



Support Groups

Positive Action

56 Fitzwilliam Square
Dublin 2
Tel: 01-676 2853 Fax: 01-662 0009
Email: info@positiveaction.ie
Website: www.positiveaction.ie

Transfusion Positive

3 Clanwilliam Square
Dublin 2
Tel: 01-639 8855 Fax: 01-639 8856

Irish Haemophilia Society

First Floor, Cathedral Court
New Street
Dublin 8
Tel: 01-657 9900 Fax: 01-657 9901
Email: info@haemophilia.ie
Website: www.haemophilia.ie

Irish Kidney Association

Donor House
Block 43a, Park West
Dublin 12
Tel: 01-620 5306 Fax: 01-620 5366
Locall: 1890-543 639
E-mail: info@ika.ie
Website: www.ika.ie



HCV project staff, Lelia, Paula, Niamh and Margaret with the report.

HPSC: HCV Project Staff

Dr Lelia Thornton, Project Co-ordinator
Ms Niamh Murphy, Surveillance Scientist
Ms Paula Flanagan, Research Nurse
Ms Sarah Gavin, Database Developer
Ms Margaret McIver, Surveillance Assistant

Specialist Hepatology Centres

Beaumont Hospital

Hepatology Unit
Beaumont Road
Dublin 9
Tel: 01-809 2220/01-809 3000

Mater Misericordiae University Hospital

Hepatology Unit
55 Eccles Street
Dublin 7
Tel: 01-803 2048/01-803 2000

St. James's Hospital

Hepatology Unit
James's Street
Dublin 8
Tel: 01-410 3417/01-410 3000

St. Vincent's University Hospital

Hepatology Unit
Elm Park
Dublin 4
Tel: 01-209 4248/01-269 4533

Our Lady's Children's Hospital

Hepatology Unit
Crumlin
Dublin 12
Tel: 01-409 6742/01-409 6100

Cork University Hospital

Hepatology Unit
Wilton
Cork
Tel: 021-492 2274/021-454 6400

University College Hospital

Hepatology Unit
Newcastle Road
Galway
Tel: 091-544 370/091-524 222

St. Luke's Hospital

Hepatology Unit
Kilkenny
Tel: 056-778 5329/056-778 5000



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Pictured at the launch of the Hepatitis C Database Report were Eleanor O'Mahony, Positive Action; Michele Tait, HSE; Noeleen White, Positive Action; Margaret Dunne, Irish Haemophilia Society; Lelia Thornton, HPSC; Minister Mary Harney; Liz Kenny, Consultative Council on Hepatitis C; Maura Long, Transfusion Positive.

Welcome to Database News

Welcome to the first edition of *Database News*, the newsletter of the National Hepatitis C Database. Our aim is to keep you up to date on everything that is happening with the database.

Special thanks are due to everyone who has taken part in the database, as it provides important information on hepatitis C. It gives information about the natural history of infection and allows us to look at the progression of the disease. It will also highlight the response to treatment, help in the planning of health services and serve as a resource for future research into hepatitis C.

The database contains medical information about people who were infected with hepatitis C by blood or blood products in Ireland. All information is anonymous, therefore the database does not contain names or addresses of patients.

All the hepatology units around the country have given great support to the database since 2004 when work on the project started. We are grateful to the staff in St James's, Beaumont, Our Lady's Hospital Crumlin, the Mater, St Vincent's, St Luke's Kilkenny, University Hospital Galway and Cork University Hospital for their help.



Health Protection
Surveillance Centre,

25-27 Middle Gardiner St,
Dublin 1.
Tel: 01-8765300

Email:
hcvdatabase@hpsc.ie

Website:
www.hpsc.ie

Database website:
www.hcvdatabase.ie

How the database came about

In 1996, the Consultative Council on Hepatitis C was set up to advise the Minister for Health on all matters relating to hepatitis C. The Council's first review of services was published in March 2000 and one of its recommendations was to set up a database to learn more about the disease and its effects on patients.

The Health Protection Surveillance Centre (HPSC), Ireland's specialist agency for infectious disease surveillance, was chosen to set up and take care of the database. HPSC works closely with the hepatology units around the country.

Everyone infected by blood and blood products can take part in the database

Everybody who has been infected with hepatitis C by blood and blood products administered in Ireland can participate at anytime, says Project Coordinator, Dr Lelia Thornton.

"Anybody who has ever attended any of the eight designated hepatology units has already been invited to take part. People who have not yet agreed to take part can still participate by contacting their hepatology unit or any of the hepatitis C patient support groups.

"To get a full picture it is really important that as many people as possible participate in the database," she added.

