

Surveillance report.

Surveillance of hepatitis C testing, diagnosis and treatment in Scotland, 2019 update

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Key points

- In 2018, there were 1423 new diagnoses of hepatitis C antibody-positivity. This figure compares with 1814, 1591, and 1511 for calendar years 2015, 2016, and 2017 respectively and represents the lowest number of new hepatitis C antibody diagnoses in Scotland since 1996.
- It is estimated that approximately 21,000 individuals were living with chronic hepatitis C infection in Scotland by the end of 2018 and approximately 10,500 of these have been diagnosed.
- Hepatitis C testing remains high with 61,376 individuals tested in NHS Greater Glasgow and Clyde, NHS Lothian, NHS Tayside, and NHS Grampian during 2018. However, the increasing trend observed between 2000 and 2015 has levelled off in the last three years.
- A total of 2,609 individuals were initiated onto hepatitis C treatment during financial year 2018/19. This exceeds the government target of 2,000 treatment initiations during that period.

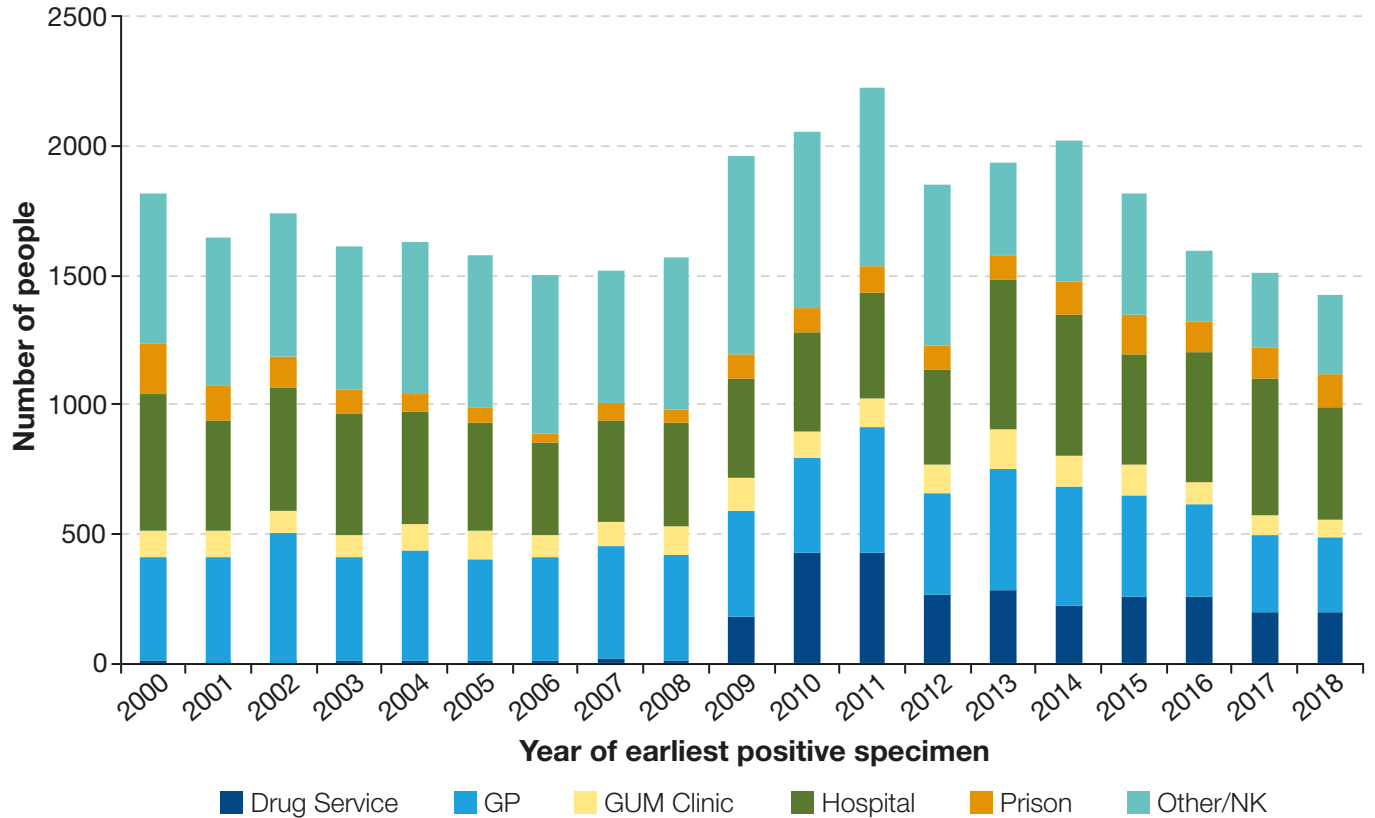
In this report, data from three hepatitis C (HCV) surveillance systems are presented:

