National Hepatitis C Database

Database News

Newsletter of the National Hepatitis C Database

Issue 3 October 2010

Contents

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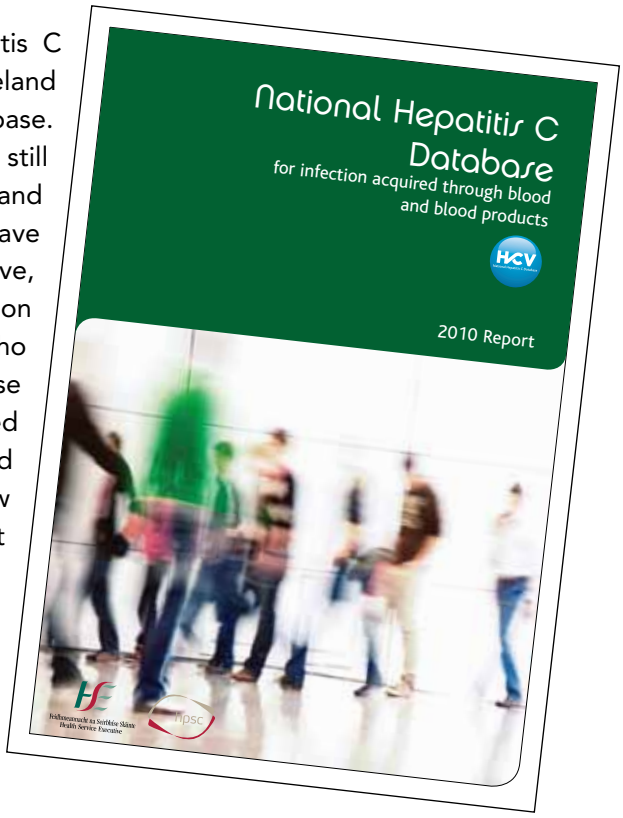
Welcome to the third edition of Database News, the newsletter of the National Hepatitis C Database. We would like to thank everyone who has taken part in the database and those who have supported the development of the database, especially the hepatology units and patient support groups.

Background

Everybody who was infected with hepatitis C through blood or blood products in Ireland is eligible to participate in the database. Information is collected on people who still have circulating virus (PCR/RNA positive) and also people who cleared the virus or have undetectable virus levels (antibody positive, but not PCR/RNA positive). The collection of information about all participants who consented to be included in the database began in 2005. Follow up data is collected each year from patients' medical notes, and the third round of data collection is now completed. Names and addresses are not collected in the database and there is no direct contact made with patients.



Please contact with your hepatology unit or patient support group if you wish to participate and have not yet given your consent.

What information is collected in the database?

Information is collected on the source of infection, current state of health, use of health services, liver biopsy and other test results, and treatment.

The database population

- The total number of participants in the database is 1,303.
- 28 people have been added to the database since 2008
- 62% of the total database population were infected through anti-D immunoglobulin, 26% were infected through receipt of blood transfusions or treatment for kidney disease, and 12% through blood clotting factors
- 76% are HCV genotype 1 and 19% are genotype 3
- 73% are females
- The average age of the database population is now 57 years
- The average duration of infection is 30 years. This varies by source of infection

Main findings so far

Table 1. Focus on the different patient groups

Anti D	Blood transfusion/renal	Inherited bleeding disorders
1977-79 outbreak (Genotype 1) - 27% uptake of anti-viral treatment. 1991-94 outbreak (Genotype 3) - 89% uptake of anti-viral treatment. Lowest prevalence of serious liver-related outcomes. Of those who had developed chronic (long term) infection nineteen percent were classified as having severe liver disease and nine percent had developed cirrhosis.	Fifty seven percent of chronically infected participants were female and forty three percent were male Most were infected in the late 1970s and 1980s This group had the highest prevalence of severe liver disease (38% of those with chronic infection) and of cirrhosis (22% of those with chronic infection)	Predominantly male (94%) and 42% were co-infected with human immunodeficiency virus (HIV). Most were infected as children in the mid-1970s to early 1980s. Of those with chronic infection, thirty one percent were classified as having severe liver disease and fourteen percent were diagnosed as having cirrhosis

Medical conditions

- Depression, hypertension, fibromyalgia/myalgia, dermatitis, diabetes, osteoporosis, and gastro-oesophageal reflux were all recorded more often for those chronically infected than those who were never chronically infected.

