"Improving outcomes for patients with Blood Borne Viruses in Dundee"

Introduction

As part of good medical practice, GPs should offer testing for BBV (Hep B, Hep C and HIV) where clinically indicated, and vaccination against Hep B for specific risk groups as defined in the Green Book. http://immunisation.dh.gov.uk/category/the-green-book. Blood Borne Viruses (BBVs) – HIV and hepatitis B and C – present a serious health problem across the world and in the UK. The prevalence of HIV has steadily increased in Scotland over recent years and the number of new diagnoses in men who have sex with men (MSM) and in UK-born heterosexuals continue to rise. The prevalence of hepatitis C amongst Scots is estimated at 1% of the population and there is a clear association between all three Blood Borne Viruses and deprivation. Many infected people continue to face stigma and social exclusion.

The impact on the health and wellbeing for individuals with BBV and their carers is considerable. The long term consequences of hepatitis B and C are significant, and up to 75% of people infected with the hepatitis C virus (HCV) go on to develop chronic infection which carries a high risk of liver disease. HCV is responsible for between a half and three quarters of all liver cancer cases, and two thirds of all liver transplants in the developed world. There remains no vaccine for HCV infection but this can be effectively treated with drug therapy and can be cured in around 70% of cases. In Tayside, there are currently 2,837 people diagnosed as being hepatitis C (HCV) positive, however prevalence studies suggest that the actual number of individuals with HCV is around 4,500.

Approximately 20% of people infected with hepatitis B become chronic carriers at risk of liver fibrosis, cirrhosis and carcinoma. Chronic infection is more likely in people from endemic areas who have acquired their infection perinatally or in childhood. Few people can be cured from hepatitis B however drug therapy is available to suppress the HBV virus and reduce adverse outcomes. There is a vaccination available for hepatitis B which is recommended for specific risk groups.

Whilst there is no cure or vaccine for HIV a near normal life expectancy is predicted for most patients who are diagnosed early and adhere to treatment.

Testing technology for all BBVs has also improved and tests are available to accurately diagnose and distinguish between acute and chronic infection. The effectiveness of testing is dependent on its roll-out, uptake and pathways for onward referral to specialist treatment services.

There is a strong association between BBV and social deprivation. The high prevalence of HIV in men who have sex with men (MSM) and in some ethnic groups contributes to the established health inequalities affecting these marginalised groups. The burden of BBV disease is significantly higher in Dundee City than in either Angus or Perth & Kinross. Dundee City accounts for 60% of the total cumulative cases of HCV and HIV.

Dundee CHP supported a pilot piece of work in February 2013 by inviting all GP Practices to submit an audit of their BBV patient population. This resulted in 20 out of 26 Practices in Dundee satisfactorily completing the audit, which gave both the CHP and MCN an overview of the information, held by GPs. The numbers of patients identified through the audit process was less than expected for two main reasons .GP Practices routinely code patients who have significant conditions such as hepatitis B and C, but there are a large number of codes available, many of which may not be easily identifiable on a more superficial search of a Practice database. BBV screening is performed outside practice in HM Prisons, the Tayside Substance Misuse Service, and during hospital admissions. The results of this testing is not always transmitted back to general practices. For these reasons, there was concern that practices might not have identified all patients with hepatitis B and C. The Tayside BBV MCN collates information on all hepatitis B and C tests performed in Tayside by patient CHI (Community Health Identifier). This is the most comprehensive register of patients with hepatitis B and C in Tayside.

As a result of this initial pilot, Dundee CHP (Community Health Partnership) in conjunction with the Tayside BBV MCN (Managed Clinical Network) introduced a project to identify patients in General Practice with a diagnosis of hepatitis B or hepatitis C with a view to encouraging appropriate investigation, management and referral of these patients. The project ran from August 2013 to March 2014 with 24 out of 26 Dundee practices agreeing to participate.

In the project practices were therefore provided with BBV MCN register information on hepatitis B and C infected patients and asked to compare this with their own practice registers, updating the practice register where necessary. The MCN data included information on patients who had never been referred to the specialist service, patients who had been referred but had never attended or had attended but were lost to follow up and those patients who had an unknown PCR status.
It was felt that reconciliation between GP and specialist records for HIV was not necessary as Health Protection Scotland records and specialist records across Scotland are compared regularly and patients who are lost to follow-up are known to specialist services. It is more likely that there are patients known to GPs who are not known to local specialist services as they access HIV care outwith NHS Tayside. The current situation in Tayside is that specialist services correspond with GPs for all known HIV patients.