- The Hepatitis C diagnoses database: Anonymised, epidemiological information from laboratory reports in Scotland since 1991, when HCV testing started, of all individuals diagnosed hepatitis C virus (HCV) antibody, Polymerase Chain Reaction (PCR) and/or antigen (Ag) positive. This includes diagnoses made on dried blood samples, which are confirmed at NHS testing laboratories.
- Hepatitis C test database: sentinel surveillance of all individuals tested for hepatitis C in NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lothian and NHS Tayside.
- Hepatitis C treatment initiates: a prospective surveillance system for monitoring the number of individuals initiated onto treatment on a monthly basis. Data are provided to Health Protection Scotland directly from NHS boards. Note: data are presented by financial year.
- Information on mortality is provided through record linkage to the National Records of Scotland (NRS) register of deaths and information on migration is provided through record linkage to the Community Health Index (CHI) database.

New Hepatitis C diagnoses: 2018

In 2018, 1423 new cases of hepatitis C antibody-positivity were diagnosed. This figure compares with 1814, 1591, and 1509 for calendar years 2015, 2016, and 2017 respectively and represents the lowest number of new hepatitis C antibody diagnoses since 1996.

Figure 1: Persons in Scotland reported to be hepatitis C antibody positive by year and source of diagnosis, during 2000 to 2018.



- 34% (478) of new cases resided in Greater Glasgow and Clyde NHS Board area, 17% (245) in Lothian, 9% (121) in Grampian, 7% (105) in Tayside, 7% (102) in Lanarkshire, 7% (95) in Ayrshire and Arran and < 5% each in the other NHS board areas.
- 67% (953) were male and 33% (465) female. Sex was not reported in fewer than 1% (5) of cases.
- At the time of diagnosis, 13% (185) were aged 20-29 years, 35% (492) were aged 30-39 years, 26% (375) were aged 40-49 years, 17% (236) were aged 50-59 years, and 7% (104) were aged 60+ years.
- Source of referral was known in 82% (1168) of cases. 38% (439) were diagnosed in the hospital setting (including infectious disease and gastroenterology units) and 20% (290) were diagnosed by general practitioners. 17% (198) were diagnosed in specialist drug services, where dried blood spot testing for hepatitis C was introduced in 2009.

