

Methodology for collation of HIV patients in Glasgow (GRI)

1. Starting point was patient-identifiable tabulated data provided from UKHCDO on patients treated in Scotland who are known to have been HIV positive. This data included date of first positive HIV test and treatment products by year (and centre of treatment) for each patient, including treatment outwith Scotland.
2. This list was compared with local details of haemophilia patients known to have been HIV positive [where available]. The UKHCDO list included all patients which we knew about locally.
3. 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.
4. Where patients were treated at both Scottish and English centres before their first positive test the patient was assigned to have likely been infected in Scotland or England on balance of probability (ie if majority of treatment prior to positive test was in England, then patient would be labelled as most likely infected in England, and therefore not included on any of the GRI or Yorkhill lists sent to PI).
5. HIV infected haemophilia patients were informed about the risk of sexual transmission and that partners should be tested. This testing could be undertaken by the partner's GP, by the Haemophilia Centre or by the Infectious Diseases Unit in Glasgow. In reality, very few partners attended the Haemophilia Centre for testing, and to the recollection of Unit staff working at this time none were HIV positive. Since the Haemophilia Centre staff had no direct contact with other partners, nor necessarily knew their identity, we have no information on their HIV status.

Note: case G1 is thought to have had considerable Factor VIII concentrate treatment at Western Infirmary, Glasgow during 1970s and early 1980s, but we have no specific transfusion records of this. Thus G1 may have contracted HIV through treatment at Western Infirmary, Glasgow rather than at Glasgow Royal – but he undoubtedly contracted HIV in Glasgow.

Addendum 25th March 2011

The originally submitted table was subsequently updated on several occasions:

1. following feedback from Penrose Inquiry which identified some typographical errors and omissions
2. following further information from HPS (who kindly undertook a cross-referencing exercise between our tabulated data and their own records) providing details on AIDS status and cause of death for some patients.

The final update also included addition of columns for:

- a. Date of last negative HIV test [taken from original data provided by UKHCDO]
- b. Date of diagnosis of AIDS [data provided from HPS]
- c. Comment on whether primary or secondary cause of death was HIV/AIDS related [data provided from HPS]

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