The CHP sought and gained Caldicott approval to enable the sharing of information between hospital and general practice.

Read codes, supported by a VISION guideline were developed and provided to practices to ensure consistency in coding so that a complete and accurate record of the BBV population was held by both the patient's own GP and the hospital service
Where patients were identified who would benefit from investigation or referral, practices were asked to organise this. The BBV MCN, together with Dundee CHP arranged for appropriate funding to enable this work to take place. Practices also agreed to perform necessary reviews, blood tests and appropriate hepatitis B vaccination and appropriate items of service payments were agreed to cover the cost of these actions. In order to support vaccination uptake, vaccine for these patients only may be obtained on stock order so that patients were not required to go away with a prescription, but rather be vaccinated at time of presentation.

Separate strands of the BBV project also encouraged practices to screen high-risk patient groups for BBVs, and to immunise at risk patients against hepatitis B. To facilitate this, a questionnaire was provided to practices to be used to identify all patients (not just new registrants) who had lived in areas where hepatitis B and C were endemic, so that appropriate screening could be offered. Case finding was extended to screen patients in other known risk groups, such as patients with a known history of IV drug use and men who have had sex with men.

Practices were encouraged to use and display health promotion material provided by the BBV MCN in patient areas. A credit card sized "BBV fast track" card was designed to enable patients to bypass a GP appointment and be directed to a Practice Nurse appointment for screening. People may present these cards at the practice when booking an appointment. These cards were made available to the wider population through a range of access points including peer group distribution.

The MCN produced a guideline on screening and immunisation for primary care giving details on appropriate screening tests for high risk groups including those for patients from endemic countries depending on country / region of origin.

Results of the Project

Returns were received from 19 of the 24 Dundee CHP practices who agreed to participate in this project.

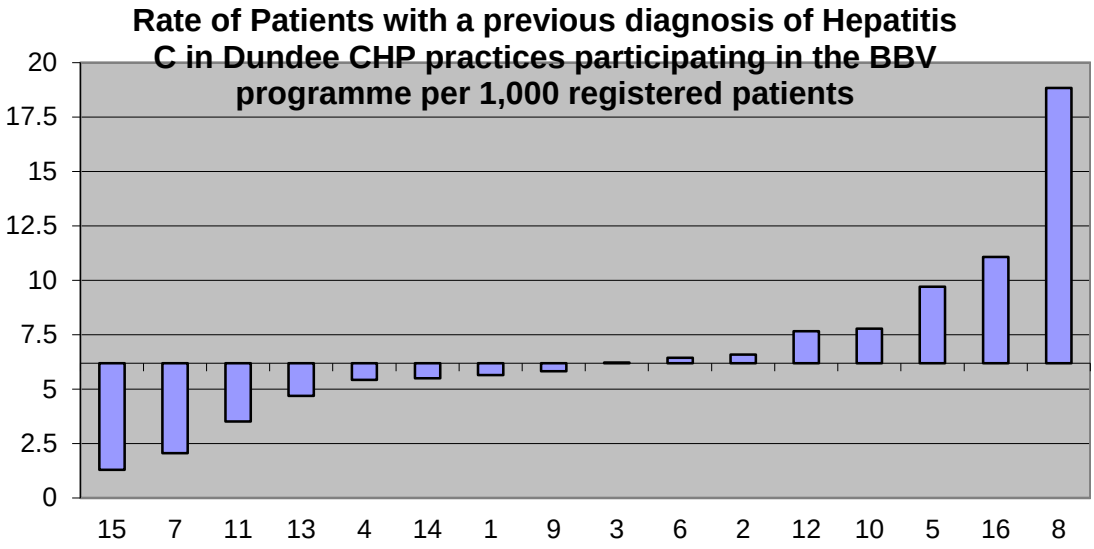
Reporting practices had a total list size of 118,504, (71% of the 167,912registered with Dundee CHP practices). The 6 practices who did not submit a report included 3 city centre practices with deprived populations more likely to have BBV and 3 suburban practices with more affluent populations less likely to have a BBV.

