data than the Annual Reports, the Inquiry does not hold a complete set of these records. It is therefore not possible to rely solely on the Monthly Reports in calculating annual mortality in primary beneficiaries of the Macfarlane Trust.

Source URN	Year (ending 31 March)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
MACF0000079_092, ep.1	1995	633	94	310
MACF0000045_022, ep.4	1996	561	71	110
MACF0000045_021, ep.4	1997	508	52	90
MACF0000045_020, ep.5	1998	480	28	60
MACF0000007_267	1999	466	14	30
MACF0000045_017, ep.5 MACF0000007_073	2000	439	27	60
MACF0000006_009, ep.5 MACF0000006_015	2001	422	17	40
MACF0000045_015, ep.5	2002	411	11	30
MACF0000009_127, ep.5 MACF0000009_263	2003	401	10	20
MACF0000045_012, ep.5 MACF0000045_013, ep.5 MACF0000009_198, ep.4-5 MACF0000009_081, para.26.03	2004	390	11	30
MACF0000045_012, ep.5	2005	380	10	30
MACF0000045_011, ep.6	2006	373	7	20
MACF0000045_010, ep.6 MACF0000004_046, ep.1	2007	366	7	20
MACF0000045_009, ep.6	2008	360	6	20
MACF0000045_008, ep.6	2009	346	14	40
MACF0000047_023, ep.6	2010	339	7	20
MACF0000047_017, ep.7	2011	327	12	40
MACF0000045_005, ep.6	2012	318	9	30
MACF0000045_004, ep.6	2013	312	6	20
MACF0000026_058, ep.6	2014	309	3	10
MACF0000045_002, ep.6	2015	304	5	20
MACF0000045_001, ep.6	2016	296	8	30
MACF0000027_096, ep.5	2017	295	1	<10

Table 1.3 Annual mortality rates for primary beneficiaries of the Macfarlane Trust who were infected with HIV and presumed to be coinfecting with HCV, 1992-2017.

Mortality in primary MFT beneficiaries coinfectd with HIV and HCV

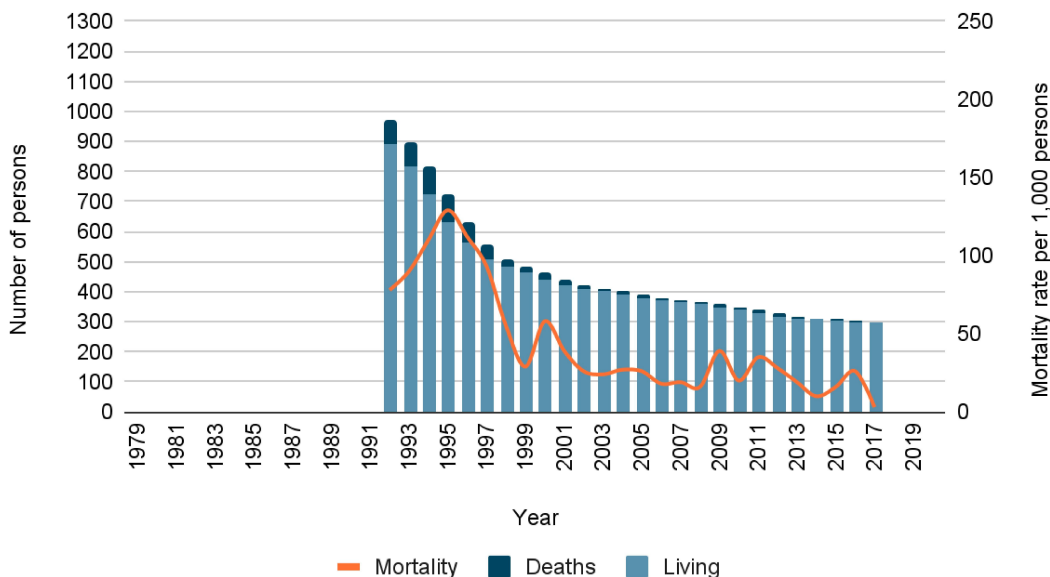


Figure 3 Annual mortality rates for primary beneficiaries of the Macfarlane Trust (“MFT”) who were infected with HIV and presumed to be coinfectd with HCV, 1992-2017.

Skipton Fund

18. The Skipton Fund made HCV stage 1 and stage 2 lump sum payments to those who met the eligibility criteria, which underwent several revisions during the scheme’s operating period resulting in expansions of the pool of eligible applicants, and from January 2011 the scheme was opened to the estates of people who had died prior to August 2003.

19. A master spreadsheet (the “SF Spreadsheet”) provided by the Skipton Fund has been used.⁵ While the SF Spreadsheet identifies applicants who were also beneficiaries of the Macfarlane Trust and therefore must have been coinfectd with HIV, this data is incomplete. Further, the pool of coinfectd Skipton Fund applicants is a small subset of the NHD, UKHSA and Macfarlane Trust datasets. For these reasons, it is unlikely that the Skipton Fund data add meaningfully to the analyses above.