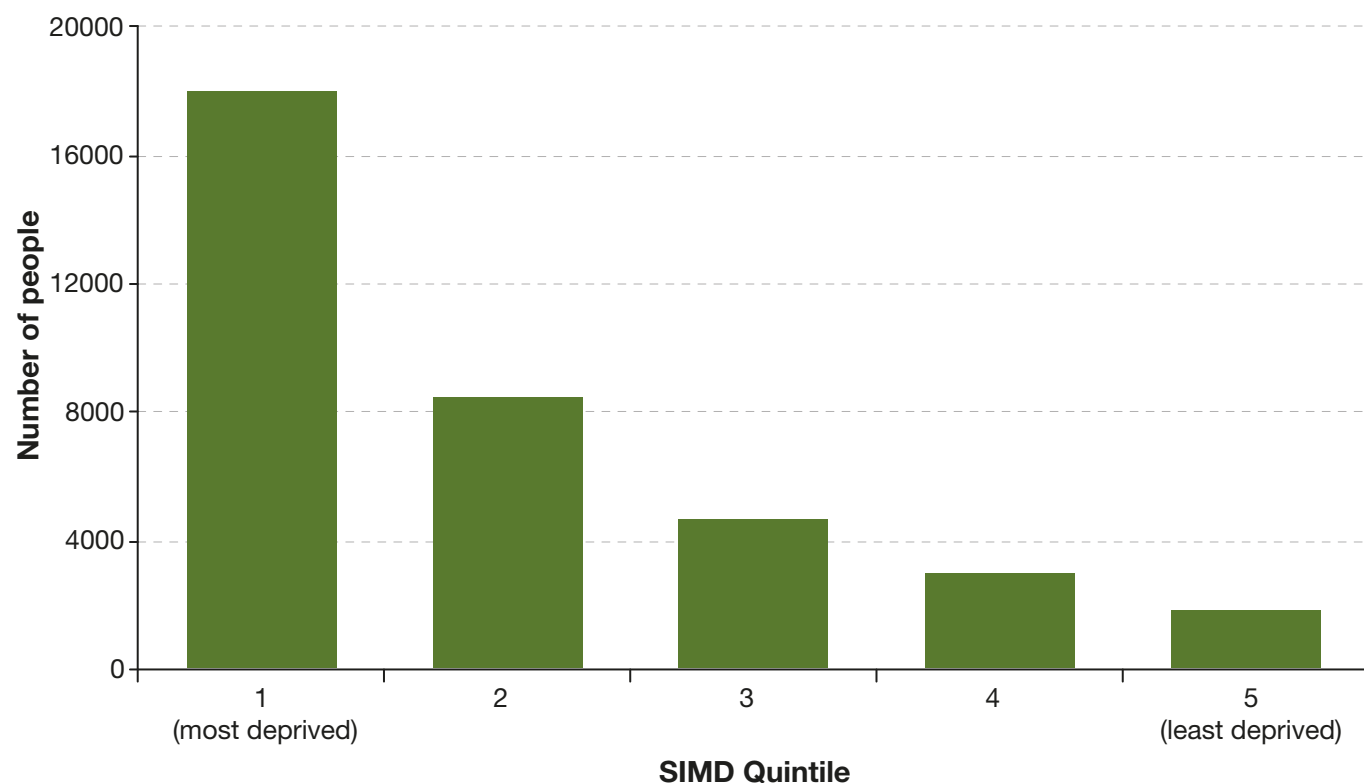
Deprivation, measured in Scottish Index of Multiple Deprivation population-weighted quintiles, was available for 83% (35,973) of all diagnoses. Among those where deprivation is known, 50% of HCV antibody diagnoses were among individuals residing in the most deprived quintile, 24% resided in quintile 4, 13% in quintile 3, 8% in quintile 2 and only 5% in the least deprived.

Table 1: Persons in Scotland reported to be hepatitis C antibody positive by NHS board and year of earliest positive specimen, to 31 December 2018.

NHS board	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	Total
AA	142	172	148	133	180	144	130	120	102	95	2861
BR	24	21	20	27	33	27	18	23	15	16	436
DG	51	53	35	39	35	29	29	32	39	33	986
FF	51	48	28	69	100	103	98	70	58	92	1464
FV	89	101	126	127	105	102	110	87	68	79	2027
GC	738	752	713	552	558	624	532	504	472	478	15053
GR	202	171	250	162	170	179	139	147	142	121	4433
HG	75	46	55	67	81	92	72	61	79	50	1372
LN	213	208	253	204	208	199	170	166	167	102	4630
LO	193	253	317	238	237	304	316	244	234	245	6058
TY	177	225	272	232	226	213	195	127	125	105	3624
Scotland	1960	2053	2229	1855	1940	2022	1814	1591	1509	1423	43080

Scotland totals include 136 cases from Orkney, Shetland, and Western Isles NHS Boards. Data for these boards cannot be featured separately due to confidentiality issues.

Figure 2: HCV diagnoses by SIMD quintile of residence in Scotland, data to 2018.