Of the 19 practices that submitted data, 15 practices included quantitative data that could be incorporated in the report.

The following report discusses the data.

BBV MCN Identified Rates of Hepatitis C

The rate of hepatitis C varied markedly across the practices submitting data. Rates were lowest in practices with a high student population and highest in practices with higher deprivation scores. The average prevalence was 6.1 per 1,000 patients with a range from 1.3 to 18.8

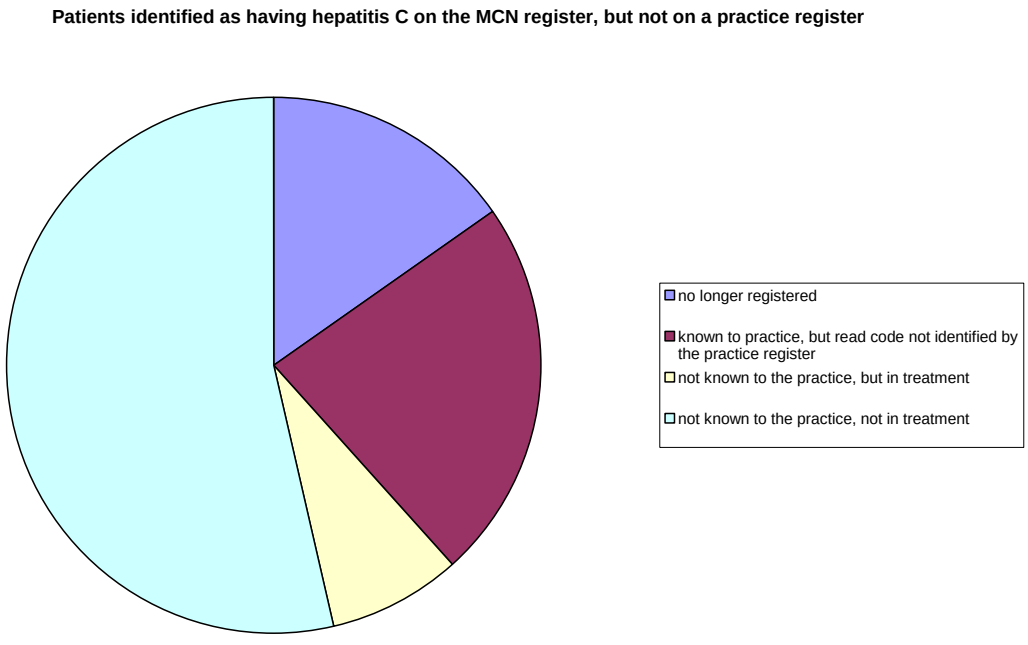


Practice Identification of Hepatitis C

At the start of this project, practices participating in the BBV were asked to identify all patients who they knew to have Hepatitis C in order to create a practice register. This practice register was then compared with the MCN register. Reporting practices were aware of 390 patients with hepatitis C, compared with the 599 known to be on the MCN register, a rate of 66%. Practices were aware of an additional 9 patients not on the MCN register

Of the 209 patients not known to practices, 32 were patients who were no longer registered to that practice; 48 were known to practices, but had been coded with a diagnosis that was not an "approved code" that could place the patient on the register. 17 of the patients not recorded on practice registers were known to secondary care and were receiving active treatment.

The remaining 112 patients on the MCN register were not known to practices and not in service