⁵ The Inquiry is not disclosing the spreadsheet itself - it is a collation of personal data relating to individual applicants, much of which would have to be redacted if disclosed.

EIBSS

20. Data for current and deceased EIBSS beneficiaries between 1 April 2017 to 30 June 2022 have been provided by Brendan Brown in his statement dated 15 August 2022 [WITN4496026] and accompanying exhibit [WITN4496027]. **Tables 1.4** and **1.5** show mortality figures for those beneficiaries who were coinfecting with HIV and HCV (stage 1 and stage 2, respectively).⁶

Year (ending 31 March)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2018	179	0	-
2019	178	0	0
2020	175	0	0
2021	176	4	20
2022	176	3	20

Table 1.4 Annual mortality rates for EIBSS beneficiaries who were coinfecting with HIV and HCV stage 1 (including 'Special Category Mechanism' beneficiaries), 2019-2022.

Year (ending 31 March)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2018	60	0	-
2019	58	0	0
2020	57	0	0
2021	56	1	20
2022	57	0	0

Table 1.5 Annual mortality rates for EIBSS beneficiaries who were coinfecting with HIV and HCV stage 2, 2019-2022.

SIBSS, WIBSS and NIIBPS

21. There is insufficient data from these support schemes to conduct a mortality analysis for beneficiaries of these schemes who were coinfecting with HIV and HCV. **Table 1.6** combines the available figures obtained from SIBSS, WIBSS and NIIBPS.

⁶ The Inquiry has been informed by EIBSS that the data for the year ending 31 March 2018 were collated on a different basis from data for subsequent years. Caution is therefore needed when interpreting the 2018 data by way of year-on-year comparison.

Total number of registered beneficiaries (including deceased)	Deaths (occurring 2017-mid 2022)
49	3

Table 1.6 Combined data for beneficiaries of SIBSS, WIBSS and NIIBPS who were coinfecting with HIV and HCV.

22. The particular figures for beneficiaries coinfecting with HIV and HCV are as follows:

- a. In Scotland, 30 were registered, of whom 2 died since 2017 [SIBS0000132; WITN4728046].
- b. In Wales, 16 were registered with no deaths occurring since 2017 [WIBS0000082].
- c. In Northern Ireland, 3 were registered, of whom 1 died in 2021 [WITN4936028; WITN4936032].

Mortality in people mono-infected with HCV

Skipton Fund

23. To obtain the most reliable figures for Skipton Fund applicants who were mono-infected with HCV, those who were recorded as being beneficiaries of the Macfarlane Trust and must therefore have been coinfecting with HIV have been excluded from the analysis. It is possible that some of the other applicants who were not recorded as beneficiaries of the Macfarlane Trust were nonetheless also coinfecting, but the Inquiry has no way of identifying those potential individuals.

24. The analysis is focused on HCV stage 2 only as the Skipton Fund was not routinely notified of the deaths of stage 1 payment recipients. There are significant limitations to the usefulness of the data for calculating annual mortality since the numbers of registrations increased as deaths occurred for a number of years. Using the number of applications (excluding posthumous applications⁷) and subsequent deaths in each year between 2004 and 2017, the annual mortality rates for Skipton Fund applicants who were mono-infected with HCV stage 2 were calculated, shown in **Table 2.1**. A graphical presentation of the data is shown in **Figure 4**.

⁷ To identify posthumous applications, the applicant's date of death was compared against the date when their application for stage 1 payment was received by the Skipton Fund. That is, where an applicant died before his or her application for stage 1 payment was received, then the application is categorised as posthumous and excluded from the analysis.

Year (ending 31 Dec)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2004	653	16	20
2005	772	35	40
2006	815	35	40
2007	843	37	40
2008	875	23	30
2009	882	39	40
2010	880	49	50
2011	880	43	50
2012	880	49	50
2013	846	56	60
2014	833	45	50
2015	813	47	60
2016	789	46	60
2017	762	40	50

Table 2.1 Annual mortality rates for Skipton Fund applicants who were mono-infected with HCV stage 2, 2004-2017.