Estimate of persons living with diagnosed chronic HCV infection in Scotland: 2018

We estimate the number of people living with diagnosed chronic HCV through record linkage to the Scottish death register and the CHI database. A cumulative total of 43080 cases of hepatitis C antibody-positivity had been diagnosed as at 31 December 2018. Of these, 84% (36,261) have a CHI number on the HCV diagnosis database, which allows for record linkage. Of these 26% (9286) had died by the end of 2018 and of those who were not known dead, 11% (3010) had migrated from Scotland. Among those diagnosed HCV antibody positive and still living in Scotland by the end of 2018 (23,965), 18% (4242) had spontaneously resolved their infection, i.e. had never developed chronic infection. Of the 19,723 who were known chronic or for whom chronic status was not known, 62% (12,221) have been cured of their virus through antiviral treatment.

For the 16% (6819) records without a CHI number and therefore unable to link, we estimate the number who have migrated or died by applying the same proportions as above, the known proportion of infection that spontaneously resolve, and estimate that a small proportion (10%) of those without CHI will have cleared their HCV through treatment.

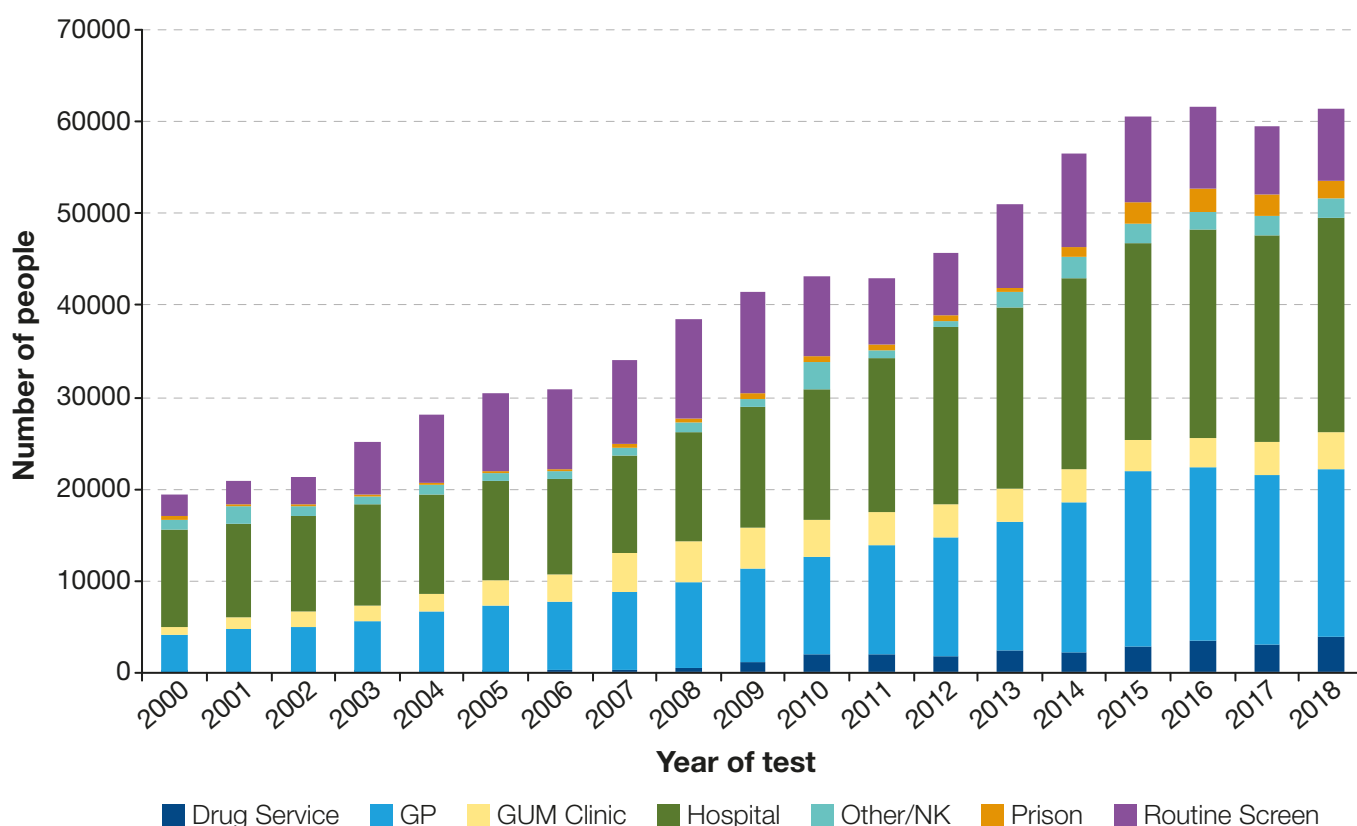
It is estimated that approximately 10,500 individuals are living with diagnosed chronic HCV infection in Scotland.

