

Factors found to be linked to more severe hepatitis C disease

- Testing PCR positive
- High alcohol consumption
- Male gender
- Older age at infection or at last visit
- Longer duration of infection
- Genotype 3 infection
- Elevated alanine aminotransferase levels (ALT – liver enzyme)

Being overweight/obese has also been found to be linked to faster disease progression in other studies. Unfortunately, height and weight were not recorded in the charts of the majority of database participants so we could not look at this.

What you can do to improve your health

- Anti-viral treatment for hepatitis C, if recommended by your doctor
- Decrease or give up alcohol
- Healthy weight
- Healthy lifestyle

Areas we hope to improve upon in the database

- Obtain weight and height data for most participants
- Obtain recent alcohol data
- Increase database participation

Please contact your hepatology unit if you have not consented and would like to. If you have any queries about the database or you would like us to look at specific issues please contact HPSC or the patient support groups. We welcome all suggestions.

Support & Contact Information

Support Groups

Positive Action

Tel: 01-676 2853 Fax: 01-662 0009
Email: info@positiveaction.ie
Website: www.positiveaction.ie

Transfusion Positive

Tel: 01-639 8855 Fax: 01-639 8856
Email: transfusionpositive@eircom.net
Website: www.transfusionpositive.ie

Irish Haemophilia Society

Tel: 01-657 9900 Fax: 01-657 9901
Email: info@haemophilia.ie,
Website: www.haemophilia.ie

Irish Kidney Association

Tel: 01-620 5306 Fax: 01-620 5366
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E-mail: info@ika.ie, Website: www.ika.ie

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Welcome to Database News

Welcome to the second edition of Database News, the newsletter of the National Hepatitis C Database. Thank you to everyone who consented to participate in the database. We hope you find the results to date useful. We are also very grateful to all the Hepatology Units and patient support groups who have given their full support since the database project started in 2004.

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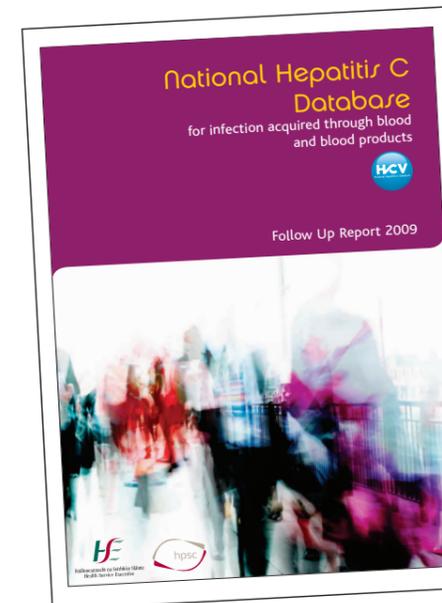
Everyone infected by blood and blood products can take part in the database

What information is collected?

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Background to the database

The National Hepatitis C Database was set up by the Health Protection Surveillance Centre (HPSC) in response to a recommendation by the Consultative Council on Hepatitis C. Its aim is to learn more about hepatitis C and its effects on patients.

Baseline data was collected in 2005 and 2006 and a report on this was published in 2007. The first round of follow-up data was collected in 2007 and the follow up report was published recently. Both reports are available in the Hepatology Units, from the hepatitis C liaison officers and at www.hcvdatabase.ie.

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

Everybody who was infected with hepatitis C through blood or blood products in Ireland is eligible to participate in the database. We are collecting information on people who still have circulating virus (PCR or RNA positive) and people who cleared the virus or have undetectable virus levels (antibody positive, but not PCR/RNA positive).

What information is collected?

The information collected includes details of the source of the hepatitis C infection, current state of health, use of health services, liver biopsy and other test results, and treatment information. A research nurse from HPSC collects this information from the hospital medical records of people who have agreed to take part or those who have died. There is no direct contact with patients. Names and addresses are not recorded in the database.