Mortality in Skipton Fund applicants mono-infected with HCV stage 2

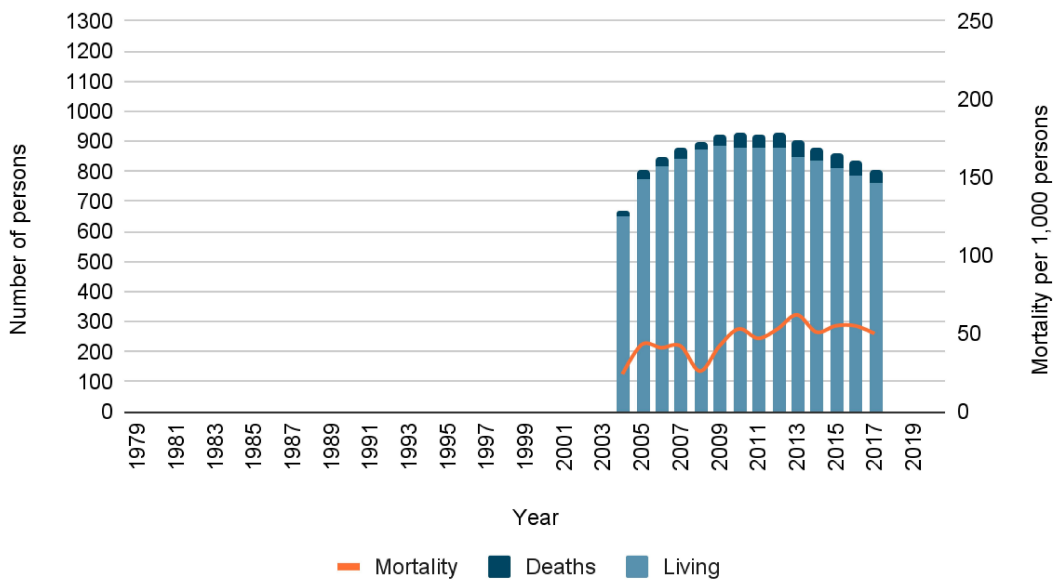


Figure 4 Annual mortality rates for Skipton Fund applicants who were mono-infected with HCV stage 2, 2004-2017.

NHD

25. **Table 2.2** shows the annual mortality rates for people with bleeding disorders who tested positive for HCV, excluding those who were also infected with HIV and those presumed to be infected with HCV but not tested. Therefore, this dataset is only some of the people infected with HCV through blood products and contains strong ascertainment bias in the years leading up to 2010 as only those who lived long enough to get tested were included. Nevertheless, this is the only NHD dataset for which data for calculating annual mortality is available and is therefore included for completeness. A graphical presentation of the data is shown in **Figure 5**.

Year	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
1979	2	0	0
1980	6	0	0
1981	19	0	0
1982	33	0	0
1983	69	0	0
1984	159	0	0
1985	332	0	0
1986	363	0	0
1987	372	0	0
1988	377	0	0
1989	379	0	0
1990	395	1	<10
1991	437	1	<10
1992	484	1	<10
1993	517	6	10
1994	545	10	20
1995	561	15	20
1996	575	5	10
1997	582	6	10
1998	585	4	10
1999	591	4	10
2000	595	6	10
2001	607	2	<10
2002	606	8	10
2003	608	5	10

Year	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2004	606	8	10
2005	605	4	10
2006	601	6	10
2007	600	1	<10
2008	598	4	10
2009	601	2	<10
2010	592	10	20
2011	584	8	10
2012	575	9	20
2013	566	9	20
2014	559	7	10
2015	550	9	20
2016	544	6	10
2017	537	7	10
2018	529	8	20
2019	521	8	20
2020	516	5	10

Table 2.2 Annual mortality rates for people with bleeding disorders who tested positive for HCV and did not test positive for HIV, calculated using NHD data, 1979-2020.

Mortality in PwBD mono-infected with HCV

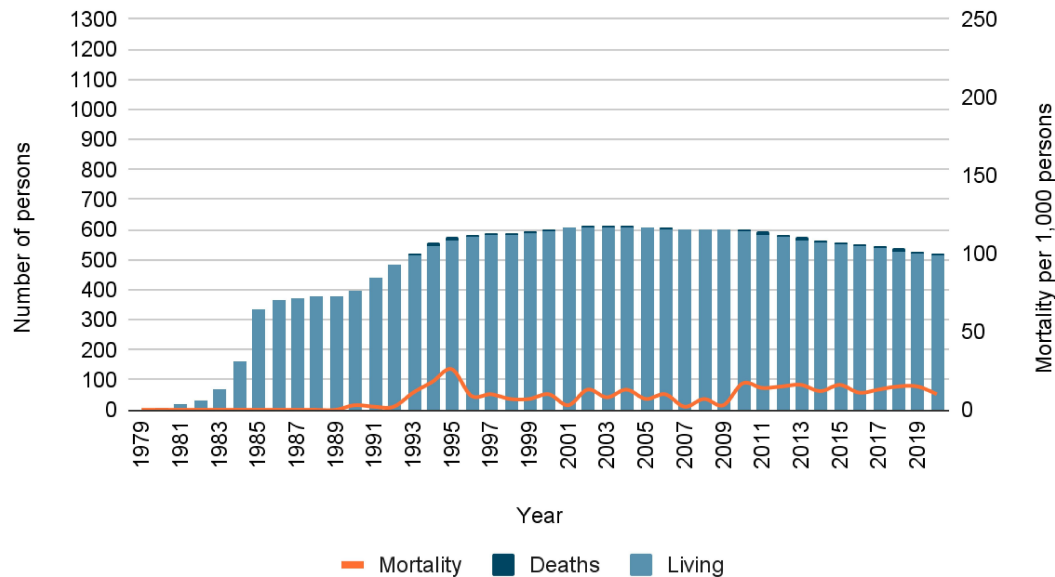


Figure 5 Annual mortality rates for people with bleeding disorders (“PwBD”) who tested positive for HCV and did not test positive for HIV, calculated using NHD data, 1979-2020.