NHS board level estimates are available on the Sexual Health and Blood Borne Virus Data portal.

Trends in hepatitis C testing in Scotland: 2018

In the four NHS boards participating in the HCV test database (NHS Greater Glasgow and Clyde, NHS Lothian, NHS Tayside, and NHS Grampian), 61,376 individuals were tested for HCV antibody in 2018. This is a 3% increase on the previous year and represents the second highest annual total. Of these, 38% (23313) were tested in the hospital setting, 30% (18419) were tested in general practice, 13% (7700) were tested as part of a 'routine screen' in occupational health/renal units/fertility clinics, 6% (3944) in GUM Clinics and 6% (3910) in drug services, and 3% (2036) in prisons.

Figure 3: Annual number of people tested for hepatitis C antibody in four NHS board areas (NHS Greater Glasgow and Clyde, NHS Lothian, NHS Grampian, NHS Tayside) in Scotland during 2000 to 2018.

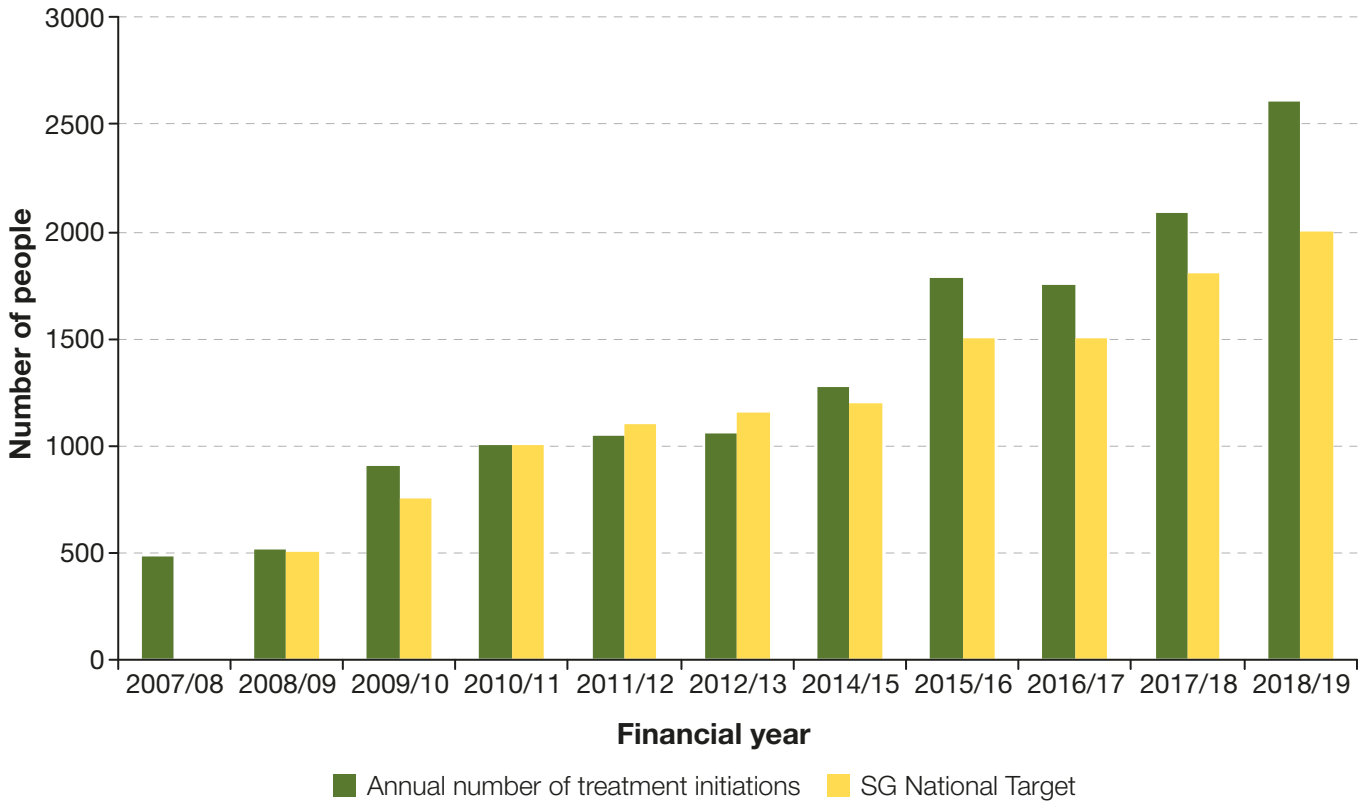


In 2018, 61,376 individuals were tested in the four participating boards and 5.1% (3128) of these were anti-HCV positive (representing new HCV diagnoses and re-testing of individuals previously diagnosed). Anti-HCV positivity varied by test setting, 26.0% (1017) individuals tested in drug services were anti-HCV positive, 16.1% (327) of those tested in prison, 3.9% (910) for those testing in hospital, 3.8% (692) for those tested general practice and 1.6% (65) for those tested in GUM clinics.

Hepatitis C treatment numbers: 2018/19

During financial year 2018/19, 2,609 individuals were initiated onto direct acting antiviral (DAA) HCV treatment. This exceeds the government target of 2,000 treatment initiations during that period. Of these, 50% were initiated in the hospital setting, 35% in the community, 12% in prison and 3% as part of a clinical trial.

Figure 4: Number of individuals treated for HCV in Scotland and Scottish Government treatment targets by financial year, data to 2018/19.



Of those initiated onto HCV treatment in financial year 2018/19, 46% were initiated in Greater Glasgow and Clyde, 11% in Lothian, 10% in Tayside, 9% in Grampian and 6% in Lanarkshire. Further information on NHS board level data are available on the Sexual Health and Blood Borne Virus Data portal.

