

DRAFT : RESTRICTED : POLICY

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CJD INCIDENT PANEL CONSULTATION ANNOUNCEMENT - HANDLING

Issue

1. The CJD Incident Panel has prepared a framework which will guide NHS responses to surgical incidents which involve possible exposure to CJD. This framework contains a number of controversial proposals. We note the Secretary of State's reservations about what is being proposed. This means that there needs to be very careful handling to ensure that the proposals are presented as the CJD Incident Panel's, not the Department's.

Timing and Handling

2. Urgent. A decision is needed to allow time to prepare for the ground for the announcement. We have provisionally arranged to announce this proposal on Wednesday 10 October 2001. Downing Street are signed up in principle to this date.
3. The key part of the handling is that the CJD Incident Panel should address the media themselves in a briefing. The aim will be to ensure that the media sees this as the Panel's proposals, not the Department's, not SEAC's, etc, and that this is presented as purely precautionary advice based on the available science. By making the announcement on 10 October, we will control when and how the Panel's proposals are presented to the media.
4. Media interviews should be conducted by members of the Panel. We should aim to restrict Department of Health comments to confirming the Panel's proposals and emphasising their precautionary nature and the desire for public debate on them. Requests for CMO and DCMO interviews should be the only bids we consider.

Detailed Q&A – including on issues like insurance and the legality of the database – will be prepared well in advance.

5. Our key messages will

- emphasise that the Incident Panel's proposals do not indicate a new assessment of the risks from surgery or other medical interventions;
- stress the Panel's role in providing Trusts with advice in specific incidents;
- explain how the proposals would affect individual patients; and
- emphasise the Panel's conclusions that there are clear public health reasons for establishing the database and the controls over access to it, and seeking public support through consultation for its proposals.

Particular areas of controversy

6. CJD remains a disease which is always fatal and for which there is no cure. Contacting people seen as possibly being at higher risk, whether they want to know or not, could be regarded as being of no use to the individual, notwithstanding the benefits to the wider public.
7. Placing a second group of people at possibly lower risk on to a data base without their consent could be equally controversial. Civil liberties groups may object; the attitude of the General Medical Council to this aspect is not known and may be hostile; and it is possible that in some circles the proposals may be seen as upping the ante unnecessarily about what is still a very rare disease. Yet again others who have raised concerns in the past about prion disease could argue that we should have produced these proposals sooner.

Risks in Delaying

8. There are five reasons which make it difficult to delay the announcement:
- The CJD Incident Panel next meets on 18 October. If progress to announce their proposals has not been made by then, there is a risk that individual panel members could talk direct to the media.
 - The CJD Incident Panel has already received requests from clinicians for specific advice about incidents involving blood. Although these are covered by the framework, because of the sensitivities surrounding haemophiliacs, their representative organisations will be briefed in advance on 27 September, and letters to the relevant clinicians will issue the following day. This will allow the haemophiliac community to be forewarned about the

announcement. In the meantime, haemophiliac doctors would be asked to respect an embargo, vis a vis the media, until 10 October.

- Panorama is making a programme based on the risks of iatrogenic transmission of CJD and on the Incident Panel's proposals. They do not know precise details yet, and they appear to be prepared to wait to broadcast their programme after these details are announced (ie the following Sunday). Delaying the announcement runs the risk of Panorama broadcasting without the full facts and they could become a vehicle for individual panel members if we delay.
 - SEAC is due to hold a special meeting on BSE and sheep on 19 October. If this becomes big news, delay on the Panel's announcement would leave us exposed to accusations of undue secrecy and not learning from the BSE Inquiry.
 - The Royal Society of Medicine are holding an open meeting on 2 October. Eight of the ten speakers are CJD Incidents Panel members. They will be speaking about the issues covered by the framework document in general terms and this could increase speculation about what the Panel will propose.
9. There is a further risk that delay will encourage journalists to speculate on the contents of the Panel's proposals, extrapolated from public summaries of the Incident Panel's meetings which are now on the DH website.
 10. This submission has been discussed and agreed with the CJD Team.

Conclusions

11. There are inherent risks in any announcement about variant CJD. In the past, these risks have been minimised through careful preparation and clarity in our media handling about the extent and limits of our knowledge. There tend to be far greater risks in accusations of undue secrecy, which harm our longer-term credibility on this issue.
12. A controlled announcement on 10 October will minimise the risk of either speculation on the contents or actual leaks of the contents of the Incident Panel's proposals.
13. You are asked to decide if you are willing to allow us to proceed on this basis and make arrangements for the Incident Panel to make its announcement on 10 October.

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