Practice outcomes

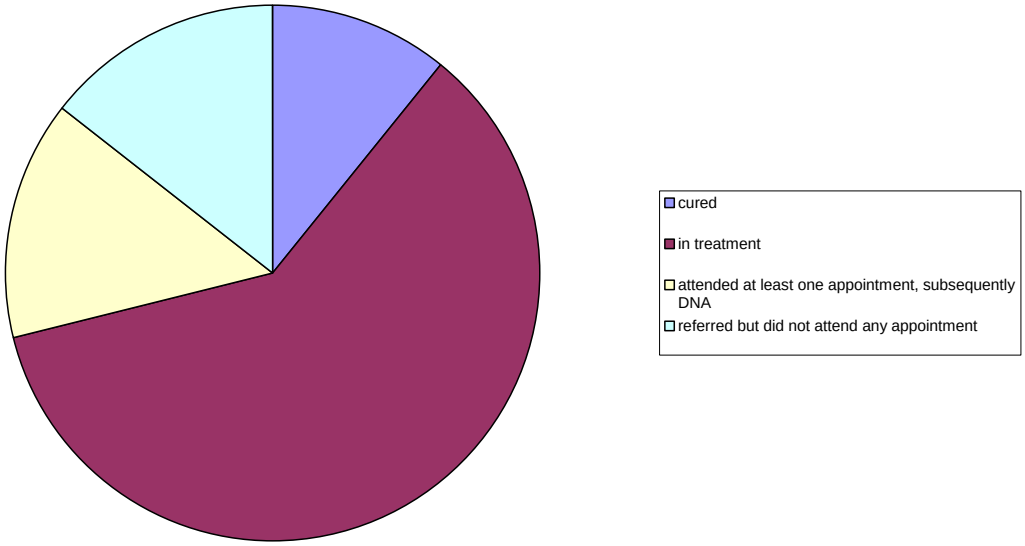
Patients not referred

154 patients not referred. 118 patients were found to be PCR –ve and required no further action. 24 patients were contacted by telephone or letter, but did not respond to prompts. 12 patients opted to decline referral.

Patients referred

117 patients were referred. 9 patients were identified as having been cured following referral, with another 50 known to be in continuing treatment. 12 patients had attended at least one appointment, but had subsequently dropped out of service, while another 12 had never attended. Outcomes for the remainder were unknown.

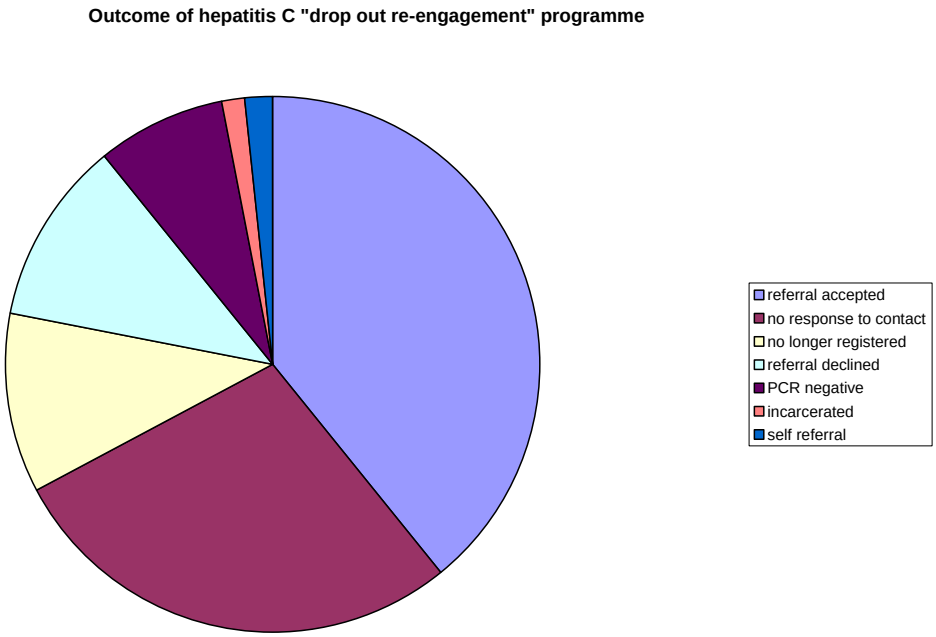
Outcome of patients referred to hepatitis C clinic through the BBV project



Re-engagement with hepatitis C clinic "drop outs"

Practices were also asked to review the records of patients who had attended the hepatitis C clinic on at least one occasion, but who had subsequently defaulted from further attendance.

64 patients were identified in this group. Of these, 5 did not require referral as subsequent blood testing showed them to be PCR –ve. A further 7 patients were no longer on the practice list, with a further patient on the list, but incarcerated. 18 patients were phoned or written to, but did not respond to an offer of referral. 7 patients who were contacted formally declined the offer of a referral. 25 patients accepted an offer of referral, while one chose to self refer.



Hepatitis C "never referred to service"

Practices were asked to review the records of 12 patients who had a positive hepatitis C result on the MCN register who had never been referred to the hepatitis C service. 4 of these patients had spontaneously cleared the virus and were PCR –ve. 4 patients were referred back into service, of which at least 2 had attended clinic. A further 4 had been written to or otherwise contacted and had not responded to prompts.