Summary

During 2018, there were 1,423 laboratory confirmed diagnosis of HCV antibody positivity in Scotland. This is the fourth year in a row where the number of new diagnoses has fallen and represents the lowest number of new diagnoses in Scotland since 1996. These data highlight the need for an increased focus on case-finding to reduce the undiagnosed HCV population. The 2018 Short Life Working Group on HCV case finding and access to care had fourteen recommendations in this area and NHS boards are in the process of bench-marking their progress towards these recommendations through the Sexual Health and Blood Borne Virus Coordination network. At the same time, efforts to re-engage those patients who were diagnosed with HCV in the past and have not yet been treated are underway across the country.

Results from the sentinel surveillance of HCV testing in four NHS boards indicate that testing levels remain high although the increasing trend observed from 2000 to 2015 has levelled off in the last three years. This would indicate that the decreases in HCV diagnoses are not related to a similar decrease in testing.

The number of individuals treated for HCV in Scotland during financial year 2018/19 was the highest ever and exceeded the Scottish Government treatment target for the fifth year in a row. More of this treatment has been delivered outside in the hospital setting than in any previous year, with more than a third delivered in the community. With the effectiveness of the DAA therapies that are now being used for all patients in Scotland, it is expected that in excess of 90% of these patients will be cured of their virus.

The combination of low new diagnoses and high treatment and cure rates has resulted in a decrease in the estimated number of individuals living in Scotland with diagnosed chronic HCV infection. As we continue to treat more cases than we diagnose, this number will continue to fall. However, it is estimated that a further 10,500 individuals with chronic HCV remain undiagnosed.

