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A national register of HCV infections with a known date of acquisition

A call for study proposals

A national register of hepatitis C virus (HCV) infections with a known date of acquisition is being established, and infections that have been acquired through transfusion of blood or blood components will form the nucleus of the register. It is hoped that the register will provide a national resource for researchers and clinicians alike, and a number of future studies can be envisaged which would benefit from linkage with, and access to, the register.

Mandatory screening of blood donations for antibodies to HCV was introduced by the National Blood Transfusion Service in the United Kingdom in September 1991.¹ As a result, a number of anti-HCV positive donors were identified some of whom had donated blood before the introduction of screening. In early 1995, the UK Health Departments announced that a "look back" at recipients of blood or blood components derived from anti-HCV positive donors would be undertaken.² A high proportion of the recipients of HCV infected blood are expected to be infected with HCV,³ and although most are likely to be asymptomatic in the early stages of infection,⁴ all infected recipients are being referred to clinicians with an interest in hepatic disease for assessment and clinical follow up.

Cases of HCV infection acquired by transfusion and identified by the "look back" are unusual in having a known date of acquisition, an identifiable source, and in having been diagnosed relatively early in the course of infection. Although few in number, the register will be extended to cover other infections of known date, such as documented seroconversions and occupational exposures. Documented seroconversions will include those individuals with virologically confirmed HCV infection for whom a reliable negative result of a test of the same type for HCV infection has been recorded at any point in the preceding four years. The register therefore provides a unique opportunity to monitor incubation period distribution from infection to disease and death, and to provide a group of HCV infections with a known date of acquisition as a resource for other studies.

All clinicians responsible for the care of eligible subjects will be invited to register their patients, and assistance with completion of forms will be available for those clinicians caring for a number of eligible patients. Information on each patient's current clinical status, test results, treatment and management will be gathered using a standard report form, and clinicians responsible for the continuing care of registered patients will be invited to complete and return follow up forms annually on each patient. Such information is urgently needed to help determine the current and future burden of hepatitis C related disease on health care services, and to assess the impact of currently available treatments and those which may become available in the future.

Any researchers interested in applying for access to information held within the national register should contact the register coordinator (details below) for a list of available data. Any study proposals should then be submitted to the register coordinator for consideration by the steering group by 16 October 1998. It is envisaged that the register will provide a national resource that could assist researchers in studies of sexual, vertical and household transmission; clinical trials of new antiviral drugs; further evaluation of existing antivirals and of alternative treatment protocols; determination of the relations between viral load, genotype, treatment and disease progression; and studies of markers prognostic for progression to disease.

NATIONAL HCV REGISTER STEERING GROUP:

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