Swindon
Hepatitis B & C
Joint Strategic Needs Assessment

June 2013
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Swindon Hepatitis B & C Joint Strategic Needs Assessment

Executive Summary

1. Scope and purpose of the needs assessment
This document presents findings and recommendations from a health needs assessment undertaken to identify the health care related needs of those infected with Hepatitis B and C in Swindon.

The needs assessment focussed on the main stages of the care pathway for each of the viruses.

1. Testing
2. Diagnosis and referral
3. Initial assessment
4. Specialist management and treatment

Although it is recognised that primary prevention of infection (sexual health promotion, drug education, needle exchange) is important, a detailed investigation of this area of the pathway was beyond the scope of this needs assessment. Areas of primary and secondary prevention relating to healthcare provision including vaccination and screening are discussed.

2. Hepatitis B and C
The focus of this needs assessment is on the blood borne viruses Hepatitis B and C. Hepatitis is a term used to describe inflammation of the liver. Whilst some hepatitis infections will pass without causing permanent damage to the liver others can persist for many years and cause liver disease, which can be fatal. Treatments are available for those diagnosed with Hepatitis B and C, however, the number of people treated in the UK is low.

Whilst the epidemiology of the infections is different, there are parallels between the two, and routes in to treatment are similar. Both infections are known to affect vulnerable population groups who tend to have less contact with health services than the general population. Paired with the fact that both Hepatitis B and C infections are largely symptom free this means that many individuals remain undiagnosed and only a small proportion of those infected come into contact with treatment services. People with an untreated infection are not only at high risk of developing liver disease but remain infectious and are therefore a risk to others.

<table>
<thead>
<tr>
<th>Hepatitis B High Risk Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>People born or brought up in Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands.</td>
</tr>
<tr>
<td>Babies born to mothers infected with hepatitis B.</td>
</tr>
<tr>
<td>People who have ever injected drugs.</td>
</tr>
<tr>
<td>Men who have sex with men.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hepatitis C High Risk Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>People who have ever injected drugs.</td>
</tr>
<tr>
<td>People who received a blood transfusion before 1991 or blood products before 1986, when screening of blood donors for hepatitis C infection, or heat treatment for inactivation of viruses were introduced.</td>
</tr>
<tr>
<td>People born or brought up in a Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands.</td>
</tr>
<tr>
<td>Babies born to mothers infected with Hepatitis C.</td>
</tr>
<tr>
<td>Prisoners, including young offenders.</td>
</tr>
</tbody>
</table>
3. Liver Disease
Liver disease is a government priority. It is associated with substantial morbidity and mortality and costs to the NHS related to hospital inpatient admissions and liver transplants and these costs are expected to increase. Yet liver disease is largely preventable.

The main causes of liver disease are alcohol abuse, obesity and to a smaller but still significant extent Hepatitis B and C. Liver disease causes approximately 2% of all deaths in the UK; viral liver disease accounts for less than 0.1% of all deaths in England (191 deaths annually). In Swindon there were 16 deaths from chronic liver disease in 2010 out of a total of 1538 deaths from all causes.

To-date interventions to prevent and treat hepatitis infections have received less attention than those for alcohol and obesity, which are also risk factors for other high profile preventable diseases such as cardiovascular disease. However, there is growing awareness of the need to invest in the prevention and treatment of viral hepatitis. The NHS and Public Health Outcomes Frameworks both set an ambition for reduction of mortality in people under 75 years from liver disease, and liver disease has recently been highlighted as a priority for action in the Chief Medical Officers Report 2011.

4. Local Policy Context
Improving prevention, screening and access to treatment for those with chronic Hepatitis C infection have been the focus of work in Swindon for a number of years. Testing rates have historically been low (although they have improved in recent years), and there is no locally provided treatment service in Swindon; services are provided by the John Radcliffe Hospital in Oxford as part of their block contract with NHS Swindon (Swindon Clinical Commissioning Group from April 1st 2013).

