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COMMS

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cc: see list at end

vCJD PATIENT NOTIFICATION EXERCISE – MEDIA HANDLING

Issue

Notification of patients of their new status as regards risk of developing vCJD

Timing

Urgent – exercise is due to start in the week commencing on 6 September with patient notification commencing on 21 September

Background

An exercise is about to begin to notify certain recipients of plasma products that they may have received sufficient dose of product derived from donors who subsequently developed vCJD to warrant taking public health precautions, and that they are now to be regarded as 'at risk' . This is the result of a risk assessment exercise carried out by the CJD Incidents Panel and the HPA following the first case of possible transmission of vCJD by blood transfusion, which was notified to Parliament in December 2003 (A further written statement about a second case of possible vCJD prion transmission via blood was made on 22 July 04).

Their new status is important because although their chance of going on to develop vCJD is extremely small, there is a possibility that they could pass on the vCJD infectious agent to other people, and so requires changes in their behaviour (e.g. no organ donation) and different treatment of these patients in hospital etc. (e.g. instruments used in surgery must be treated differently.)

Clinicians will be notified of plasma products that need to be traced to patients, and subsequently the HPA can undertake a risk assessment for those patients if required.

The affected patients fall into three groups:

1. **People with haemophilia and other bleeding disorders who received particular UK-sourced products between 1980 and 2001. These are thought to number around 4,000 out of a total of 6,000 UK people with haemophilia and other bleeding disorders. They should be easily identified by their specialist doctors.**

2. **People with primary immunodeficiency who received a particular product – Vigam – in relatively large quantities. There are 2,500 people with primary immunodeficiency; around 200 of them received Vigam; clinicians treating these patients believe that around 50 of them may have possibly received large enough doses to put them at risk, but will be confirmed by individual risk assessment. They too should be easily identified by their specialist doctors.**

3. **Another group of patients who received sufficient quantities of particular blood products to put them at risk. They include people suffering from a range of conditions e.g. severe burns. Numbers are hard to estimate and tracing these patients will depend on the adequacy of records at individual NHS Trusts and the efforts devoted to checking them.**

Notification is taking place through the clinicians who have been treating these patients. Haemophilia centres (for group 1), primary immunodeficiency specialists (group 2) and NHS Trust Medical Directors (group 3) are being written to on 7 September so that information is received by 8 September.

Doctors dealing with the first two groups will be asked to prepare to write to relevant patients on September 20. Trust Medical Directors will be asked to consider how far they will be able to trace patients who may fall into group 3.

Media handling

Media handling draws upon the principles set out in the communications strategy attached at Annex A.

The exercise falls into four stages, each requiring different handling:

A. From now until the sending out of letters to clinicians in the week commencing September 6th
B. The period between clinicians receiving letters and their writing to notify patients on 20 September
C. When patients receive their initial notification
D. The period after this

A. From now until the sending out of letters to clinicians

Communications activity is being limited to those who need to know within DH, HPA and the National Blood Service. However some information about this exercise has been given to relevant specialist clinicians and patient groups. One leak has occurred, leading to coverage in a Scottish Sunday paper which was not widely followed up. In response we used previously prepared lines to take, attached at Annex B. A script for broadcast interviews has also been drawn up for press office and interviewees, attached at Annex C, although we have so far been able to avoid giving interviews. We feel strongly that we should avoid giving interviews prior to the scheduled press briefing in order to ensure that proper information and support is available to patients. NHS Direct has been given briefing material and a special helpline run by NHS Direct (with a dedicated number and team of call handlers) is ready to be mobilised in the event of a large number of calls to the normal NHSD number.

B. The period between clinicians receiving letters and their notifying patients

The risk of more leaks is much higher, even though all recipients of the letters have been asked to minimise the spread of the information and to refer any media inquiries to DH press office. The lines to take and script mentioned above will remain the same.

C. Notification of the patients

Letters being sent to 6,000 people with haemophilia and other bleeding disorders plus other patients raising the prospect of their having received plasma products from patients who subsequently developed vCJD will lead some to contact the media. In particular, some people with haemophilia and other bleeding disorders have already been infected with HIV and Hepatitis C through blood transfusions and will raise questions about compensation.

It is important therefore that DH sets out clearly the facts in this exercise and sets in the context of the precautionary measures we have taken regarding vCJD.

The best way to do this is to hold a press briefing, backed up by a press release and a written ministerial statement to Parliament. This will ensure the media and MPs receive accurate, clear information as quickly as possible.

Failure to make a clear public statement risks our being accused of 'sneaking out' this announcement

and spreading confusion about an important public health issue.

It is proposed that the press briefingand press notice take place on Tuesday 21 September. We recommend that this is supported by a WMS rather than an oral statement to Parliament as reference was made to this in John Reid's statement on 17 December 2003. Most (but not all) patients will have received their letters by then and we can expect the media to become aware. Delaying the press conference etc. to Wednesday 22 Sept was considered but doing so will leave a vacuum of official information for 24 hours. The No 10 grid also makes 22 Sept impossible for this announcement.

The press briefing will be chaired by CMO. Its purpose should be to set this exercise in context as the latest in a long series of highly precautionary measures which DH has taken on vCJD in response to advances in knowledge and technology.

Speakers should include:

- CMO – to chair panel of experts to answer questions – Angela Robinson (National Blood Service); Lindsey Davies (Director of Public Health and chair of expert group); Don Jeffries(chair of CJD Incidents Panel); providing an authoritative overview
- HPA representative – explaining the notification process
- Haemophilia / immunodeficiency doctors
- Patient group representatives – they are willing to attend
- National Blood Service – to talk about risks of receiving and giving blood and the safety measures taken in the past

Consistent with the successful handling of the December announcement, bids will be picked up by the expert from the National Blood Service with CMO held in reserve.

The special NHS Direct helpline will be activated at this point and publicised. Patient groups will also activate their helplines.

D. The period after notification
The NHS Direct helpline will remain active for several weeks, as will support from patient groups. Clinicians of the affected patients will continue to provide support as appropriate.

RISKS

Leaks now, and leaks after letters to clinicians
These are significant and increase with time. We have a contingency plan in place to deal with this.

Leaks from patients after receiving letters, before our press briefing
This is likely but our press briefing will take place a few hours after the first letters arrive, allowing us to set out the situation clearly.

Press briefing taking place before some letters arrive
Given the unpredictability of the postal service, this will happen no matter when we hold the briefing. We have to balance our desire for patients to be notified by their doctors with the need to ensure clear accurate information is made public quickly.

Other risks

- **Accusations of delay in the notification exercise**
- Concern about safety of NHS blood and operating procedures, now and in the past
- Concern about patients in group 3 who cannot be traced.
- Concern among recipients of other plasma products such as mothers who received Anti-D for rhesus babies – expert advice is that these people are not considered to be at potential additional risk. This line is already with NHS Direct.
- Compensation

These will have to be addressed in the press briefing / press notice, details of which will be finalised nearer the time.

Michael Clarke

GRO-C