HCV Research UK

26. A spreadsheet provided by HCV Research UK has been used.⁸ Their clinical database was set up in 2012 and includes over 10,000 patients from across the UK who have attended a specialist HCV clinic for care/management of their HCV infection. This has data about people infected through blood and blood products, with and without bleeding disorders. Their data from people with bleeding disorders is less complete than the NHD and is therefore not included. **Table 2.3** shows the annual mortality rates for people without bleeding disorders who were mono-infected with HCV through blood or blood products.⁹ This is believed to be a sub-set of those infected (with consequent limitations for the calculation of annual mortality) since the Statistics Expert Group estimated that some 2,700 people were chronically infected and survived to the end of 2019.¹⁰ A graphical presentation of the data is shown in **Figure 6**.

⁸ As with the SF Spreadsheet, the Inquiry is not disclosing this spreadsheet to protect the personal data in it.

⁹ It is not known whether these individuals were infected as a result of treatment received in the UK. The only proxy to that information is their country of birth data which show that, of the total of 108 people who died (including two whose date of death is unknown and therefore not included in Table 2.3), 34 (31%) are recorded as having been born outside the UK.

¹⁰ *Expert Report to the Infected Blood Inquiry: Statistics* (Statistics Expert Report), EXPG0000049 p.4.

Year	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2013	863	9	10
2014	884	18	20
2015	873	20	20
2016	861	16	20
2017	843	18	20
2018	828	15	20
2019	818	10	10
2020	818	0	0

Table 2.3 Annual mortality rates for people without bleeding disorders who tested positive for HCV, calculated using HCV Research UK data, 2013-2020.

Mortality in non-PwBD mono-infected with HCV

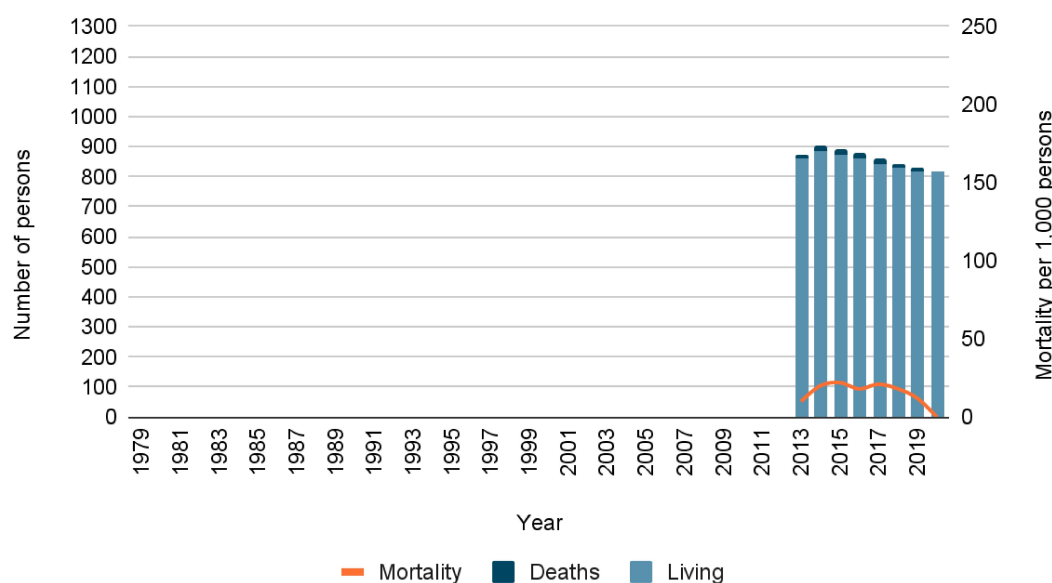


Figure 6 Annual mortality rates for people without bleeding disorders (“non-PwBD”) who tested positive for HCV, calculated using HCV Research UK data, 2013-2020.

EIBSS

27. **Tables 2.4** and **2.5** show figures for EIBSS beneficiaries who were mono-infected with HCV (stage 1 and 2, respectively).¹¹ A graphical presentation of the annual mortality rates is shown in **Figure 7**.

¹¹ The Inquiry has been informed by EIBSS that the data for the year ending 31 March 2018 were collated on a different basis from data for subsequent years. Caution is therefore needed when interpreting the 2018 data by way of year-on-year comparison.