Clinical management

- The proportion of chronically infected participants taking long-term medications to treat depression, anxiety or diabetes was higher than for those not chronically infected.
- The specialist hospital services, other than hepatology, most commonly attended by chronically infected participants were haematology, psychiatry/psychology/counselling, endocrinology and rheumatology.

Liver biopsy results

- Nineteen percent of chronically infected participants had a high fibrosis score on their most recent biopsy and 14% had cirrhosis
- A high fibrosis score was associated with high alcohol intake, older age at biopsy, longer duration of infection, male gender, infection through blood transfusion or renal disease and genotype 3.
- Progression rates were lower in females who had never had high alcohol intake and who had been infected when aged less than 40 years.

Anti-viral treatment

- Those with HCV genotype 2 or 3 were more likely to have been treated than those with genotype 1
- Successful response to treatment has been similar in database participants to that reported in the international literature
- Participants infected through clotting factors were less likely to respond to treatment
- The factors associated with achieving a sustained virological response (successful response) to treatment were:
    - Treatment with combination therapy (2 drugs) rather than monotherapy (1 drug)
    - Having HCV genotypes 2 or 3 rather than genotype 1
    - Longer duration of treatment, younger age at treatment, female gender and lower fibrosis scores on biopsy.

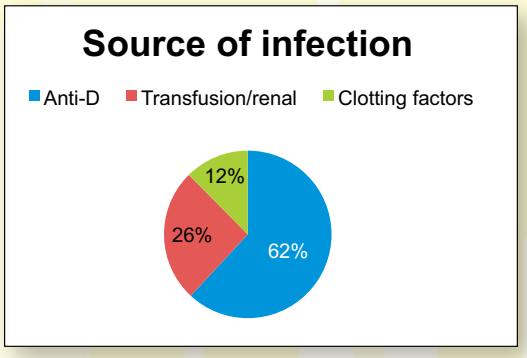


Figure 1. Database population by source of infection

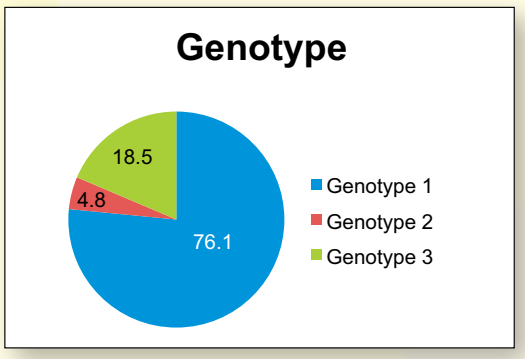


Figure 2 Genotype

Deceased participants

- One hundred and eighty eight participants had died by latest follow up. This represents fifteen additional deceased participants compared to the previous round of data collection.
- Death was directly caused by liver disease for 48 participants
- Death rates were higher in males or participants infected through blood transfusions or clotting factors, those who had high alcohol intake and participants who were older at infection.

Alcohol consumption

- Males and females differed in their reported exposure to alcohol with 32% of chronically infected males exceeding the recommended national limits for alcohol intake compared to 9% of females
- Alcohol consumption also differed by source of infection with participants infected through anti-D less likely to consume alcohol in excess of recommendations compared to those infected through other means
- Participants who had high alcohol intake were almost 5 times as likely to have severe liver disease

Summary

Although there is evidence of progression of disease in some people, the majority of the database population, even those chronically infected, do not have any evidence of serious liver disease. The factors found to be linked to more severe liver disease were:

- **Testing PCR/RNA positive**
- **High alcohol intake**
- **Male gender**
- **Older age at end of latest follow-up**
- **Longer duration of RNA positivity**
- **Genotype 3**

