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"Reverse RA: for discussion at 3 today"

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Rowena Jecock
14/07/2005 14:00

To: Ailsa Wight/PH6/DOH/GB@GRO-C Eileen Lawrence/PH5/DOH/GB@GRO-C, Neil Ebenezer/PH5/DOH/GB@GRO-C, Janet Gibson/PH6/DOH/GB@GRO-C
cc:
bcc:
Subject: Reverse RA: for discussion at 3 today

Can we discuss the attached from Kate when we meet at 3 this pm.
Thanks,
R

----- Forwarded by Rowena Jecock/PH6/DOH/GB on 14/07/2005 13:59 -----

"Cfl - Soldan, Kate"
<Kate.Soldan@GRO-C GRO-C
14/07/2005 13:01

To: Rowena Jecock/PH6/DOH/GB@GRO-C
cc: "Pat Hewitt (E-mail)" <patricia.hewitt@GRO-C>, "Cfl - Janecek, Helen" <Helen.Janecek@GRO-C>
bcc:
Subject: Reply to queries, and final draft documents

Dear Rowena

Below is the joint response from us (HPA and NBS) to the issues you raised yesterday:

1. Date of notifying lapsed donors.

The NBS will contact the GPs in late July/early August and the donors themselves notified as soon as their GPs (or other clinicians) are able to facilitate this. The exact timing of each lapsed donor's notification will depend on the information provided by GPs and the ease of contacting these donors.

2. Strategy for individuals in the 'lapsed donor' group who call up asking for information before they are notified.
Enquiries from donors who could be in this group will all be taken by (or referred to) NBS, and this would precipitate full notification by the NBS. The NBS would then inform the HPA so the information letter and pack could be sent to the GP (and CCDC) straight away.
(Note: NBS and HPA will also be keeping track of 'notification status' of all the donors involved, based on a) contacts to NBS call-line (including any lapsed who actively contact in this way) and b) return of a form from GPs to HPA, in order to verify donors have in fact received and understood posted information.)

3. DH suggestion of a 'conference call' on Monday afternoon for the ~40 GPs involved next week - to brief them and answer questions etc.
The HPA letter to these GPs invites them to call the HPA with any queries. The GPs also have the telephone number for the NBS specialist call-line (on copy of NBS letter sent to their patient). It is expected that the NBS specialist call-line will be the primary first point of contact by donors with questions, rather than GPs. Therefore we suggest that GPs have sufficient support to meet expected demands on them without this meeting.

4. Rationale for notification by letter (response to Ailsa's email 13 July 2005 13:14)
In short, we consider this approach to notifying these donors to provide the best quality notification in the circumstances. This approach address the requirements for: NBS to maintain its high-standard of care for its donors; expert consultation to be available to those notified (by telephone with NBS); face-to-face consultation to be available (from GP); all current donors to be notified directly before they hear rumours/messages from elsewhere.

Please see the full explanation of the rationale for this provided by Pat below.

Very early on (at the CJD IP/ MSBTO meeting in late February) it was suggested that this is a public health exercise and should therefore be managed by the HPA. I think I recall Angela Robinson supporting this view very strongly. I understand that, if managed by the HPA, the donors would have been called in by their GPs, who would be given full information but would not necessarily be very expert in CJD issues. The donors would therefore have a 1 to 1/ face to face with their GP, but with someone who is not necessarily well versed in CJD issues.

In the context of blood donors, as opposed to patients, we thought that this approach alone would not be the most appropriate. Some of these donors have continued to be very active and regular donors, and it would seem very strange to them that a message relating to their blood donations was being passed on by someone other than the NBS. We thought this could provoke a very negative image from those donors, and create a lot of resentment. Almost as if the NBS was washing their hands of them. This is something we would all want to avoid.

We therefore came to the conclusion that we would want the initial message to come from the NBS. In support of this, we will provide a telephone helpline for these donors so that they can talk to a senior member of the NBS clinical staff who is well experienced in CJD issues and in talking over difficult issues by phone. We believe that this will provide the best quality service to these donors. We do not believe that this would be achieved by contacting donors and asking them to come in for an interview. Many live a distance from the NBS centres. Inevitably, people contacted would want to know why they were being asked to travel a distance to see someone in the NBS. We then have the difficult issue of a telephone discussion being the means of breaking the news, or insisting that they can be told nothing until seen in person. If contacted after the announcement on Wednesday, some, undoubtedly, would put 2 and 2 together. They would then "know" why they had been called, but have no information other than the announcement. This is not a good way to handle such a difficult issue, and it would not be surprising if there was much criticism and negative publicity following that type of approach.

Even dividing the donors into two groups, and dealing only with active donors next week, we still have 37 donors to contact. We have a small group of expert clinical staff and in the circumstances we strongly believe that the donors will have a higher quality service by speaking to these clinical staff over the telephone rather than having donors or staff travelling across northern England for a face to face interview. A telephone interview is still 1 to 1. I believe that this will be a higher quality interaction than a face to face interview with someone (either GP or NBS) who is not fully conversant with the issues. Following that interaction (if indeed it is required by the donor) there will be an opportunity for support from the GP, with the local CCDC providing back-up.

We do have available, for any very regular donors who attend the Leeds fixed site for blood donation, the opportunity for a face to face interview with one of the Consultant medical staff.

I understand that patient lookback exercises, where patients are being notified of a possible risk of HBV, HCV or HIV infection through an infected healthcare worker, are carried out through an initial letter and information sent to the patient, the offer of a helpline, and then an interview. This is very similar to the approach being used with the donors identified as at possible risk of vCJD. We are using well tested methods of notification, adapted to the needs of blood donors. It may well be that we have more cases of donors identified as at risk of vCJD in the future, but those cases will not be accompanied by a public announcement, which makes this current exercise all the more challenging.

Of interest, SNBTS was originally planning to call in the donors for face to face interviews. However, this is peak holiday season in Scotland and the key medical staff are on leave. It was therefore proposed that notification would be delayed until the key staff returned from leave and could see the donors face to face. The Scottish executive has not agreed with the proposal to delay notification of SNBTS donors until August and has instructed SNBTS to follow the DH timetable. SNBTS has decided that the best way of managing the notification in these circumstances is to use the same approach as in the NBS, and they will be using common timetables and documentation.

We will be monitoring the response of these donors very carefully, and will take note of any learning points. We will undoubtedly have some donors who respond badly, however they are notified. Our job is to try and make sure that we give the best service possible, given the circumstances and the available resources, that will satisfy the needs of as many donors as possible.

5. Delivery of letters to GPs and donors
Finally, just to confirm, both the HPA and NBS are arranging appropriate methods to ensure that letters will be received by the GPs (from HPA) on Monday morning and the donors (from NBS) on Wednesday morning, and not before.

Please find attached our final draft documents:
vCJD and Blood Donors - Letter to GP.doc
vCJD and Blood Donors - Information for Donors to vCJD Cases.doc
vCJD and Blood Donors - Clinical Information.doc
vCJD and Blood Donors - Recommendations of the CJD Incidents Panel.doc
vCJD and Blood Donors - Summary of Donor Notification.doc

Am sending this just to you, for you to circulate on to your colleagues as appropriate. Please pass on thanks to all for the very helpful comments!

Regards,

Kate

<<vCJD and Blood Donors - Letter to GP .doc>> <<vCJD and Blood Donors - Information for Donors to vCJD Cases.doc>> <<vCJD and Blood Donors - Clinical Information.doc>> <<vCJD and Blood Donors - Recommendations of the CJD Incidents Panel.doc>> <<vCJD and Blood Donors - Summary of Donor Notification.doc>>

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