

ACDP/SEAC/WG/TSE/P95  
Appendix 5

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Dear Professor Donaldson

I have pleasure in sending to you the framework for the advice of the CJD Incidents Panel regarding the management of possible exposure to CJD through medical procedures. The Sections dealing with the general principles and surgical instruments are now completed; the section on blood and blood products is still under consideration, pending completion of the blood risk assessment and sections on dentistry and tissue and organ donations have yet to be added.

As you know, the CJD Incidents Panel was established in August 2000. At the first meeting of the Panel in November 2000, we agreed to draw up a draft framework document setting out the principles underlying the Panel's advice on individual incidents. The draft framework document was made publicly available for consultation in October 2001. A total of 336 written responses, which is 11.5% of the total mailed, were received. In addition, key elements of the proposals were discussed at a public meeting attended by just over 300 individuals from throughout the UK, including a range of professional healthcare workers, patient representative groups, relatives of CJD patients, representatives of professional bodies and national organisations, and those with ethics, legal or insurance backgrounds. A report summarising the responses is available on the CJD Incidents Panel website and it is intended to put all the responses received on this site. Further discussions have also taken place with the British Medical Association and the Information Commissioner.

In the light of the consultation, which made a vital contribution to our thinking about the scientific, ethical and practical aspects of our proposals, we have revised the framework document. Some of the key issues raised are further discussed in the accompanying discussion paper.

It is important, I believe, to draw your attention to three particular areas of concern to the Panel.

Firstly, our proposals for the management of CJD incidents represent, we believe, a coherent package of measures and it is important that they are recognised as such. In particular, it is crucial that the establishment of a database and the identification of a contactable group be accompanied by an effective communications strategy regarding CJD and its management, including the proper provision and funding of appropriate counselling services.

Second, for our proposals to be workable there are certain practical issues to be addressed, and these can be tackled more appropriately by the Departments than by the Panel itself. In particular, it is vital that steps be taken to ensure that the actions taken to protect public health do not compromise the ability of individuals to obtain access to financial services. In addition, we are aware that the precise terms under which the database could be established raises legal questions in relation to the use of confidential patient information.

Third, although the Panel is charged with advising on the management of incidents arising from medical procedures, it believes it appropriate to stress how important it is that the risk of future incidents be reduced by the appropriate introduction of single use instruments and the effective implementation of the Departments' policies for improvements in decontamination. In addition, the speedy introduction of traceability of instruments will crucially assist the Panel in providing appropriate and effective advice in the years to come.

I know that you welcome the open way in which the Panel has gone about its work and in accordance with that practice, I propose to make this letter and the accompanying documents, together with the reports of the response to the consultation and the open meeting, available on our web page. I would anticipate that this could be accomplished by early November 2002.

I appreciate that many of the issues for the Departments that are raised in section 3 of the discussion paper will take some time to resolve fully. I seek at this point an agreement in principle to the Panel's proposals and a commitment to take forward the Departmental actions required in order for the Panel's advice to be implemented. If you think it would be helpful, I would be happy to discuss our proposals with you. You will wish to know that I have the agreement of the Chairman of the ACDP/SEAC Joint TSE Working Group in forwarding our proposals to you.

Yours sincerely,

Professor Michael Banner  
CJD Incidents Panel

enc. Revised CJD Incidents Panel framework document  
Discussion paper of key issues