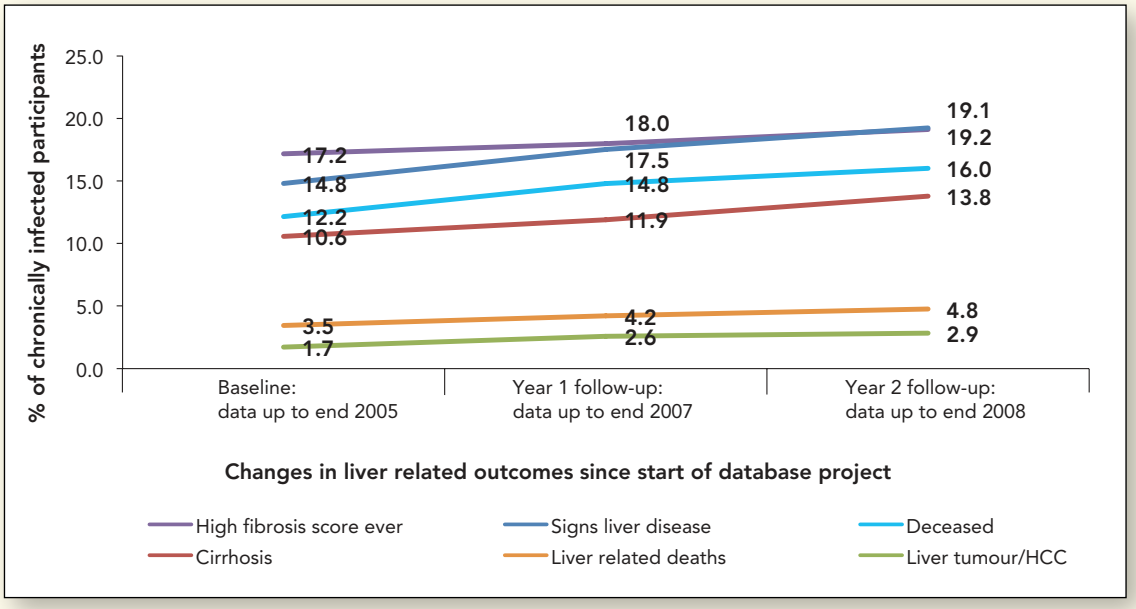


Figure 3. Changes since baseline data collection

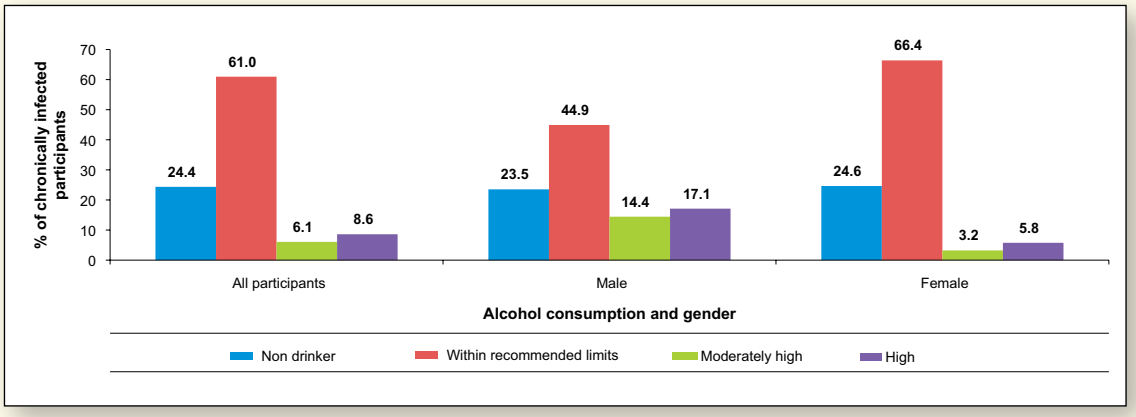


Figure 4. Highest reported alcohol consumption by gender for participants who became chronically infected.

Michael Griffin and Larry Bathe at the launch of the 2010 Database Report

Areas we hope to improve upon in the database

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

What you can do to improve your health

- Consider anti-viral treatment for hepatitis C, if recommended by your doctor
- Decrease or give up alcohol
- Maintain a healthy weight
- Live a healthy lifestyle

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.

Database website: www.hcvdatabase.ie

Support & Contact Information

Support Groups

Positive Action
56 Fitzwilliam Square, Dublin 2.
Tel: 01-676 2853, Fax: 01-662 0009.
www.positiveaction.ie

Transfusion Positive
3 Clanwilliam Square, Dublin 2.
Tel: 01-639 8855. Fax: 01-639 8856
www.transfusionpositive.ie

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

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

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