Participation in the database

The total number of participants so far is 1,275, which is 75% of those who are eligible to participate. This is already a very good participation rate, but a higher participation rate will mean better information about the whole group of people infected with hepatitis C through blood and blood products in Ireland. Eighty five people have been added to the database since the baseline data collection. If you are eligible and have not yet agreed to take part, but would like to participate, consent forms are available in the hepatology units. You can consent at any time. If you are unsure whether or not you consented already, just ask your hepatology nurse or consultant.



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Email:
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Website:
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Database website:
www.hcvdatabase.ie

Main findings so far

Database population

- 78% of database participants are women, due to the large number infected with hepatitis C through contaminated anti-D, 787 of whom are included in the database (figure 1)
- Over half of participating men are haemophiliacs who were infected through contaminated clotting factors (figure 1)
- The average age at follow up data collection was 56 years for women and 46 years for men
- On average, women had been infected for 29 years and men for 22 years when the follow up data was collected
- 46% of those who are still alive remain hepatitis C PCR positive and 54% no longer test positive for circulating virus (figure 2)

Alcohol consumption

- Information on alcohol consumption was infrequently recorded except at the first visit
- 12% of patients reported moderately high or high alcohol intake
- Men were much more likely to report excess alcohol consumption (figure 3)
- High alcohol intake was found to be associated with severe liver disease - 62% of PCR positive patients with high alcohol intake had severe liver disease, compared to 22% of those who reported moderately high alcohol intake or alcohol consumption within recommended limits

Signs of liver disease

- 148 database participants (12%) had clinical signs of serious liver disease
- PCR positive patients (18%) were more likely to have

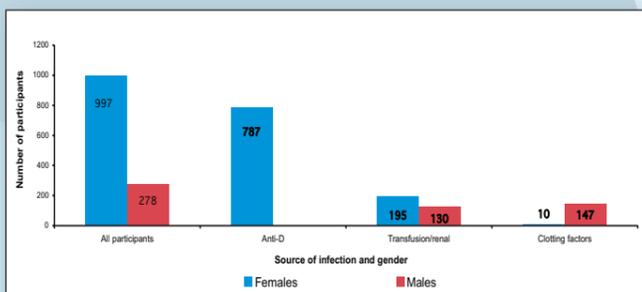


Figure 1. Number of database participants by source of infection and gender (source=other for 6 patients)

serious liver disease than PCR negative (or virus undetectable) patients (1%)

Cirrhosis

- 97 patients had developed cirrhosis of the liver by latest follow up
- 93 were PCR positive (12% of PCR positive patients) and 4 had no PCR results in their charts
- Cirrhosis was more common in patients with high alcohol consumption – 27% of patients with cirrhosis had high alcohol consumption compared to 5% of those without cirrhosis
- Men and older participants were more likely to have developed cirrhosis

Biopsy results

- 763 database participants had one or more liver biopsies
- 141 PCR positive patients (18%) had a high fibrosis score on biopsy
- Characteristics associated with having high fibrosis scores included being PCR positive, older age, male gender and high alcohol intake

Other medical conditions

- Almost all patients had medical conditions other than hepatitis C recorded in their charts. We do not know if the percentage of database participants with these conditions is different from the general population. However, if a condition is strongly linked to hepatitis C infection, we would expect to see it occurring more frequently in PCR positive patients compared to those who have been PCR negative (or virus undetectable) for a long time

