

Scottish Bleeding Disorder Patients HCV update March 2018

In 2011-12 Scottish Haemophilia Directors provided, to the Penrose Inquiry, their estimate of the maximum number of bleeding disorder cases likely to have contracted hepatitis C virus (HCV) infection through transfusion of coagulation factor concentrates or plasma. This estimate had been based on review of Scottish haemophilia treatment centre and UKHCDO records prior to 1991, and subsequent hepatitis and HCV data for those treated patients. This process identified 314 patients either known to have been HCV positive or to have been diagnosed with non-A non-B hepatitis but deceased prior to HCV testing became available in 1991. However a further 145 treated patients had been lost to follow-up and their HCV status was unknown. Hence the estimate for the maximum number potentially contracting HCV was 459 [314+145].

During 2013-2017 further information became available for some of the 145 'unknowns' from:

1. a UK-wide HCV lookback exercise coordinated by UKHCDO
2. tracing of patients by Scottish Haemophilia Centres

Of the 145, 14 were found to be HCV positive and 7 HCV negative while 55 were deceased (mostly prior to 1991) and HCV status would remain unknown.

In 2017, with the assistance of Prof David Goldberg and colleagues at HPS, details of the remaining 69 'unknowns' who may still be alive underwent a CHI linkage analysis to ascertain if any were still living in Scotland. This process identified:

- 16 who were still alive and living in Scotland – 7 had in the interim been identified as HCV negative by Scottish Haemophilia Centres, and the remaining 9 were notified to their GPs as potentially needing assessed for past or present HCV infection. One of these 9 was discovered to have moved outside Scotland. The remaining 8 were offered HCV testing by either their GP or their local Haemophilia Centre – 7 proving to be HCV negative and 1 positive (who has subsequently received HCV antiviral therapy).
- 25 were not positively identified in the CHI search, suggesting they may never have been resident in Scotland and certainly not since the CHI system was introduced.
- 13 were noted to be deceased, mostly before 1991, and HCV status would remain unknown.
- 15 were identified in the CHI search as having moved out of Scotland – 1 was known to be outside the UK, for 9 their location was uncertain, and 5 were identified in England, where subsequent enquiries revealed that 2 were known to be HCV positive, 2 HCV negative and 1 is awaiting HCV testing by their haemophilia centre (although it is suspected he will not have active HCV infection).

Therefore, this CHI linkage analysis allowed identification of 16 HCV negative and 3 HCV positive patients and a further 1 likely unaffected patient awaiting testing. A further 13 were noted to be deceased and their HCV status unknown, 11 were identified but untraceable and 25 were not identified in the search.

In summary, since the Penrose Inquiry we have been able to identify and confirm 23 HCV negative and 17 positive patients. However we now believe that no further patients will be successfully traced, and that all traced patients have now been offered HCV screening.

Therefore our final estimates of patients definitely or possibly contracting HCV through treatment in Scotland is as follows:

- 331 known or highly likely to have suffered HCV infection
- 104 deceased or unable to be traced, whose HCV status will remain unknown
- 1 awaiting assessment in England

That is a minimum of 331 and a maximum of 436 patients likely to have contracted HCV infection following transfusion of coagulation factor concentrates or plasma.

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