Year (ending 31 March)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2018	1678	17	-
2019	1688	32	20
2020	1728	23	10
2021	1735	36	20
2022	1752	26	20

Table 2.4 Annual mortality rates for EIBSS beneficiaries who were mono-infected with HCV stage 1 (including 'Special Category Mechanism' beneficiaries), calculated using data obtained from **WITN4496026**, 2019-2022.

Year (ending 31 March)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2018	642	12	-
2019	579	33	50
2020	575	38	60
2021	569	29	50
2022	560	22	40

Table 2.5 Annual mortality rates for EIBSS beneficiaries who were mono-infected with HCV stage 2, calculated using data obtained from **WITN4496026**, 2019-2022.

Mortality in EIBSS beneficiaries mono-infected with HCV

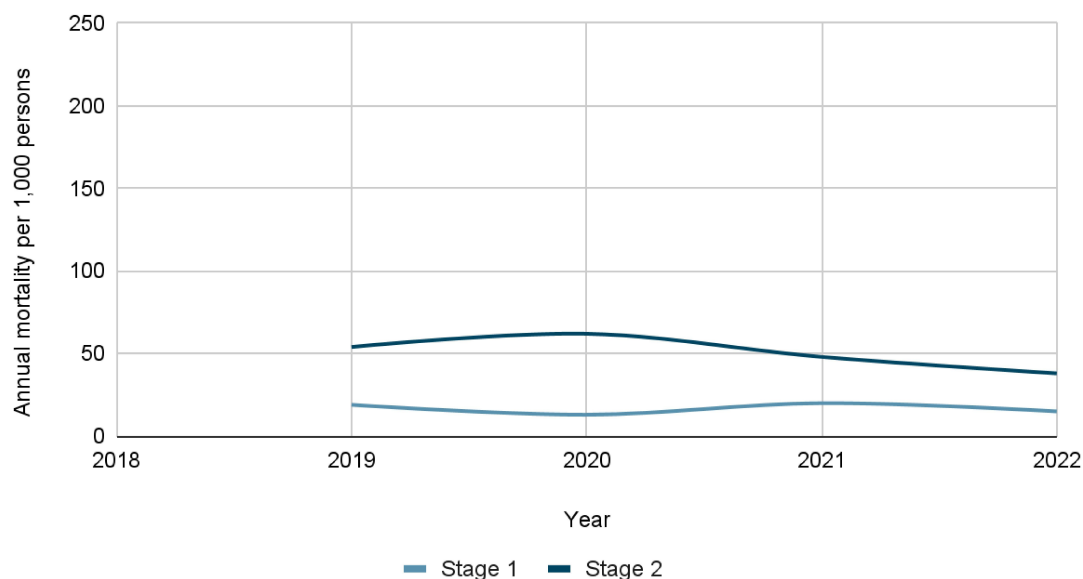


Figure 7 Annual mortality rates for EIBSS beneficiaries who were mono-infected with HCV, 2019-2022.

SIBSS

28. **Tables 2.6** and **2.7** show figures for SIBSS beneficiaries who were mono-infected with HCV (stage 1 and 2, respectively).

Year (ending 31 December)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2017 ¹	87	10	-
2018	282	6	20
2019	307	8	30
2020	321	7	20
2021	338	10	30
2022 ²	-	0	-

Table 2.6 Annual mortality rates for SIBSS beneficiaries who were mono-infected with HCV stage 1, calculated using data obtained from **WITN4728046**, 2018-2021.

Note:

1. SIBSS began operation in April 2017.
2. Data for 2022 is incomplete.

Year (ending 31 December)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2017 ¹	117	10	-
2018	117	6	50
2019	113	8	70
2020	108	8	70
2021	96	13	120
2022 ²	-	2	-

Table 2.7 Annual mortality rates for SIBSS beneficiaries who were mono-infected with HCV stage 2, calculated using data obtained from **WITN4728046**, 2018-2021.

Note:

1. SIBSS began operation in April 2017.
2. Data for 2022 is incomplete.

NIIBPS

29. **Table 2.8** shows figures for NIIBPS beneficiaries who were mono-infected with HCV.

Year (ending 31 December)	Living at year end	Deaths in year	Annual Mortality per 1,000 persons
2018	78	2	30
2019	82	0	0
2020	80	3	40
2021	79	2	30
2022 ¹	-	1	-

Table 2.8 Annual mortality rates for NIIBPS beneficiaries who were mono-infected with HCV, calculated using data obtained from **WITN4936028**, 2018-2022. Note:

1. Data for 2022 is incomplete.

WIBSS

30. 167 people who were mono-infected with HCV registered with the scheme between 2017 and mid-2022, with 13 deaths occurring during that period [**WIBS0000082**].¹²

¹² The Inquiry has been informed by WIBSS that, in WIBS0000082, deceased figures are not included in the total number of beneficiaries. This was not known when the Inquiry's Statistics Expert Group prepared their Statistics Expert Report published in September 2022, which explains the discrepancy in their figures shown in EXPG0000049 p.87 Table 5.2.