Hepatitis C service data

Pre study	Number	Post study	Number
No referral to specialist service	40	Bloods tested PCR negative referral not required. No referral Referred to specialist service • 10 attended (4 PCR negative and discharged) • 5 did not attend • 1 died • 1 HMP	3 20 17
No referral required PCR negative Referred attended and discharged PCR negative	81 91	Re-infections PCR negative	3 169
Referred and in follow up	193	Referred and in follow up Lost to follow up Discharged PCR negative End treatment negative/lost to follow up Treated and cured	156 7 7 2 21
Referred never attended clinic	99	Referred never attended clinic Back in follow up	65 30

		• Discharged PCR negative -10 Moved from Dundee	1
Referred, attended then lost to follow up	126	Referred, attended then lost to follow up (39 referred back but did not attend) Back in follow up • 3 discharged PCR negative • 4 treated	89 34
Referred treated and cured	148	Dead Re-infection Cured	1 3 144
Completed treatment/no SVR results	5	Bloods taken and bloods obtained/all SVRS	5
Total	783	Total	

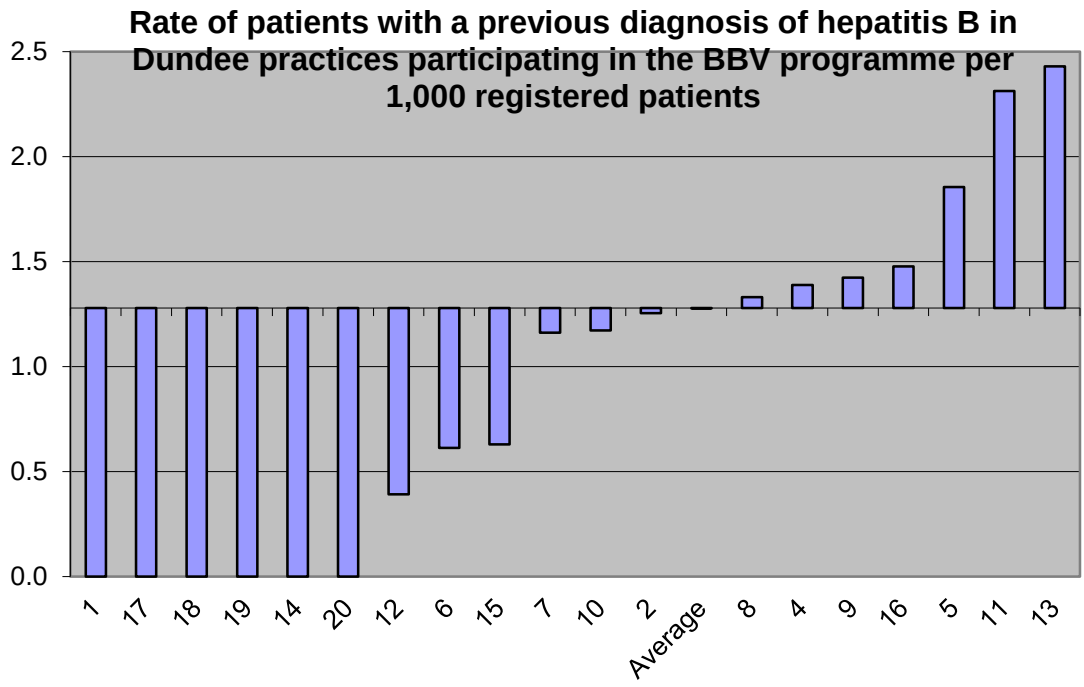
Summary
17 new referrals and 10 who have attended clinic
30 patients referred attended first clinic
34 back in follow up who were lost to follow up
3 bloods taken PCR negative no referral required
5 SVR bloods taken
50% reduction in number of patients never referred
30% reduction in number of patients referred but never attended
25% reduction in number of patients referred attended but lost to follow-up

BBV MCN Identified Rates of Hepatitis B

The Tayside BBV MCN (Managed Clinical Network) collates information on all Hepatitis B tests performed in Tayside by patient CHI. This is the most comprehensive register of patients with hepatitis B in Tayside. There are a small number of patients who have a BBV identified outside Tayside who do not appear on this MCN register.