Additional Resources

For more detailed information on HCV in Scotland, visit the Sexual Health and Blood Borne Virus (SHBBV) open access Data Portal which contains a wealth of information together in a format which allows users to easily monitor Scotland's progress nationally and locally against the Scottish Government's SHBBV framework outcomes: <https://hpsmicrosites.scot.nhs.uk/shbbv-framework-data-portal.aspx>

For more information on the prevalence of blood borne viruses (BBVs) and injecting risk behaviour among people who inject drugs (PWID) in Scotland, see the Needle Exchange Surveillance Initiative (NESI) report: <https://www.hps.scot.nhs.uk/a-to-z-of-topics/needle-exchange-surveillance-initiative-nesi/>

Data for HCV in the UK, including outcome data for HCV related liver disease in Scotland, are available in the Hepatitis C in the UK report lead by Public Health England <https://www.gov.uk/government/publications/hepatitis-c-in-the-uk>

Methods

For details of methods of the hepatitis C diagnosis database see: SCIEH Weekly Report vol.33 no.99/29 (at <https://www.documents.hps.scot.nhs.uk/ewr/pdf1999/9929.pdf>).

For details of methods of the hepatitis C test database see: McLeod A, Weir A, Aitken C, Gunson R, Templeton K, Molyneaux P, McIntyre P, McDonald S, Goldberg D, Hutchinson S. Rise in testing and diagnosis associated with Scotland's Action Plan on Hepatitis C and introduction of dried blood spot testing. *J Epidemiol Community Health*. 2014 Dec;68(12):1182-8. doi: 10.1136/jech-2014-204451. Epub 2014 Aug 28.

For details of methods of the HCV Clinical database see:

McDonald SA, Hutchinson SJ, Innes HA, Allen S, Bramley P, Bhattacharyya D, Carman W, Dillon JF, Fox R, Fraser A, Goldberg DJ, Kennedy N, Mills PR, Morris J, Stanley AJ, Wilks D, Hayes PC. Attendance at specialist hepatitis clinics and initiation of antiviral treatment among persons chronically infected with hepatitis C: examining the early impact of Scotland's Hepatitis C Action Plan. *J Viral Hepat*. 2014 May;21(5):366-76. doi: 10.1111/jvh.12153. Epub 2013 Sep 2.

Innes HA, Hutchinson SJ, Allen S, Bhattacharyya D, Bramley P, Carman B, Delahooke TE, Dillon JF, Goldberg DJ, Kennedy N, Mills PR, Morris J, Morris J, Robertson C, Stanley AJ, Hayes P; Hepatitis C Clinical Database Monitoring Committee. Ranking predictors of a sustained viral response for patients with chronic hepatitis C treated with pegylated interferon and ribavirin in Scotland. *Eur J Gastroenterol Hepatol*. 2012 Jun;24(6):646-55. doi: 10.1097/MEG.0b013e32835201a4.

Acknowledgements

HPS thanks collaborators and contributors to national HCV surveillance throughout Scotland for their assistance in the compilation and production of these data.

Hepatitis C diagnosis and test databases: Rory Gunson (West of Scotland Specialist Virology Centre), Kate Templeton (East of Scotland Specialist Virology Centre), Paul McIntyre (Ninewells Hospital and Medical School), Noha El Sakka (Aberdeen Royal Infirmary)

HCV Clinical Database: the members of the Scottish HCV Clinical Database monitoring committee Peter Hayes, Andrew Fraser, Stephen Barclay, John Dillon, Ray Fox, Daire O'Shea, Jose Fernandez-Montero, Nick Kennedy, and the clinical data entry staff at HCV clinics in Scotland.

NHS board abbreviations

AA Ayrshire & Arran	BR Borders	DG Dumfries & Galloway	GGC Greater Glasgow & Clyde
FF Fife	FV Forth Valley	GR Grampian	HG Highland
LO Lothian	LN Lanarkshire	OR Orkney	SH Shetland
TY Tayside	WI Western Isles		

HPS Surveillance Report

Published by: Health Protection Scotland

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