

Note by Counsel to the Inquiry on the number of children with bleeding disorders who were infected with HIV

Introduction

1. On 16 September 2022, the Inquiry published a report by its Statistics Expert Group. The report concluded that: *“around 1,250 people with bleeding disorders were infected with HIV in the UK between 1970 and 1991”* [EXPG0000049, ep.12].
2. On 6 October 2022, BBC News published an article titled: *“HIV: How 175 British children were infected with disease”* [RLIT0001834]. The article reported that: *“at least 175 children with the blood disorder haemophilia were infected with HIV in the 1980s, according to documents from the national archives”*.
3. The wording “at least” suggests the number might be greater. The purpose of this note is to examine whether a greater accuracy can be given to it.

Conclusion

4. The Inquiry’s current view of the number of children likely to have been infected with HIV through blood products in the UK is that the figure of 175 derives from the HIV Haemophilia Litigation as the number who were still children at the time of the settlement. The Inquiry estimates that the number of people who were children when infected is more than two times that number.

Reasons for this Conclusion

5. The Inquiry has made three estimates. The first estimate is based on the proportion of children among people with bleeding disorders. This suggests that ~375 people are likely to have been infected with HIV as children. The second estimate is based on data published in *The Lancet* in 1996. It suggests around ~400 people with bleeding disorders were infected with HIV as children. The third estimate is based on data provided by the UK Haemophilia Doctors’ Organisation. It suggests that ~360 people with bleeding disorders were infected with HIV as children in the UK. Overall, we estimate with moderate confidence that almost a third of people infected with HIV through blood products were children.

¹ Available online: <https://www.bbc.co.uk/news/health-63080849>

6. In this note, except where otherwise stated: ‘child’ means any person 17 years old or younger; ‘children with bleeding disorders’ refers to children diagnosed with Haemophilia A, B or C or Von Willebrand Disease.² It is important to point out that this note does not include numbers of children infected in the UK as a result of blood transfusion.

HIV Haemophilia Litigation

7. The earliest reference to ‘175 children’ is found in the Plaintiffs’ *“Proposed Heads of Compromise”* in the HIV Haemophilia Litigation [DHSC0003654_117]. The *Compromise* is undated but appears to have been produced around 11 November 1990 [ibid. ep.3].
8. The *Compromise* indicated the Plaintiffs would settle the Litigation for £42 million. This sum was to be paid to Plaintiffs and registrants to the Macfarlane Trust - a total of 1,390 people - in six categories:

<i>“Category</i>	<i>number</i>	<i>quantum each</i>	<i>total</i>
<i>child</i>	175	£21,500	£3,762,500
<i>single man</i>	533	£23,500	£12,525,500
<i>married but childless</i>	214	£32,000	£6,848,000
<i>married with children*</i>	293	£60,500	£17,726,500
<i>infected intimates</i>	25	£23,500	£587,500
<i>category G</i>	150	£2,000	£300,000
		<i>Total:</i>	<i>£41,750,000”</i>

[DHSC0003654_117, ep.1]

9. It is therefore likely that ‘175 children’ refers to people who were under 18 in November 1990. If so, ‘175 children’ will be an undercount, as it excludes people infected with HIV as children who had reached adulthood by late 1990.
10. The Government’s *“Proposed Detailed Terms of Settlement,”* dated December 1990, confirms that ‘175 children’ excludes people who had reached adulthood by late 1990. A child³ is defined as: *“a haemophiliac under 18 years old on 13th December 1990”* [DHSC0003655_022, ep.2].
11. On 12 December 1990, *The Guardian* and *Daily Telegraph* reported that the Government had offered compensation to people infected with HIV, including ‘175 children’ [DHSC0003654_039; DHSC0032267_105]. ‘175 children’ are

² This definition follows that in “Expert Report to the Infected Blood Inquiry: Bleeding Disorders and Blood Disorders” [EXPG0000002, ep.13]

³ Some copies of the *Settlement* use the term “infant”, other copies use “child” [DHSC0003655_048]

referred to in other contemporaneous material from the National Archives:
DHSC0003654_110; DHSC0105650_026.

12. Furthermore, the figure of 175 children, because it originates in the HIV Haemophilia Litigation, will, self-evidently, only include those who were part of that litigation. The figure does not, as the Inquiry understands it, include those infected in Scotland.

