

Table 18 vCJD

| Coagulation Defect | Patients 'at risk' for public health purposes 1980 - 2001 (old risk period) | | | Patients 'at risk' or no longer 'at risk' for public health purposes 1990 - 2001 (new risk period) | | |
|------------------------------------|--|--|--|--|--|---|
| | NHD Estimate (based on treatment records) | Confirmed by Centres to be 'at risk' | Patients who received an implicated batch(es) | NHD Estimate (based on treatment records) | Centre-list no longer at risk (NHD estimate) | Confirmed by Centres to be no longer 'at risk' |
| Haemophilia A (including carriers) | 2,783 | 2,035 | 517 | 2,392 | 129 | 62 |
| Haemophilia B (including carriers) | 830 | 571 | 154 | 689 | 43 | 26 |
| von Willebrand disease | 757 | 518 | 34 | 663 | 38 | 17 |
| F.XI Deficiency | 142 | 99 | 0 | 134 | 3 | 2 |
| F.VII deficiency | 49 | 33 | 0 | 46 | 1 | 1 |
| F.X deficiency | 35 | 27 | 8 | 32 | 0 | 2 |
| Other bleeding disorders | 101 | 94 | 5 | 75 | 8 | 4 |
| Total | 4,697 | 3,377 | 718 | 4,031 | 222 | 114 |

Table 18: This shows the number of patients alive in March 2013 and considered to be "at-risk" of vCJD for public health purposes on the basis that they have been reported to us as having been treated with UK-sourced blood products during the risk period. This is broken down by exposure between 1980 and 2001 (the original risk-period) and exposure between 1990 and 2001 (the new risk-period in current use).

Unlike previous reports, we have reported the number of patients we estimate to have been exposed to UK blood products during the period of risk estimated from the contemporary factor VIII returns reported to NHD annually and then quarterly since 2008. Although this estimate may include inaccuracies in centre reports, we believe that this is the most complete estimate, since it was collected prospectively and includes some reports of treatment of which the current managing centre may be unaware.

According to this estimate, 4,697 patients, who are still alive, were thought to be at public health risk using the old risk period, of whom 4,031 are still considered at risk using the current (1990-2001) criteria.

In the original exercise only 3,377 of these patients were confirmed to be at risk by their Haemophilia Centre using the old criteria (Table 18). We believe that although centres expended considerable effort to check these data they remain incomplete because many patients attended several centres during the period and their present centre may have been unaware of treatment administered elsewhere. Furthermore treatment records, including some from 25-30 years ago may no longer exist. Where specific batches of product were traced, the use of only 52% to 90% of each batch could be accounted for, which illustrates this point perfectly. Since no new implicated batches have been identified in recent years, the risk that further batches will be identified is becoming remote. Inevitably, therefore, some patients who have received implicated batches cannot now be confirmed as having been so treated.

For reports of patients who received an implicated batch, we are entirely dependent on reports from Haemophilia Centres since NHD did not collect or record batch data during this period. Reports of patients treated with implicated batches are likely to be correct, as far as they go, but incomplete. Since we cannot account for the disposal of all of each implicated batches, some exposed patients may remain unidentified and unreported by centres.

Our data, derived from contemporary factor VIII returns suggest that 666 patients originally considered at public health risk based on NHD data alone and using the old criteria (1980-2001) are no longer at public health risk using the new criteria. Centres were notified of these patients and asked to cross-check with their records. We were anxious that if patients were to be told that they were no longer at risk, that this data should be correct.

Of the 222/3377 patients originally thought to be at risk but no longer considered at risk by NHD following the revision of the risk-period, centres have confirmed this "de-designation" in only 114 individuals. Repeated reminders to centres have yielded no further confirmatory data.

Table 19 Summary of patients 'at risk' of vCJD for public health purposes who received UK sourced plasma products as reported by Centres

| Summary table of 'at risk' bleeding disorder patients who received UK sourced plasma products | | | | |
|---|-----------|--------------------|----------------|----------|
| | | Implicated batches | Non-implicated | Combined |
| Current status of 'at risk' patients | Alive | 705 | 2647 | 3352 |
| | Dead | 104 | 521 | 625 |
| | Total | 809 | 3168 | 3977 |
| Sex | M | 769 | 2606 | 3375 |
| | F | 40 | 562 | 602 |
| Current age band of living 'at risk' patients | 0-19 | 6 | 55 | 61 |
| | 20-39 | 357 | 877 | 1234 |
| | 40-59 | 246 | 1064 | 1310 |
| | 60-79 | 91 | 534 | 625 |
| | 80+ | 5 | 115 | 120 |
| | Not known | 0 | 2 | 2 |

These data were last updated on 01/07/2014

Table 19: This table shows a breakdown of living patients considered to be 'at-risk' of vCJD for public health purposes using the original risk period (1980 – 2001).