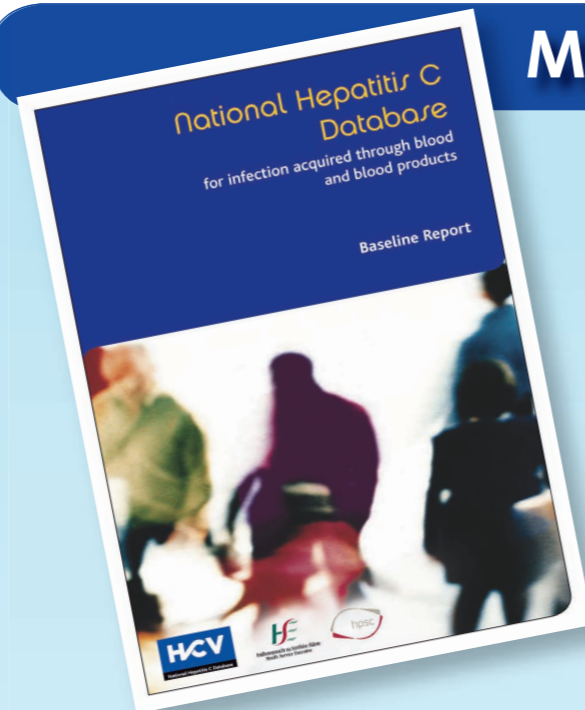
What information is collected in the database?

Information is collected on people who agree to participate in the database and on people who have died.

As data is taken from the patient's medical records in the eight hepatology units, there is no need to contact patients. Patient names or addresses are not recorded in the database. The information collected includes details of the source of the hepatitis C infection, current state of health, attendance at health services, liver biopsy and other test results, and treatment information.

A research nurse from HPSC collects the data. Information from the first round of data collection - which goes back over the years to the time of diagnosis - has now been published, and is available at www.hcvdatabase.ie. If you haven't already received a copy of this report then contact your hepatology unit, liaison officer or support group.

Follow up on participants has already started, and will be completed on a yearly basis - allowing us to monitor the progression of disease in the group.



Main findings from first data collection

Hepatitis C results

- 63% had tested PCR positive at some time, indicating active infection.
- Of those tested for genotype, three quarters of all participants, and 90% of the anti-D group, were genotype 1. Genotype 1 is associated with a less successful response to anti-viral treatment.

Alcohol

- Ten percent had indicators of excess alcohol consumption. Alcohol intake information was infrequently recorded except at the first visit.
- Alcohol excess was more prevalent in men. Alcohol is an important factor in the progression of hepatitis C liver disease.
- Patients who consumed alcohol in excess were more likely to have moderate or severe inflammation on liver biopsy, to have high fibrosis scores and to have cirrhosis.

Clinical condition

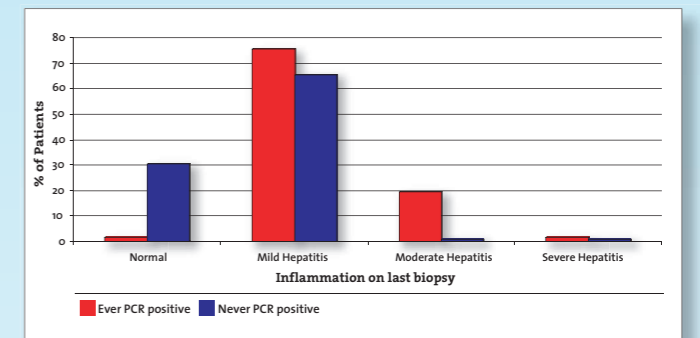
- The most commonly recorded medical conditions were fatigue and lethargy (30%), depression (27%) and arthralgia and joint pain (24%).
- Fatigue or lethargy were more likely to be reported for females and were slightly more likely in patients who tested PCR positive at some stage.
- Depression was also more likely to be reported for females and for those who tested PCR positive.
- Without a comparison group, it is not possible to say if the prevalence of these conditions is different from the general population. Also, these conditions are not necessarily diagnosed according to standardised criteria, and they may be unrelated to hepatitis C infection.

Liver biopsies

- Of patients who tested PCR positive and had a liver biopsy, 77% had mild inflammation, 20% had moderate inflammation and 2% had severe inflammation.
- Patients who consumed alcohol in excess were infected for longer and were older, and they were significantly more likely to have moderate or severe inflammation.
- High fibrosis scores on liver biopsy were less prevalent in the anti-D group (8%) than in the blood transfusion (28%), blood clotting disorder (21%) or renal (20%) groups.

- Patients infected by blood transfusion were more likely to have cirrhosis of the liver than those infected by any of the other routes.

Source of infection	% of patients with cirrhosis	% of ever PCR positive patients with cirrhosis
Anti-D	3.4	6.1
Blood transfusion	13.7	16.9
Blood clotting disorders	6.5	8.2
Renal	8.0	8.3
Total	6.2	9.7



Treatment

- The data shows that only 37% (276 patients) who tested PCR positive had ever received anti-viral treatment to date.
- Patients with genotype 2 or 3 responded better to treatment. This was also seen in patients who received combination therapy (treatment with more than one drug), who were under 45 years old when treatment started, who received treatment for a longer time or who were infected for less than 20 years.

The graph below shows the response (sustained viral response) to the first course of treatment, by duration of treatment and genotype, for patients on monotherapy (one drug) and combination therapy.

