vCJD Donor Notification Exercise: Commenced July 2005

SUMMARY

The UK blood services, supported by the HPA/HPS, carried out an exercise over the summer of 2005 to notify 110 donors whose blood was transfused to three recipients who later developed vCJD. The notification began on 20 July 2005 and was completed at the end of the first week of October 2005. Apart from 2 donors who had died, contact was attempted with all donors, including 4 who were not currently registered with a GP. The blood services and HPA/HPS have evidence that 60 donors have received the information and have discussed it with either the blood services or their GP. Efforts are continuing to confirm that all other donors have received and understood the information, and to locate 3 donors whose current whereabouts are unknown.

BACKGROUND

The notification of donors to vCJD cases was announced by a public statement in the House of Commons on 20 July 2005.

The exercise related to donors to 3 vCJD cases who had received blood transfusions prior to the onset of vCJD, and where blood transfusion could not be excluded as a source of the vCJD infection.

Two of the vCJD cases received blood transfusion in England: both were transfused in 1993. One case received 3 units and the other received 103 units of blood components. The third case received blood transfusion in Scotland and was transfused in 1994 with 4 units of blood components. The blood transfused in Scotland was collected by the Scottish National Blood Transfusion Service (SNBTS). One of the English recipients received some blood collected by SNBTS in addition to blood collected by the National Blood Service (NBS). One NBS donor subsequently transferred to the Welsh Blood Service (WBS). Of the total of 110 donors to the 3 recipients, 104 were NBS donors (one of whom subsequently became a WBS donor)and 6 were SNBTS donors.

PROCEDURE

Phase 1: The public statement announced that “active” (current) blood donors would be notified by letter on 20 July 2005. Active/current donors were arbitrarily defined by NBS as those who had donated in 2000 or later. The NBS/WBS/SNBTS sent letters to each donor together with a comprehensive information leaflet from the Health Protection Agency (HPA) or Health Protection Scotland (HPS). For every donor registered with a GP, the HPA and HPS (in Scotland) sent to the GP a notification letter, comprehensive clinical information, and copies of the correspondence provided to the donor, timed to arrive at least 48 hours before the donor received the notification letter. GPs were provided with details of further support either through the local Consultant in Communicable Disease Control (CCDC), or equivalent (CPHM) in Scotland) or the HPA CJD section. Relevant CCDCs/CPHMs were also sent prior warning of the notification of an individual in their area so that they were prepared to offer support to the GP if requested, and to assist with any subsequent public health measures.

Phase 2 of the notification exercise in England involved notification of the lapsed donors (who had not donated within the last 5 years). As the blood service had no knowledge of the lapsed donors' current situation, each lasped donor's GP was contacted and asked for any information which might be of relevance to the notification of their patient. On receipt of a response from the GP, the lapsed donor was then notified, using the same procedure as for active donors, with GP and CCDC/CPHM informed at least 48 hours before the scheduled receipt of the notification letter by the lapsed donor.

All donors were offered access to further advice and support from their GP, and invited to use a contact number for discussion with a senior member of the NBS/SNBTS medical staff. This number was available 24 hours/day. In addition, notified donors were provided with the CJD Support Network contact number .

Because the implicated donations were given in 1993 and 1994, it was necessary to check current details of the donors – specifically their current address and current GP. This information was obtained by NBS staff accessing SHST (Strategic Health Service Tracing). This allowed matching and checking of details for individuals who had changed their name (through marriage) or address since 1993/1994, and provided some confidence that the correct individuals had been identified for notification.

During further checking of current details of donors who were believed to have lapsed, NBS identified a small number who had re-registered and donated within the last 5 years. Some of these were women who had married and registered under a different name, and others had re-registered in the interval between the original drawing up of the list earlier in 2005 and the notification date. These donors were therefore notified as if in Phase 1, but after 20 July (Phase 1a).

Because the number of donors in Scotland was small, they were all notified as active donors on 20 July 2005. The work in England was phased, so that active donors were notified (wherever possible) on 20 July, and lapsed donors as soon as possible thereafter. In order to help planning, the NBS maintained a regular timetable for management of the lapsed donors. Enquiry letters to GPs were posted in two batches, in August according to CCDC area. Replies from GPs were handled in weekly batches. Each Tuesday, HPA was informed of the donors to be notified the following week. HPA sent out information packs to the relevant GPs (and CCDCs) on the following day, so that the GPs should receive the communication by the end of the week: , the letters to the donors were timed to arrive the following Wednesday.

For all notifications, GPs were asked to return a form confirming that their patient had received and understood the information sent to them, and reporting any other donation history or recent healthcare that may require investigation by the CJD Incidents Panel. Details of calls received by the NBS helpline number and by NBS Customer Services in relation to the exercise were recorded and reviewed. Replies to both HPA and NBS were cross-checked (6th September for Phase 1/1a, and subsequently for Phase 2) to identify any donors who had not responded either personally to NBS or through their GP.

NHS Direct set-up a dedicated helpline to respond to queries from the public.
Deceased donors were notified to HPA for further consideration of any necessary public health measures.

Results

1. Phase 1 (20 July)

NBS: 38 "active" donors: included 1 deceased donor and 1 donor who had transferred to Wales (and was therefore notified by Welsh Blood Service), so 36 letters were sent by NBS.

SNBTS: 6 donors: included all donors, whether active or lapsed

Welsh Blood Service: 1 donor (transferred from NBS)

Total: 43 letters sent by UKBTS to arrive with donors on 20 July. All but 1 donor registered with a GP. This latter donor believed to be in the armed forces. 43 letters sent by HPA/HPS to arrive with GPs (and CCDCs/CPHMs) on 18th July.