With the abolition of Primary Care Trusts on 31st March 2013 and the move of Public Health to Local Authorities and much of local NHS commissioning to GP led Clinical Commissioning Groups the NHS Swindon Public Health Directorate have identified the need to draw together the learning from previous work in this area in to one document, and to clarify the need for service improvements. Because of the parallels between Hepatitis B and C in terms of risk groups and pathways in to treatment it was felt that the opportunity should be taken to include both infections in this needs assessment.

5. Hepatitis B and C in Swindon
Understanding the incidence and prevalence of Hepatitis B and C infections in Swindon is difficult. Many infections are undiagnosed, and there are limitations associated with small numbers and the way in which laboratory data are collected. This needs assessment has collected data from a range of sources to build a picture of the likely numbers of people affected in the area.

Number of laboratory identified cases of Hepatitis B (acute and chronic) in Swindon by year, 2007-2011.
Source: Health Protection Agency - extracted from CoSurv on 23/11/2012
Number of laboratory identified cases of Hepatitis C (acute and chronic) in Swindon by year, 2007-2011
Source: Health Protection Agency - extracted from CoSurv on 23/11/2012

Estimated Hepatitis B and C prevalence in Swindon

<table>
<thead>
<tr>
<th>National Prevalence Estimate</th>
<th>Expected number of cases in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of chronic Hepatitis B infection</td>
<td>0.3%</td>
</tr>
<tr>
<td>Prevalence of chronic Hepatitis C infection</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

The Health Protection Agency (now Public Health England) has produced a template to help local areas estimate the prevalence of Hepatitis C in their local population more accurately. It takes account of the estimated number of intravenous drug users in the population and also ethnic mix. From this it can be estimated that there are 519 people in Swindon infected with Hepatitis C. This is a much lower than the very crude estimate of 836; the true value is likely to lie somewhere between the two.

Health Protection Agency Prevalence template: estimated number of Hepatitis C cases in Swindon

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Estimated number of cases in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infected current intravenous drug users (15-64y)</td>
<td>208</td>
</tr>
<tr>
<td>Infected ex-intravenous drug users (15-64y)</td>
<td>232</td>
</tr>
<tr>
<td>Infected non-IDUs (16-59y)</td>
<td>47</td>
</tr>
<tr>
<td>Infected Asian/Asian-British (16-59+y)</td>
<td>28</td>
</tr>
<tr>
<td>Infected Asian/Asian-British (60+y)</td>
<td>5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>519</td>
</tr>
</tbody>
</table>
6. Swindon Hepatitis B & C Care Pathways
There is currently no formal pathway for Hepatitis B or C in Swindon that covers the whole patient journey from testing through to specialist treatment, although specific pathways for antenatal screening and vaccination of babies born to Hepatitis B positive mothers are in place.

A key aim of this needs assessment was to map the patient pathways for Hepatitis B & C in Swindon from testing and diagnosis through to specialist care and management and treatment. The figure below shows the key services offering testing and referral routes in to specialist treatment identified.

![Diagram showing testing and treatment pathways for Hepatitis B & C in Swindon](image)

**Figure 1:** Diagram showing routes in to testing and treatment for Hepatitis B & C in Swindon (From 1st April 2013 services provided by the drug services Inclusion and DHI have moved to the new service provider CRI).
- **Testing**
No systematic review of the level of testing in Primary Care in Swindon was undertaken as part of this needs assessment, however discussions with stakeholders suggested that there is little targeted screening of high risk groups carried out and low awareness amongst GPs of Hepatitis B and C.

Testing for Hepatitis C in drug services is done through both venous and dried blood spot testing. Discussions with stakeholders and service users highlighted a number of challenges to the current system of testing, and improvements which could be made. These were related to the lack of consistency in the way in which testing is offered and data sharing between services.

There are opportunities to extend testing for Hepatitis B and C and Hepatitis B vaccination in Primary Care and drug services and to ensure that all those in 'high risk' groups are routinely offered testing according to NICE Guidelines.

