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### **The Penrose Inquiry – Acquisition of “Cause of Death” codes for Scottish HIV-infected haemophiliacs from Health Protection Scotland’s national HIV database**

Health Protection Scotland (HPS) routinely receives – on a monthly basis - extracts of death certificates from the General Registrar Office (Scotland) for all cases where the cause of death makes mention of HIV or AIDS. From these death certificates, the date of death and the cause of death codes (codes from the International Classification of Diseases - ICD - as published by the World Health Organisation) are extracted and appended to the case record on the national HIV database.

In some cases, however, the certifying physician may not mention HIV or AIDS as a cause of death or contributory factor, which ultimately leads to a death certificate extract not being generated for HPS. In this circumstance, HPS relies on local clinicians or NHS staff to inform us of deaths among patients under their care. For these cases, HPS obtains the date of death, but not the cause of death codes. Death codes will also be unavailable if the case is known to have died outwith Scotland.

For the purposes of the Inquiry, case records on HIV infected persons held by Scotland's main centres for haemophilia were compared to the national HIV database held by HPS. This exercise resulted in the centres being informed of several deaths not previously known to them. As at 31 December 2010, HPS had recorded 46 deaths among 76 haemophiliac cases who are presumed to have been infected via the receipt of contaminated blood products in Scotland. Cause of death codings had been recorded for 32 of these cases.

In order to more fully inform the Penrose Inquiry, HPS has endeavoured - in association with the General Registrar Office (Scotland) - to obtain cause of death codes for the remaining 14 cases. This exercise has resulted in the identification of codes for a further 10 cases, bringing the total to 42 of 46. Of the remaining cases, 3 did not match with the Scottish Death Register based on the identifiers provided, while 1 shows some evidence of death possibly occurring outwith Scotland.

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*NHS National Services Scotland is the common name of the  
Common Services Agency for the Scottish Health Service*