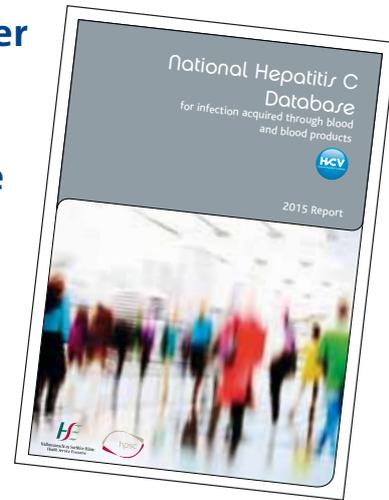


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Welcome to *Database News*, the newsletter of the National Hepatitis C Database. We would like to thank everyone who has taken part in the database, and also those who have supported the development of the database, especially the hepatology units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



Background

This edition of *Database News* provides information about all participants who consented to be included in the database. Everybody who was infected with hepatitis C through blood or blood products in Ireland is eligible to participate in the database and information is collected from patients' medical charts. We have now finished the fifth round of data collection and this includes information up to December 2013. The total number of participants in the database is currently 1,320.

Please contact your hepatology unit or patient support group if you wish to participate and have not yet given your consent. Names and addresses are not collected in the database and there is no direct contact made with patients.

The database population

- There are 1,320 database participants
- There are 1025 females and 295 males in the database
- The average age at the time of last follow-up was 60 years
- The average time interval from infection to last follow-up was 32 years
- There were 390 participants still alive and chronically infected at the end of 2013. Of these, 261 were infected through anti-D immunoglobulin, 99 were infected through blood transfusion or treatment for renal disease and 28 were infected through blood clotting factors

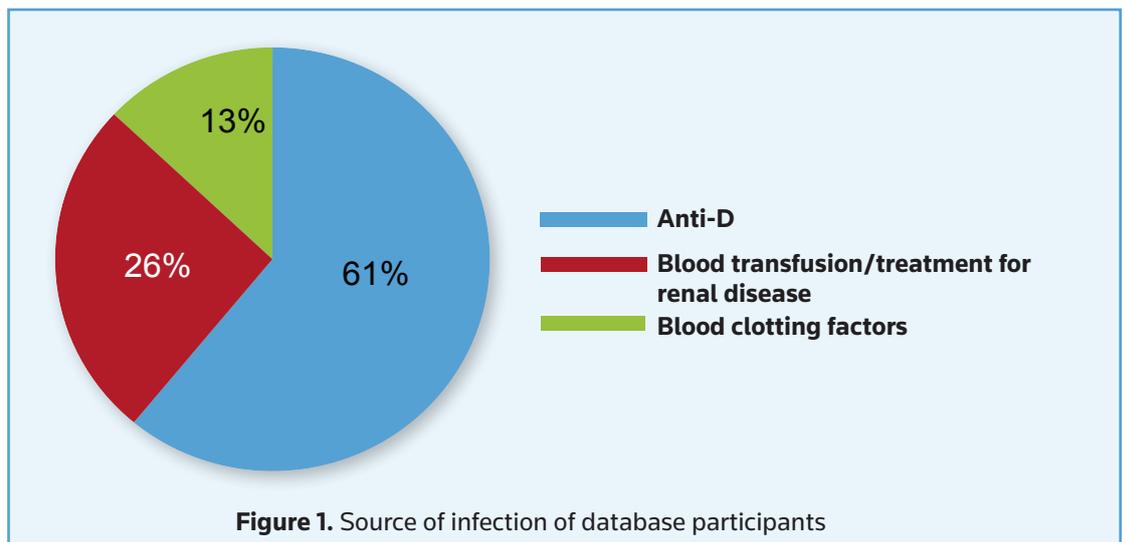


Figure 1. Source of infection of database participants



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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