Mortality in people mono-infected with HIV

UKHSA

31. **Table 3.1** shows the 5-yearly pooled mortality rates for people infected with HIV via blood, tissue or organ transfer in the UK as annual estimates would not be appropriate due to the small population. A graphical presentation of the data is shown in **Figure 8**.

Period	Living at period end	Deaths in period	Pooled Mortality per 1,000 persons
1983-1990	139	32	190
1991-1995	101	24	190
1996-2000	69	9	120
2001-2005	65	0	0
2006-2010	65	0	0
2011-2015	62	1	20
2016-2020	60	0	0

Table 3.1 5-yearly pooled mortality rates for people infected with HIV via blood, tissue or organ transfer in the UK, calculated using UKHSA data, 1983-2020.

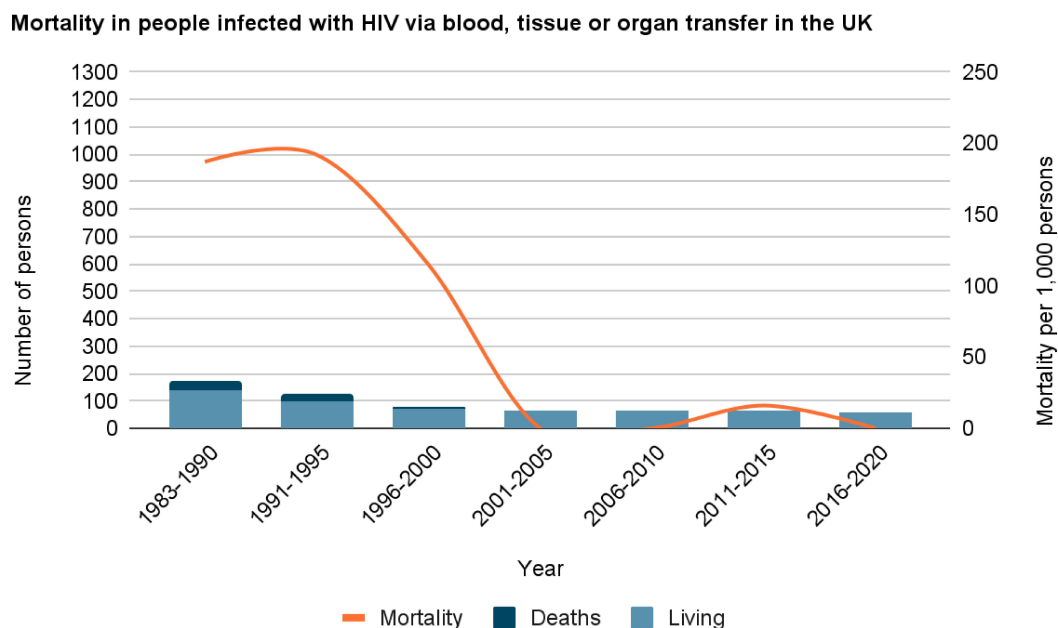


Figure 8 5-yearly pooled mortality rates for people infected with HIV via blood, tissue or organ transfer in the UK, calculated using UKHSA data, 1983-2020.

Eileen Trust

32. From the Eileen Trust's Annual Reports, the Inquiry obtained data for people who were infected with HIV other than by blood products produced for the treatment of haemophilia and who registered with the Eileen Trust. However, due to inconsistencies in the way figures were reported throughout the Trust's operating period and the small sample size, it has not been possible to conduct an accurate or meaningful mortality analysis. The available data are therefore presented in **Table 3.2** without calculating annual mortality figures.

Source URN	Year (ending 31 March)	Living infected registrants	Deaths in year
EILN0000016_060; EILN0000006_185	1994	13	5
DHSC0002779_002; EILN0000006_165	1995	12	12
<i>For the years 1996-2003 the figure in brackets represents indirectly infected registrants.</i>			
EILN0000016_058	1996	12 (2)	5
EILN0000016_057	1997	8 (5)	4
EILN0000016_056	1998	9 (1)	2
EILN0000016_055	1999	9 (2)	0
EILN0000016_054	2000	10 (2)	2
EILN0000016_053	2001	10 (2)	0
EILN0000016_052	2002	10 (4)	0
EILN0000016_051	2003	11 (4)	0
<i>From 2004 ET stopped reporting on "directly infected" registrants but instead on "registrants and other qualifying beneficiaries ... whose infection arose through medical treatment".</i>			
EILN0000016_050	2004	28	0
EILN0000016_043	2005	28	0
EILN0000016_042	2006	28	0
EILN0000017_007	2007	27	1
EILN0000016_038	2008	23	1
<i>From 2009 ET started to report on the "number of registrants". This could be assumed to be directly and indirectly infected individuals. The figure in brackets (2009-2017) represents the total number of beneficiaries to whom the Trust provides assistance.</i>			
EILN0000016_037	2009	16 (23)	2
EILN0000016_036	2010	16 (21)	0
EILN0000016_035	2011	16 (19)	0
EILN0000016_034	2012	17 (20)	0
EILN0000016_033	2013	15 (16)	0
EILN0000016_032	2014	17	1