- **Diagnosis and initial assessment**
Patients face a long wait (2-3 months) for a first gastroenterology appointment at the Great Western Hospital following diagnosis in Primary Care. Patients reported a lack of support following diagnosis, and the need for better co-ordination of care between services. The role of the Hepatitis C Co-ordinator, working in partnership with Hepatitis C Positive group has provided a highly valued source of support to many people living with Hepatitis C in Swindon.

- **Treatment**
Limited data was available about the numbers of patients being treated for their infection in Swindon. Nationally the number of patients being treated is low; it is estimated that only 26% of those with chronic Hepatitis B have had their infection diagnosed and of these 5% receive antiviral treatment each year, whilst approximately 3% of those chronically infected with Hepatitis C are currently treated each year. Patients with Hepatitis C report receiving excellent care at the John Radcliffe Hospital in Oxford, but that travel is difficult.

7. **Conclusion**
The findings of this needs assessment show that whilst only a small proportion of the Swindon population are affected by Hepatitis B (0.3% - estimated 627 people) and Hepatitis C (0.4% - estimated 836 people (HPA adjusted estimate taking account of Swindon demography 519)) numbers are expected to grow. In order to prevent further infections and unnecessary liver disease and deaths testing and diagnosis needs to expand and access to treatment improved.

There are strong arguments for investing in prevention and treatment for hepatitis.
- To prevent further infections
- To reduce under-75 mortality from liver disease
- To reduce costs to the NHS
- To reduce health inequalities

8. **Recommendations**
Recommend actions to achieve this have been highlighted throughout this document. These have been summarised in to a set of recommendations based on evidence of best practice and NICE Public Health and Clinical Guidelines and are set out below.

It should be noted that a whole system approach to implementing these is required, with collaboration between commissioners and service providers at all stages of the care pathway. Whilst raising awareness of the viruses and increasing the number of people being tested is important it is also essential that there is adequate capacity within secondary care and specialist treatment services to manage the increased demand this creates. Consultation should take place regarding the capacity of treatment services to deal safely and effectively with increased numbers resulting from any planned expansion of testing.
1. Local service providers and community and voluntary groups including the Blood Borne Virus Co-
ordinator should work together with support from Swindon Borough Council Public Health leads
to develop and deliver evidence based campaigns, materials and resources to raise awareness
about Hepatitis B and C among the general population and those at increased risk of infection. This
should build on existing nationally produced materials wherever possible and include up-to-date
information on:
- The main routes of infection and transmission
- Local services providing testing and Hepatitis B vaccination
- The potential for infection to be asymptomatic
- The benefits of early testing and treatment
- Overcoming social and cultural barriers and improve access to testing and treatment

2. Swindon Borough Council Public Health leads should work with local commissioners and service
providers to develop and deliver education programmes to improve the knowledge and skills of
healthcare professionals and others providing services for people at increased risk of Hepatitis B
or C infection. This should build on existing nationally produced materials wherever possible and
include up-to-date information on:
- Epidemiology of Hepatitis B and C – local prevalence, at risk groups
- Testing and diagnosis
- Treatment
- National guidance on testing and delivery of care
- Skills to overcome social and cultural barriers and improve access to testing and treatment

3. Commissioners in the Local Authority, Clinical Commissioning Group and NHS Commissioning
Board should ensure testing for Hepatitis B and C (venous and/or dried blood spot as appropriate)
and Hepatitis B vaccination is available in-line with NICE Guidance in:
- Primary Care
- Drug and Alcohol Services
- Sexual Health Services

4. Swindon Borough Council Drug and Alcohol Treatment Commissioners should work with the new
Swindon drug service provider, CRI, to ensure that all service users entering drug treatment are
routinely offered Hepatitis B and C testing and Hepatitis B vaccination at their initial assessment,
and that annual testing for Hepatitis C is offered to people who test negative but remain at risk of
infection. Commissioners should routinely audit data collected.

5. Services providing testing should ensure that all those who undertake testing are trained and
competent to provide appropriate pre- and post-test discussions and that testing is accompanied
by appropriate information resources and support while waiting for test results and following
diagnosis.