Estimates of the number of children with bleeding disorders infected with HIV

Estimate based on the proportion of children among people with bleeding disorders

13. Until the introduction of cryoprecipitate, people with bleeding disorders did not enjoy the same life expectancy as those free of the condition. The proportion who were children was consequently greater than that in the general population. A survey of 5,098 people with bleeding disorders published in March 1983 found 1,766 people were aged 0-19 [**HCDO0000586, epp.3-4**].⁴ Of these people, 1,580 (90%) can be expected to have been 17 or younger, and therefore children.⁵ Therefore, ~30% of people with bleeding disorders were children in 1980.

14. Given that around 1,250 people with bleeding disorders were infected with HIV in the UK [**EXPG0000049, ep.12**], 30% would suggest with moderate confidence that ~375 people are likely to have been infected as children (assuming an even distribution of infections across age groups). Some children under 6 years old were treated with lower-risk blood products such as cryoprecipitate or NHS concentrates, meaning the proportion infected as children may have been lower than 30%, though some large treatment centres for children made extensive use of commercial products including Treloar's, Birmingham Children's Hospital, Alder Hey and Yorkhill.

Estimate using data published by The Lancet

15. A study for UKHCDO published by *The Lancet* in 1996 estimated that of 1,229 people with haemophilia and HIV, 307 people (25% of the cohort) had experienced seroconversion under the age of 15 [**HSOC0002661, ep.2**].
16. A further 595 people experienced seroconversion between the ages of 15-34. Of these people, ~90 (15%⁶) would have been infected with HIV as children, assuming an even distribution of infections across age groups. Therefore, the

⁴ Tables II and III: (A. 206 + 322 + 962) + (B. 39 + 69 + 168) = 1,766

⁵ 2/20 year-groups studied were adults (aged 18 and 19). The remaining 90% were children.

⁶ 3/20 = 0.15

1996 study would suggest with moderate confidence that ~400 people were infected with HIV as children. This could be a slight undercount. Around 1,250 people with bleeding disorders were infected with HIV in the UK, whereas only 1,229 people featured in the 1996 study.

Estimate using data provided by UKHCDO

17. The UK Haemophilia Centre Directors' Organisation ("UKHCDO") reported that 1,338 people with bleeding disorders were infected with HIV [WITN3826016, **ep.39-42**]. Of these people, around 1,250 were infected in the UK and the remainder were infected abroad [EXPG0000049, **ep.12**].
18. UKHCDO provided anonymised age data as of 31 December 2020 for 1,336⁷ people infected with HIV [WITN3826021, **Source data**]. From this data, it is possible to calculate ages in previous years. For instance, a person aged 51 or younger on 31 December 2020 would have been 17 or younger on 31 December 1986.
19. Evidence currently available to the Inquiry indicates that HIV infections in people with bleeding disorders occurred in the UK between approximately June 1979 and October 1986 [HCDO0000264_095 **ep.2**]. Assuming for the purposes of this estimate that no infections occurred outside these dates, 297 people were 17 or younger on 31 December 1986 and can be treated as 'confirmed' to have been infected as children, though not all will have been infected in the UK.
20. An additional 288⁸ people with bleeding disorders were under 18 in December 1978 and over 18 in December 1986. These people may have been infected with HIV when they were children. Because no central record was kept of infected batches, it is necessary to estimate the number of these 288 people who were infected as children. Applying the proportion of children from the survey of March 1983⁹ (30%) suggests an additional 86¹⁰ of these people would have been infected with HIV as children. This source thus leads to an estimate of 383 (297 + 86) infected as children. Not every person in this data source will have been infected in the UK.
21. The Inquiry's Statistics Expert Report estimated that around 1,250 people with bleeding disorders were infected in the UK [EXPG0000049, **ep.12**] - a proportion of 93%.¹¹ Assuming that to be correct, and that this proportion applies to children, this third source therefore would also suggest with moderate

⁷ Data for 2 people is missing.

⁸ WITN3826021, **Source data**. Including 2 patients for whom age data is missing.

⁹ HCDO0000586

¹⁰ $288 \times 0.3 = 86$

¹¹ $1,250/1,338 = 0.93$

confidence that ~360¹² children with bleeding disorders were infected with HIV in the UK.

22. These are, of course, estimates, based on incomplete data. Nonetheless, they produce a similar total figure. From them it appears that ~380¹³ people with bleeding disorders are likely to have been infected with HIV as children. It is thus clear that significantly more than 175 children with bleeding disorders were infected with HIV through blood products, to the extent that the likely total is more than double that figure.

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¹² $0.93 \times 383 = 356$

¹³ Between the lowest estimate of ~360 and the highest of ~400, very close to the second estimate of ~375.