Main findings so far

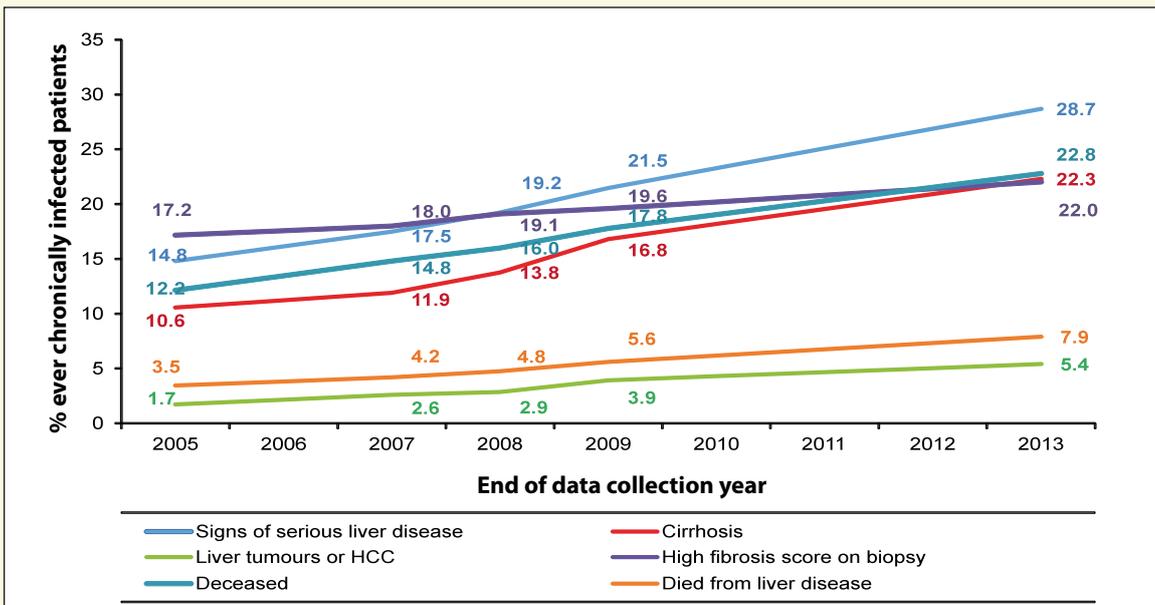


Figure 2. Changes in the prevalence of liver-related outcomes and death for chronically infected participants since baseline data were collected.

Outcomes

- More than half of the database participants are now in the fourth decade since they acquired hepatitis C and it is clear that those patients who did not develop chronic hepatitis C infection do not show signs of liver-related disease.

Signs of serious liver disease

- 29% of those who were chronically infected had clinical signs of serious liver disease such as cirrhosis, oesophageal varices, portal hypertension, or ascites
- The factors associated with having signs of serious liver disease were: being infected for longer, male sex, older age, high alcohol intake and genotype 3
- Participants infected through blood transfusion or treatment for renal disease were more likely to have signs of serious liver disease compared to anti-D participants

Cirrhosis

- Of the 813 participants who developed chronic infection, 181 (22%) had developed cirrhosis by the end of 2013

Hepatocellular carcinoma (HCC)(Liver Cancer)

- 44 (5%) of participants with chronic infection developed HCC, having been infected for an average of 30 years

Deaths from liver disease

- Death from liver disease occurred in 73 participants
- The factors associated with liver-related deaths were high alcohol intake, male sex, and current chronic infection
- Those infected through blood transfusion or clotting factors were more likely to have died from liver-related causes than the anti-D participants

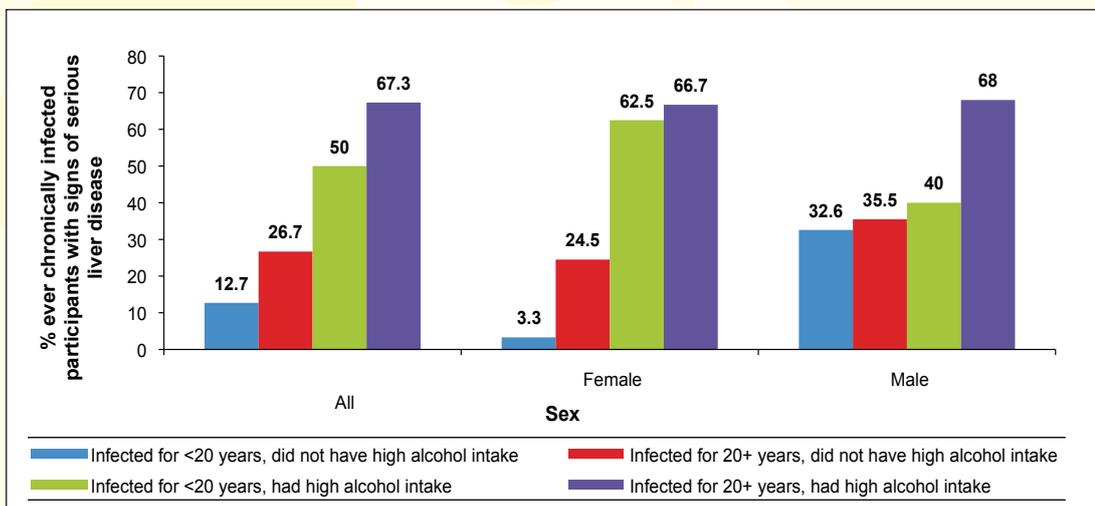


Figure 3. Percentage of chronically infected participants with one or more clinical signs of serious liver disease, by sex, duration of RNA positivity and alcohol consumption.