Source URN	Year (ending 31 March)	Living infected registrants	Deaths in year
EILN0000016_031	2015	17	0
EILN0000016_030	2016	17	0
EILN0000016_029	2017	19 (25)	0

Table 3.2 Figures obtained from the Eileen Trust's Annual Reports, 1996-2017.

EIBSS, SIBSS, WIBSS and NIIBPS

33. **Table 3.3** shows the combined numbers of beneficiaries who were mono-infected with HIV and deaths between 2017 and mid 2022 as recorded by EIBSS, SIBSS, WIBSS and NIIBPS.

Total number of registered beneficiaries	Deaths (occurring 2017-mid 2022)
78	3

Table 3.3 Combined data for beneficiaries of EIBSS, SIBSS, WIBSS and NIIBPS who were mono-infected with HIV.

34. The particular figures for beneficiaries mono-infected with HIV are as follows:

- a. In England, 66 were registered, of whom 2 died since 2017 [WITN4496026].
- b. In Scotland, 7 were registered with no deaths since 2017 [SIBS0000132; WITN4728046].
- c. In Wales, 3 beneficiaries were registered, of whom 1 died since 2017 [WIBS0000082].
- d. In Northern Ireland, 2 were registered with no deaths since 2017 [WITN4936028].

Comparison of mortality in different infection types

35. A comparison was undertaken of the annual mortality rates over time for people with different infection types using the above calculations for organisations operating:

- a. pre-2017, shown in **Figure 9**;
- b. post-2017, shown in **Figure 10**.

Mortality by infection type, pre-2017

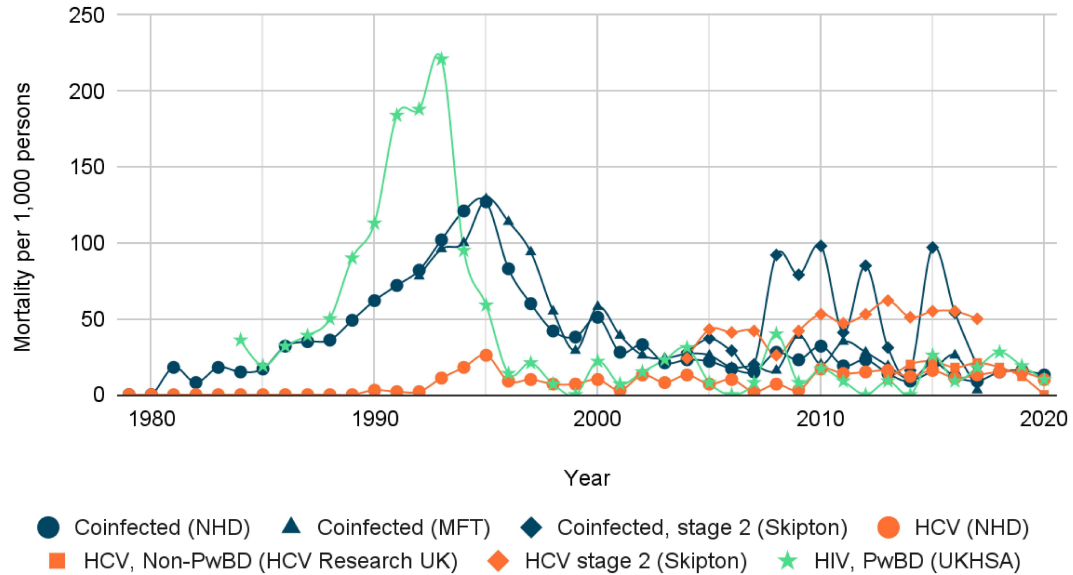


Figure 9 Annual mortality rates for people with (“PwBD”) and without bleeding disorders (“Non-PwBD”) by infection type. NHD (1980-2020), Macfarlane Trust (“MFT”) (1992-2017), Skipton Fund (2004-2017) and HCV Research UK (2013-2020).

