

**Methodology for collation of HIV patients in Edinburgh  
For The Penrose Inquiry**

1. The starting point was patient-identifiable tabulated data from UKHCDO on patients treated in Scotland who are known to have been HIV positive. These data included date of first positive HIV and last negative HIV test and treatment products by year (and centre of treatment) for each patient, including treatment out with Scotland. For patients who had died a cause of death was reported for some patients.
2. The UKHCDO list was reviewed at each Haemophilia Centre and discussions took place between each of the Scottish Centres to agree at which Centre (within Scotland) it was most likely that a patient contracted HIV. In this way there should be no double counting of Scottish infected patients.
3. This list was compared with local details of haemophilia patients known to have been HIV positive. The UKHCDO list included all patients which we knew about locally. Additional data from local records was added where available.
4. The list of patients considered to have been infected whilst attending the Edinburgh Haemophilia Centre was submitted to Health Protection Scotland for any additional information to be added from their register of HIV infected individuals including details from death certificate records.
5. Based on the information available a judgement was made as to whether deaths were related to HIV/AIDS. The deaths were classified as
  - i. Related to HIV/AIDS
  - ii. HIV contributed
  - iii. Probably not related to HIV/AIDS
  - iv. Not due to HIV/AIDS
6. It was our policy, with patient's permission, to tell partners of those with haemophilia of the possible risk of sexual transmission of HIV infection. Counselling and testing was offered which could be at the Haemophilia Centre, General Practitioner or other clinic, e.g. infectious diseases. I am not aware of any partner who became infected.
7. As routine blood samples were regularly stored in Edinburgh on many patients it was possible to retrospectively ascertain approximately when

*CML*  
26/3/11

patients seroconverted to HIV. Thus it was also possible to know the HIV status on all new patients arriving to live in Edinburgh from out with Scotland. Those who were HIV seropositive at the time of arrival in Edinburgh from out with Scotland have been removed from the list supplied by UKHCDO.

8. Summary of HIV infection occurring in Scotland in those with haemophilia attending the Edinburgh Haemophilia Centre

Total	23
Alive	4
Dead	19

Causes of death

Related to HIV/AIDS	10
HIV contributed	4
Probably not related to HIV/AIDS	4
Not related to HIV/AIDS	1

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*25/3/11*  
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