A number of historic diagnoses of hepatitis B from the 1970's and 1980's were identified by practices as part of the practice register formation work that they performed. These patients were recalled for testing as part of the BBV project. Several were found to be still hepatitis B positive and potentially infective, and have been referred in for treatment and public health screening.

The rate of hepatitis B varied markedly across the practices submitting data. Rates were highest in practices with a high overseas student population, those with a high proportion of patients using intravenous drugs, and those with a high immigrant Asian population.

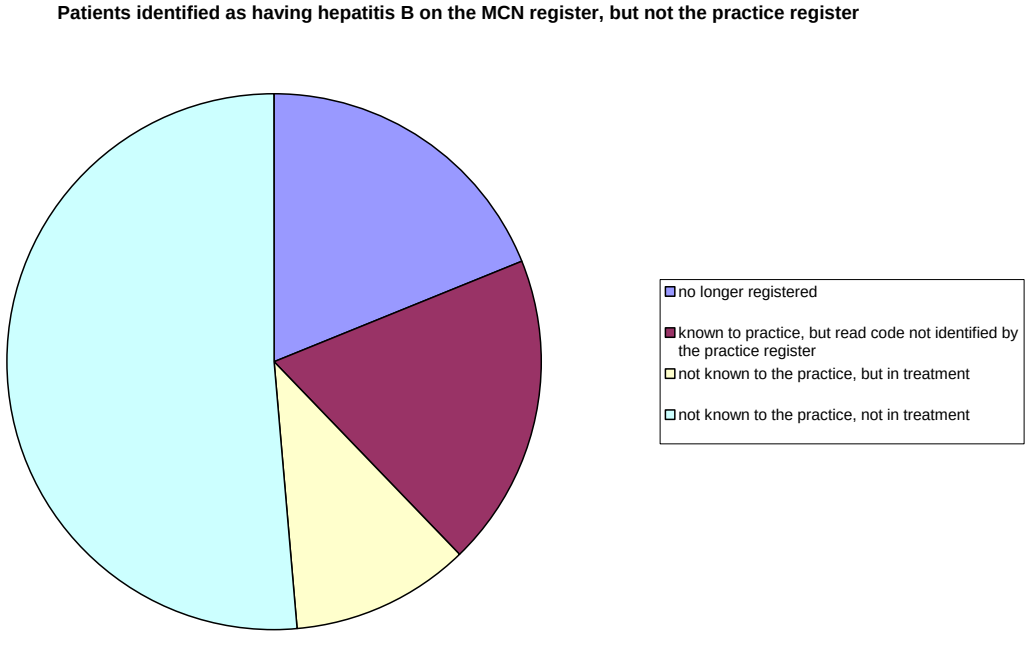


Practice Identification of Hepatitis B

At the start of this project, practices participating in the BBV were asked to identify all patients who they knew to have hepatitis B in order to create a practice register. This practice register was then compared with the MCN register. Reporting practices were aware of 84 patients with hepatitis B, compared with the 121 known to be on the MCN register, a rate of 69%. Of these 121 patients, 32 were attending the hepatitis B service.

Of the 37 patients not known to practices, 7 were patients who were no longer registered to that practice; 7 were known to practices, but had been coded with a diagnosis that was not an "approved code" that could place the patient on the register. 4 of the patients not recorded on practice registers were known to secondary care and were receiving active treatment.

The remaining 19 patients on the MCN register were not known to practices and not in service.