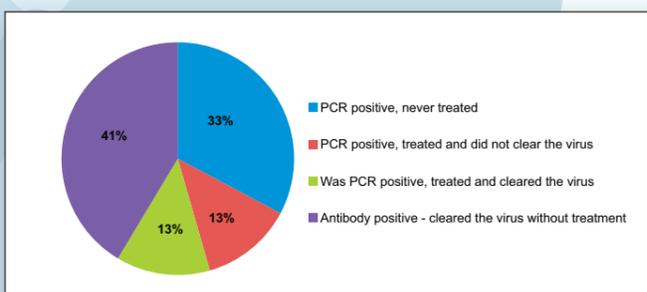


Figure 2. Percentage of living participants by latest PCR status

- 369 patients had depression or anxiety recorded in their medical charts. Long term medications commonly used to treat depression, anxiety or sleep disorders were noted in the charts of more than half of these. Depression or anxiety were more likely to be recorded for PCR positive patients (34%) than for PCR negative patients (22%)
- Osteoporosis and osteopaenia were also more likely to be recorded for PCR positive database participants (16%)
- Other commonly reported medical conditions included fatigue and lethargy (31%), arthralgia/joint pain (24%), hysterectomies (22%) and fibromyalgia (11%)
- HPSC has recently sent a health and lifestyle questionnaire to all HAA card holders to see whether these and other medical conditions differ between the database population and the general population. Results will be compared to a similar study carried out in the general population in Ireland

Deceased participants

- 173 participants had died by latest follow-up
- Death certificates were available for 95%
- Death was directly caused by liver disease for 43 participants: 33 were PCR positive, 8 had no PCR results in their charts and the remaining 2 had PCR results in their charts, but had never tested PCR positive
- The cause of death was hepatitis C for 19, liver cell carcinoma for 12, liver failure for 3, cirrhosis of the liver for 3 and other liver related conditions for 6
- Information on alcohol consumption was available for 34 of the participants who died from liver disease and 53% of these had high alcohol consumption

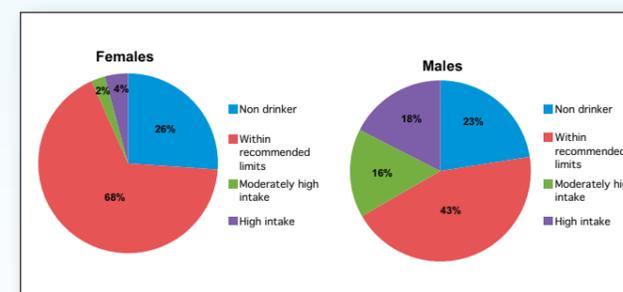


Figure 3. Percentage of participants by alcohol intake and gender

Anti-viral treatment

- Almost 40% (n=309) of PCR positive participants had one or more courses of anti-viral treatment by the latest follow-up
- Patients with higher fibrosis scores, those with hepatitis C genotypes 2 or 3 and those infected through clotting factors or blood transfusions were more likely to have been treated
- Response to treatment has improved dramatically since the introduction of combined therapy with pegylated interferon and ribavirin. Sustained virological response (viral clearance) is now being achieved for almost half of genotype 1 patients and approximately 70% of patients with genotypes 2 or 3 (figure 4)

Changes in biopsy results post treatment

- 106 PCR positive participants had liver biopsies before and after treatment
- Fibrosis scores had improved for 61% (n=23) of those who achieved SVR
- A significant proportion of those who were treated but did not achieve SVR also showed improvements in biopsy scores after treatment (n=21, 31%)

Liver transplants

- Fifteen patients had received liver transplants
- The average age at transplant was 51 years and the average duration of infection at transplant was 27 years
- All transplant recipients were PCR positive when transplanted

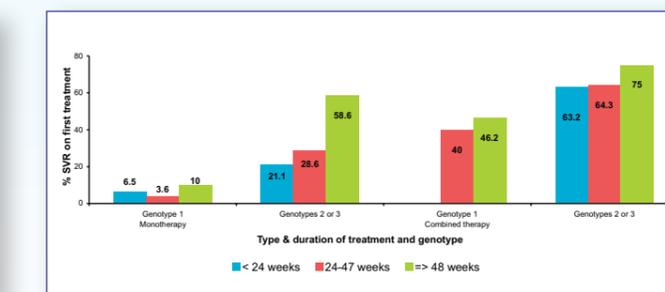


Figure 4. Percentage sustained virological response after first treatment course by genotype and duration of therapy for monotherapy with Interferon, and combined therapy with Interferon and ribavirin or pegylated interferon and ribavirin