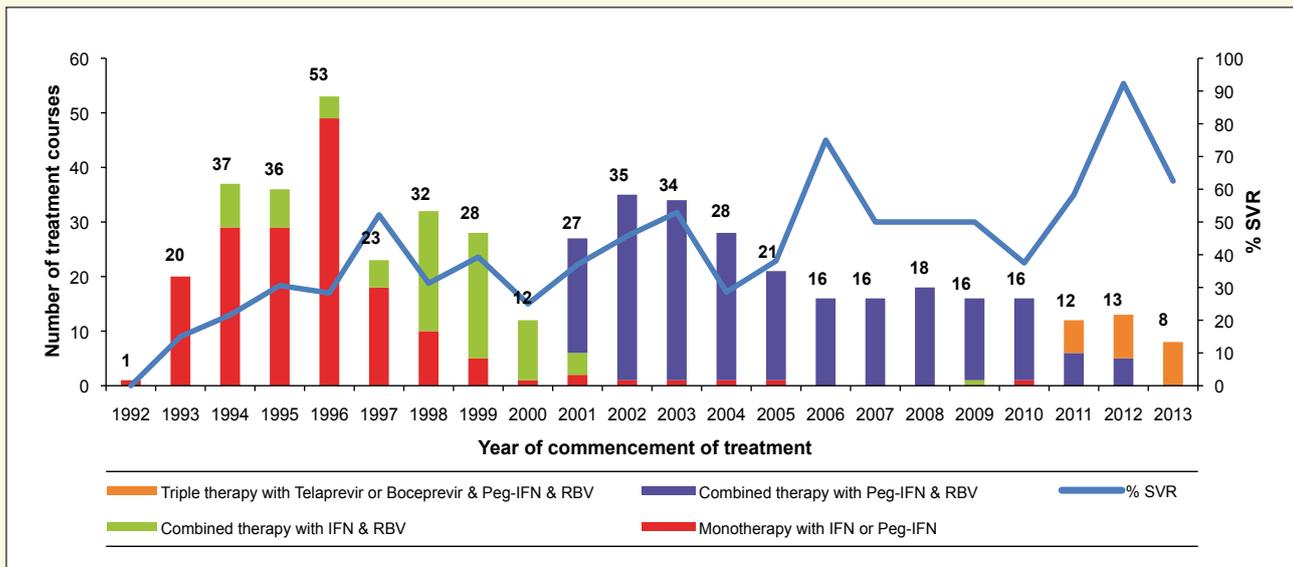


Figure 4. Number of treatment courses by type of treatment and percentage SVR, 1992-2013

Body Mass Index (BMI)

- BMI was available for only 44% of participants
- Of these, 30% were obese and a further 37% were overweight

Alcohol consumption

- Alcohol consumption in excess of national recommended levels was recorded for 17% of those with chronic infection
- This was higher in males and younger people
- Participants with high alcohol consumption had more than five times higher odds of having serious liver disease compared to those without

Anti-viral treatment

- A total of 390 (48%) database participants with chronic infection had received at least one course of anti-viral treatment by the end of 2013
- 37 participants with genotype 1 were treated with either telaprevir or boceprevir, in combination with Peg-IFN and RBV, by the end of 2013.
- Treatment response was available for 21 of these, of whom 17 achieved a sustained virological response (SVR)

New hepatitis C treatments

- A number of powerful new direct-acting antiviral therapies are now licensed for use in Ireland, offering a more optimistic future for those who still have chronic HCV infection. (A total of 390 participants were alive and still hepatitis C infected at the end of 2013) These new treatments are of shorter duration, have fewer side effects and result in higher cure rates
- In 2014, an early access programme was set up to facilitate rapid access to these new treatments for those with greatest clinical need
- A National Hepatitis C Treatment Programme has been established in the HSE during 2015 to govern the ongoing access to hepatitis C treatment on a phased basis

Summary

More than half the database population are now in the fourth decade since they acquired hepatitis C infection. It is clear that those who did not develop chronic hepatitis C infection do not show signs of liver-related disease. There has been a clear progression in the prevalence of liver-related disease in those participants who have chronic infection. The arrival of new highly effective drug treatments offers a more optimistic future for those who still have infection.

What can you do?

- Consider anti-viral treatment if recommended by your doctor
- Decrease or give up alcohol

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

Support & Contact Information

Support Groups

Transfusion Positive

3 Clanwilliam Square, Dublin 2.

Tel: 01-639 8855.

Fax: 01-639 8856,

Website: www.transfusionpositive.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

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.ie

HPSC: HCV Database Team

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Ms Margaret McIver, Surveillance Assistant



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