NBS received 11 telephone calls by or on behalf of notified donors (36 letters sent). One was from a GP who had mislaid the letter, and one was from a GP on behalf of his patient. The remainder of the calls were from the notified donors. Most callers were asking for clarification of certain points, in particular trying to assess individual risk. A number of calls from notified donors who were health care workers related to occupational issues (not covered in the HPA/HPS information leaflet). In addition, one letter was received. Only one telephone call was received by NBS outside office hours (at 19.00). One SNBTS donor reported attempting contact (which was unsuccessful) at the weekend. This donor then contacted the CJD Support Network.

SNBTS actively contacted all 6 notified donors in the period following the notification.

The Welsh Blood Service was not contacted by the one notified donor.

The CJD Support Network also received one call from a GP (who also contacted NBS) and four calls from notified donors, including the Scottish donor who could not contact the 24 hour helpline (reason unknown). This latter donor was anxious, but all donors were judged to have handled the information well. The calls mainly revolved around trying to further clarify individual risk.

No caller (to blood services or CJD Support Network) was judged to be distressed. Some provided helpful suggestions (e.g. carrying the information on a special card). Others were seeking assurance that they would be contacted and offered a test when one became available. The majority of people commented that the notification letter and information leaflet were clear and informative. They understood the reasons for the public health precautions.

2. Phase 1a

NBS notified 12 further "active" donors in the following 2 weeks. This resulted in 2 telephone calls. One was from the husband of a notified donor who was too distressed to speak in person. The GP had contacted the donor before she had received the notification letter from the NBS, and this had caused the distress. The other caller was a health care worker requesting information on occupational issues.

The HPA received no comments indicating adverse reaction to the Phase 1 and Phase 1a notification. Several healthcare procedures were reported that will be followed up by the CJDIP secretariat.

3. Phase 2 (NBS only)

Total 54 donors, including 1 deceased, and 3 not readily contactable (not registered with a GP-one known to have moved to Spain, two unknown whereabouts). This left 50 donors to be notified after receipt of GP reply.

Many GPs responded very promptly (by return post) to the NBS's request for information relevant to the notification relating to their patient. The majority provided details of current health, and details which might be relevant to the notification (e.g. one woman had recently had a baby and would need reassurance about the health of her baby, one woman was on treatment for depression etc). One GP refused to provide any information without his patient's consent, and another telephoned with the same concern but was reassured by discussion that provision of relevant details was in his patient's best interest. One GP wrote to express his gratitude for the prior warning about his patient's notification, which he found "refreshing" and "unusually proactive".
Non-responding GPs were telephoned in the week of 05 September to expedite replies, but replies from 5 GPs were still outstanding by the end of September. Notification of the final 5 donors took place following a telephone conversation with the GP, but without return of any written information.

24.08.05: 11 letters
31.08.05: 16 letters
07.09.05: 5 letters
14.09.05: 4 letters
21.09.05: 5 letters
28.09.05: 4 letters
05.10.05: 5 letters.
Total: 50

The NBS received contact from two of these donors: the donor with the history of depression and the pregnant lady, illustrating the value to the NBS of having this information in advance of any contact with the donor. The GP of a third donor also made contact expressing concern about the notification which he felt would deeply distress his patient. He made suggestions for changes in the letters sent to the GP and the donor. These suggestions were noted and his concerns acknowledged. The donor subsequently wrote to the NBS and was contacted by a senior member of the medical staff. A long telephone discussion took place which helped to address some of the donor's concerns and distress. A report was made to the GP who expressed extreme satisfaction with the NBS's response to him and his patient, and gratitude for the personal response to them both.

~~The donor who had moved to Spain was traced and notified with the assistance of colleagues at the Centro Nacional de Epidemiología in Madrid, and a public health officer in the region of the patient's residence in Spain. A report has been received indicating that the donor accepted the notification information well and had no queries that were not addressed by the documents provided and discussions with the pubic health officer and GP.~~

Follow-up

GPs have been asked to return a form to confirm their patient received and understood the notification information, and with details of any healthcare or other donations that may require public health precautions to be taken. To mid-November 2005, 53 forms relating to NBS donors had been returned to HPA. Forty-eight forms confirmed the patient had received and understood the information from the NBS. Many of these GPs had seen their patient in person. Five GPs were unable to confirm this as they had not had any contact with their patient since the notification. Two of these five patients, and a further 3 whose GPs have not yet returned the

form, are know to have received and understood the information because they called the NBS help-line, making a total of 53 donors who are known to have received and understood the notification information from the NBS. All six SNBTS donors were contaced proactively, and the WBS donor was confirmed by the HPA to have received the information. Follow-up of GP forms is continuing in order to obtain confirmation that all donors have received and understood the NBS notification letter.

Other Contacts

NBS Customer Services received 12 communications following the public announcement, and one letter was forwarded from CMO's office for a response. Six calls and the forwarded letter were from donors who were not affected by the announcement but disagreed with the decision to notify the affected donors. These 7 donors all received a telephone discussion or written response. None of the donors had seen the contents of the announcement or the communications sent to the notified donors: they were all responding to media reports. The other calls were not directly connected with the announcement, but related to other CJD precautions and donor selection. All donors received a personal response.

NHS Direct received a very low number of calls (<20) during the first 48 hours after the announcement, and therefore stood-down its dedicated line and transferred any further calls to the routine service. No calls to NHS Direct were referred to HPA as outside the pre-prepared answers.

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