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cc Mr Jones ✓

11 June 1999

Dear Bob

INFORMATION SHEET ON BLOOD AND CJD

I am writing in reply to your letter of 11 May seeking my comments on the Information Sheet on Blood and Creutzfeldt-Jacob Disease which you are now supplying to the relatives of individuals who are interviewed in the course of the study. I am sorry that I have not replied sooner but I felt I should first consult with medical and legal colleagues here prior to forming a view.

You ask whether there should be a clause at the bottom providing the opportunity to individuals to refuse permission to supply this information to third parties. You also express your concern that a major ethical dilemma could result in the eventuality of relatives of a patient with new variant CJD who has been a blood donor refusing to allow the disclosure of the information.

In considering this point I feel we need to draw a distinction between vCJD patients and the controls. In the circumstances of a living patient suffering from vCJD a duty of confidence is owed in respect of information about their health. In principle the patient should be asked for consent if that information is to be passed on to third parties. In practice this may not be possible if the patient's comprehension is impaired or lost. However, where there is a real risk that their blood could transmit vCJD then on public health protection grounds it is justifiable to pass on that information, as there will be a public duty in preventing harm to others. This may also be the case where the information is essential for medical research purposes. Where the patient is no longer capable of consenting to disclosure, unless there is a court appointed receiver or someone with an enduring power of attorney who can consent on their behalf, the only question is that of the public interest and whether that is strong enough to override the patient's rights to confidentiality.

For patients who have died from vCJD, I understand that the duty to the patient may subsist depending on the circumstances. The personal representatives of the deceased will acquire certain rights in relation to the estate of the deceased and it is at least arguable that they could sue for breach of confidence in order to protect relatives or friends of the deceased from distress. Therefore, even though strictly speaking they have no right to consent to disclosure on behalf of the deceased, it may be sensible to ask for their agreement. At the same time, if they do not agree, they should be told that the public interest may require disclosure nevertheless.

In the case of controls, in theory, the position is the same as for patients. In practice however the public interest is not overriding in these cases and thus does not justify disclosure without consent.

Finally, on a minor drafting point, I suggest that in the second last paragraph the national blood authorities should be spelt in the lower case. The NBA and the SHA are appropriate to England only.

In conclusion for cases of vCJD there is justification for public health protection to pass on the fact of the patient's vCJD to the blood service. This justification would not apply in the case of controls.

I am sorry if all this appears long winded but it is most important that we effectively deal with all the possible pitfalls in advance. Thanks for seeking out my views, I hope you find them helpful. Please do not hesitate to contact me again if you have any further queries.

Yours sincerely

GRO-C

J S METTERS
Deputy Chief Medical Officer

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