THE SCOTTISH OFFICE
Department of Health

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cc. Dr C. Lloyd, Haem
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For Info & Action

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Dear Colleague

nvCJD - PATIENTS WHO HAVE RECEIVED IMPLICATED BLOOD PRODUCTS

As you are aware, the UK has adopted a policy of withdrawal of any unused blood components or products made from blood donated by persons who have subsequently developed New Variant Creutzfeld-Jakob disease (nvCJD). As a result of this purely precautionary measure, there have been a number of recall exercises over recent months.

A number of clinicians and Trusts affected by these recall exercises have contacted the Departments of Health to ask for their view on what patients who have received nvCJD-implicated blood components or products should be told. This raises some very difficult issues on which the Department of Health in England has taken expert ethical advice. I thought it might be helpful to set out that advice, which the Scottish Office Department of Health endorses.

On the basis of the advice which has been received from ethics experts and other advisory bodies we believe that there is no need to inform patients because:

i. It is thought unlikely that nvCJD will be transmitted in this way.

ii. There is no diagnostic test for nvCJD.

iii. Even if a test was available, there is no preventative treatment that could be offered.

In these circumstances the general view is that patients will not benefit from this knowledge, and uncertainty created by informing patients could have the counter-effect of causing unjustified worry and creating a permanent blight on their lives, for example in relation to obtaining life or healthcare insurance.

The local Ethics Committee that advises the CJD Surveillance Unit reached the same view when considering whether to inform patients included in the epidemiological study.

In deciding whether or not to inform a particular patient, the benefit/harm balance for their individual situation must be carefully considered. In communicating with patients who have received implicated products, it is therefore up to individual clinicians to decide whether to follow this general ethical advice.

There may clearly be some circumstances where clinicians will decide to inform a particular patient of the reasons for the withdrawal, for example where the product involved is one that is generally held by the patient at home, or where the recall action has prompted an individual patient specifically to ask whether he/she has received the implicated blood product. In such circumstances it is for the clinician to decide how best to respond, having taken careful consideration of all aspects of his/her patient's circumstances.

It should be noted that this ethical advice reflects current circumstances and knowledge, and will be under regular review in the light of scientific advances and any further advice from national and international committees.

Yours sincerely

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SIR DAVID CARTER

Copy to: Trust Chief Executives
Health Board General Managers