Mortality by infection type, post-2017

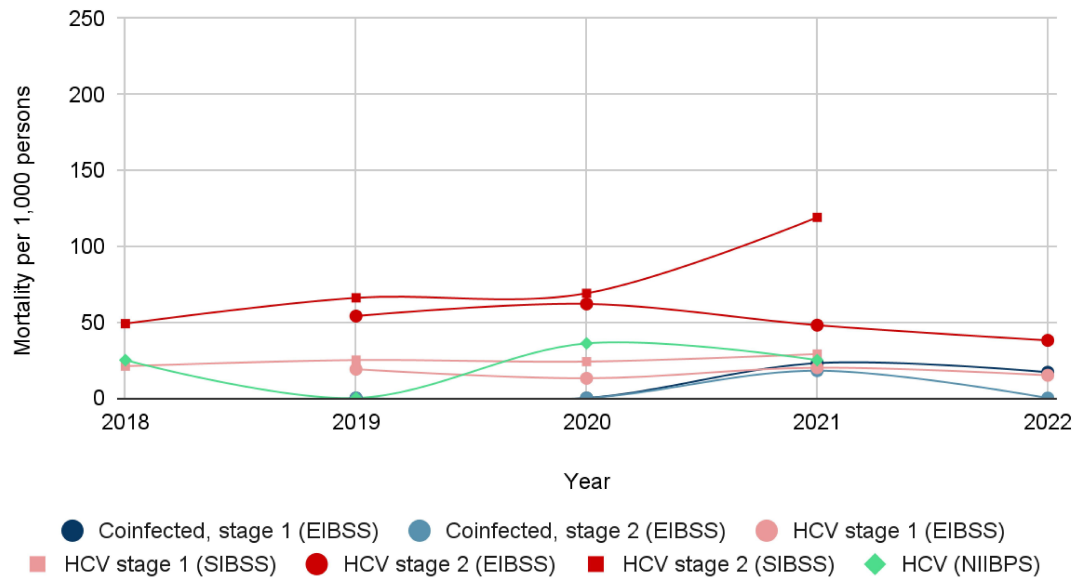


Figure 10 Annual mortality rates for national support/payment scheme beneficiaries by infection type. EIBSS (2019-2022), SIBSS (2018-2021) and NIIBPS (2018-2021).

Organisations' observations on the impact of HIV and/or HCV infection

36. In addition to the numerical data presented above, individuals in the various organisations made some observations about mortality. Some examples are given below.

- a. In an article entitled "*The impact of HIV on mortality rates in the complete UK haemophilia population*" published by UKHCDO in 2004 in AIDS [PARA0000145], the authors noted that although "*the impact of co-infection with HCV on mortality in HIV infection is hard to estimate precisely*", it was "*probably proportionately small*" before 1997 but increased substantially during 1997-1999 [ep6].
- b. The Macfarlane Trust in their 2001 Annual Report described coinfection with HCV as a "*serious complication for treatment of HIV*" and reported that it had "*become the leading cause of mortality among the Trust's registrants*" [MACF0000006_009 ep5]. This observation was repeated in their 2003 Long Term Review: "*Development of combination drug therapies in the mid to late 1990s substantially reduced the death rate of registrants from HIV/AIDS. HCV is now the largest cause of death for people living with haemophilia, HIV and HCV*" [MACF0000172_001 ep.9].
- c. In the "*Skipton Fund Administrator's Report for the Year Ending 31 March 2010*", Nicholas Fish stated: "*Nearly 20% of total applicants who received the stage 1 payment have also received the stage 2 payment; this figure was 17% at the end of March 2008 and just 14% in 2006. Unfortunately this percentage continues to increase slowly over time due to the damaging effect that hepatitis C has on the liver. Further analysis of the above figure shows that 26% of Macfarlane Trust beneficiaries have received both payments and only 19% of non-Macfarlane Trust beneficiaries, almost definitely due to the further damaging effects on the liver of co-infection with HIV*" [SKIP0000030_105 ep.2].
- d. In November 2010 a "*Review of support to patients affected by contaminated blood: Assumptions used in modelling*" was conducted by the Health Protection Analytical Team at the Department of Health to estimate future costs of the support schemes [SKIP0000031_059]. Those contributing to the Review included Peter Stephens (Eileen Trust), Christopher FitzGerard (Macfarlane Trust), Nicholas Fish (Skipton Fund) and Charles Hay (UKHCDO). The Review used the following assumptions on annual mortality [ep.9]:

- i. *“For Skipton Fund Stage 1 recipients, we assume that the annual mortality rate is 3%, increasing by 0.5%-points roughly every 10 years, broadly in line with the increase seen for those in the HCV National Register.”*
- ii. *“For Skipton Fund Stage 2 recipients, we assume that the annual mortality rate is 5%, increasing by 1%-point roughly every 10 years. This is an average for all Skipton Fund Stage 2 recipients, i.e. those with cirrhosis and liver cancer.”*
- iii. *“For MacFarlane Trust recipients, we assume that the average annual mortality rate is 2%, increasing by 1%-point roughly every 10 years. This is lower than the average annual mortality rate for the average Skipton Fund Stage 1 recipient, since it takes into consideration that the majority of HIV infectees have bleeding disorders, and therefore were infected at a younger age than those infected via blood transfusion.”*

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31 March 2023