Practice outcomes

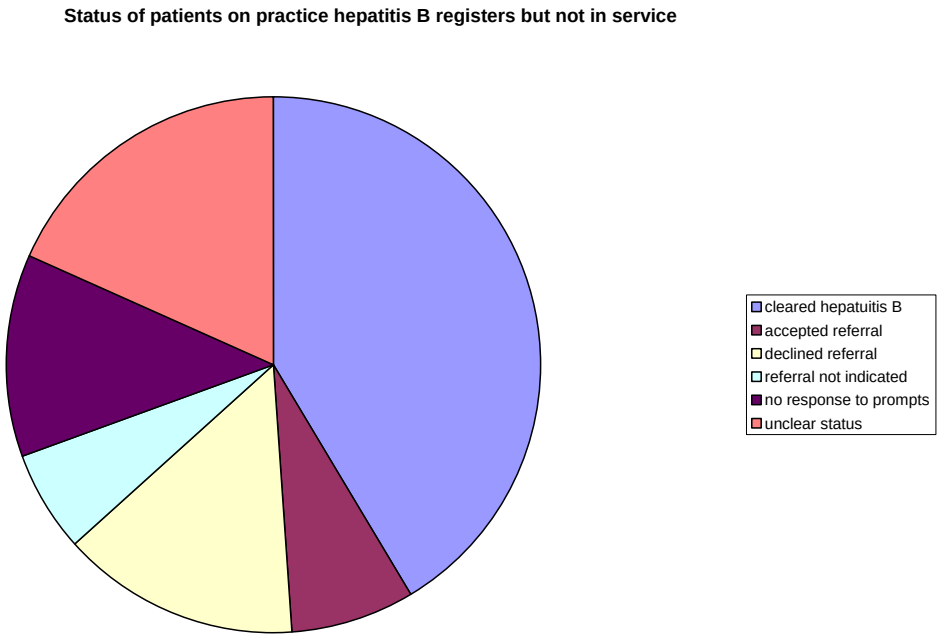
Patients not referred, not in service but on the hepatitis B register

82 patients were known to have a previous diagnosis of hepatitis B and were still registered with the participating practices and were not in service. 34 of these patients were found to have cleared their hepatitis B and required no further action. 10 patients were contacted by telephone or letter, but did not respond to prompts. 12 patients opted to decline referral. 5 patients were discussed with the service and did not require referral, or were deemed unsuitable for referral due to other more serious health concerns. The status of the remainder was unclear

Patients referred

6 patients accepted a referral.

The chart below shows the status of all patients who were known to have a previous diagnosis of hepatitis B, still registered with the participating practices and who were not in service at the end of the project.



Hepatitis B "never referred to service"

Practices were asked to review the records of 9 patients who had a positive hepatitis B result on the MCN register who had never been referred to the hepatitis B service. 1 patient had left the practice, 2 were written to, but had not responded to prompts and 6 were identified as low risk, not requiring referral.

Immunisation rates

Quantitative data was received from 7 practices. A total of 124 immunisations were given:

1st HBV	44
2nd HBV	41
3rd HBV	29
3rd HAV/HBV	4
Booster	4

Screening of High Risk Groups

17 out of 24 GP Practices opted to take part in Part 2 of the project with screening of high-risk individuals using the health screening questionnaire and fast track cards. Only 8 practices provided any quantitative data on screening showing that 79 tests were taken.

However we were able to get data from the virology lab on all BBV screening taken in the period of the project broken down to individual practices and compare this to the same period 12 months before.

Test	2012/13	Positive result	2013/14	Positive result
HIV	394	3	638	3
HBV	620	16	719	16
HCV	571	32	675	33

This data shows an increase in testing by;

HIV 62%
HBV 16%
HCV 18%

The increase in HIV testing was significantly higher between the 2 years compared to both HBV and HCV testing. This may be due to a number of reasons. There has been recent guidance on HIV testing given out to primary care in the last year. It might also reflect that practices are requesting BBV screening as a "bundle" on ICE, (the computerised blood test request system used by practices), where all three tests are displayed together to allow ease of requesting.

Assessment

The Dundee CHP BBV project has resulted in the creation of effective practice registers that should help to support a call/recall system for patients who have defaulted from treatment. It has also promoted the use of a dedicated set of codes; so that newly diagnosed patients are not lost to follow up.

The project has also resulted in significant numbers of patients lost to follow up being referred back in to service. As the project has only just finished this cycle, overall cure rates as a result of the project are considerably understated. Referral numbers are also understated as the data from practices involved in the project but who did not submit analysable data could not be included.

The project has demonstrated considerable variability in the prevalence of hepatitis B and C across Dundee practices. This may in part relate to true variation, and may in part relate to differences in the number of screening tests performed in practice. There may be benefits in exploring whether it is worth investing in increasing screening in low prevalence practices to see whether that low prevalence relates to under recognition rather than a true low prevalence.

Significant numbers of patients with hepatitis B and C remain out of treatment that would benefit from it. As there are extremely effective treatments available for both of these conditions, both of which are associated with considerable long term morbidity and mortality, it may be worth continuing to invest in engaging with this population. The project has demonstrated the utility of engaging directly with general practices in reaching and engaging with this population.

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