

Who will have access to the database?

Access to the database will be strictly controlled. Apart from relevant staff within the NDSC and the hepatologists from the designated hepatology units having access, other requests for information will have to be approved by the Database Steering Committee.

How can I help?

If you would like to participate in this database please read and sign the consent form and return it to your consultant at the hepatology unit you are attending (or if you are no longer attending one of the eight listed units, the unit you last attended). To get a complete picture of hepatitis C infection in people infected through blood and blood products it is really important that as many people as possible participate in the database.

What if I do not want to participate?

If you do not wish to participate, please return the consent form to your consultant hepatologist indicating you do not wish to participate. If you choose not to participate your care will not be affected in any way.

I'm still not sure, where can I get more information?

You can get more information from your own consultant hepatologist, or from any of the organisations listed on the back of this leaflet.

Irish Haemophilia Society
Iceland House
Arran Court
Arran Quay
Dublin 7.
Email: haemophiliasociety@eircom.net
Phone: (01) 8724466
Fax: (01) 8724494
Website: www.haemophilia-society.ie

Irish Kidney Association
Donor House
Block 43A
Parkwest
Dublin 12.
Email: info@ika.ie
Phone: (01) 668 9788 / 668 9789
Fax: (01) 668 3820
Website: www.ika.ie

National Disease Surveillance Centre
Aline Brennan/Dr Lelia Thornton
25-27 Middle Gardiner Street
Dublin 1
Email: hcvdatabase@ndsc.ie
Phone: (01) 8765300
Fax: (01) 8561299
Website: www.hcvdatabase.ie or www.ndsc.ie

Positive Action
56 Fitzwilliam Square
Dublin 2
Email: posact@indigo.ie
Phone: (01) 676 2853
(9.30am - 5.00pm Mon - Fri)
Fax: (01) 662 0009

Transfusion Positive
3 Clanwilliam Square
Dublin 2.
Email: transfusionpositive@eircom.net
Phone: (01) 6398855 / 6398857
Fax: (01) 6398856

Jul/04

National Hepatitis C Database

for infection acquired through blood and blood products

Patient Information Leaflet



What is the National Hepatitis C Database for infection acquired through blood and blood products?

A clearly defined group of people in Ireland were infected with the hepatitis C virus by contaminated blood or blood products. This presents an important opportunity to study the disease caused by hepatitis C. The Consultative Council on Hepatitis C recommended that a national database, located at an independent coordinating agency, should be set up for research purposes. The database (a type of register) is a way of collecting medical information on the people who were infected with hepatitis C in this way.

Why do we need this database?

The virus that causes hepatitis C was identified relatively recently. Doctors are still learning about the kind of illness it can cause. By collecting medical information on people who were infected with hepatitis C the Hepatitis C Database will help us to learn more about the disease caused by the hepatitis C virus.

It can also be used to help in planning the services needed in the future by those who have hepatitis C infection.

Who can participate?

Anybody who has been infected with hepatitis C through the administration of blood and blood products within the state is eligible to participate. People who have ever attended one of the eight designated hepatology units (St Vincent's University Hospital, St James's Hospital, Beaumont Hospital, the Mater Misericordiae University Hospital and Our Lady's Hospital for Sick Children, Crumlin, in Dublin and St Luke's General Hospital in Kilkenny, Cork University Hospital and University College Hospital Galway) will be invited to participate. Others not identified in this way may also join at any time.

What kind of information will the database contain?

If you agree to participate, we will ask your consultant to pass on information from your medical notes to the database. We will be asking for the following kinds of information:

- Age
- Sex
- How you became infected
- Your medical condition
- Results of tests
- Treatments received

The database will NOT contain people's names or addresses. We will collect your initials and date of birth so that we can identify duplicates (i.e. people who have attended more than one hepatology unit).

Where will the database be located?

The database will be located in the National Disease Surveillance Centre (NDSC). The National Disease Surveillance Centre is Ireland's leading specialist centre for surveillance of communicable diseases. The centre was set up in 1998 conjointly by Ireland's eight Health Boards and with the approval of the Minister for Health and Children.

Who will oversee the database

The Database Steering Committee will oversee the running of the database. Its membership includes representatives from the patient support groups, the consultant hepatologists and the Department of Health and Children.