6. A named commissioning lead for viral hepatitis should be identified in the Swindon Clinical
Commissioning Group, NHS Commissioning Board Local Area Team and Swindon Borough Council
who should agree ways to work together to ensure effective commissioning of a fully integrated
care pathway for those who test positive for Hepatitis B or C infection from the point of diagnosis.
This should take account of the patient’s psychosocial and support needs as well as treatment for
their infection and include mechanisms for following up patients who defer treatment.
7. Swindon Borough Council Public Health leads should work with Commissioners and Service Providers to develop clear data recording and sharing protocols which support those receiving positive results for Hepatitis B or C to access support and move along the treatment care pathway as appropriate, and which enable the number and source of referrals for Hepatitis B and C; appointment attendance; treatment and discharge or onward referral to specialist services to be monitored.

8. Swindon Clinical Commissioning Group Commissioners should audit services available for the management and treatment of Hepatitis B and C in Swindon and ensure compliance with NICE Guidelines when they are published.

9. Swindon Borough Council Public Health leads should work with Antenatal Screening Commissioners in the NHS England Local Area Team to undertake regular audit of the Hepatitis B vaccination programme for babies in Swindon and pathways for mothers identified as Hepatitis B positive and take action if standards are not being met.

10. Findings of this needs assessment should be used by the Clinical Commissioning Group to consider redesign of current treatment pathways. This should include development of an options appraisal outlining models of care which would support and improve access to specialist Hepatitis B & C treatment services for patients in Swindon. Options might include:

   a. A nurse led in-reach service from the John Radcliffe Hospital in Oxford for Hepatitis C treatment.
   b. A nurse led service providing co-ordinated care and support hosted by the Great Western Hospital (Gastroenterology or Sexual Health Department).
   c. A community based Blood Borne Virus or Hepatitis Nurse (possible hosting organisations suggested by stakeholders in this needs assessment include Carfax Medical Centre or CRI).
   d. Development of the Blood Borne Virus Co-ordinator pilot and the Hepatitis C Positive group to provide non-clinical community based support for all those diagnosed with Hepatitis B and C.
   e. Development of a GP with a Special Interest role in Swindon.

11. Swindon Borough Council Public Health and Drug and Alcohol Commissioners should work together to evaluate the role of the Blood Borne Virus Co-ordinator (and Hepatitis C Positive group) and secure ongoing funding for the projects.
1. Introduction

1.1 Scope and purpose of the needs assessment
This document presents findings and recommendations from a health needs assessment undertaken to identify the health care related needs of those infected with Hepatitis B and C in Swindon.

The needs assessment focussed on the main stages of the care pathway for each of the viruses.

1. Testing
2. Diagnosis and referral
3. Initial assessment
4. Specialist management and treatment

Although it is recognised that primary prevention of infection (sexual health promotion, drug education, needle exchange) is important, a detailed investigation of this area of the pathway was beyond the scope of this needs assessment. Areas of primary and secondary prevention relating to healthcare provision are discussed.

Specific objectives of the needs assessment were:

- To describe current incidence and prevalence of Hepatitis B & C in Swindon.
- To understand future population projections for Swindon and what this may mean in terms of the needs of local people and demand for services.
- To map the current care pathways for Hepatitis B & C in Swindon from testing and diagnosis through to specialist care and management and treatment.
- To understand the number of individuals progressing through the care pathway and identify gaps, barriers to treatment, and points on the pathway where patients ‘drop off’.
- To describe current evidence and best practice for prevention, diagnosis and treatment of Hepatitis B & C and compare to Swindon services to identify areas for improvement.
- To identify priorities for action and make recommendations for service commissioning and delivery to bring about change and improvement.

1.2 Swindon’s JSNA process
Joint Strategic Needs Assessment (JSNA) is a mandatory process for understanding the current and future health and wellbeing needs of the local population. This involves gathering different types of information, interpreting it and pointing to the priorities for improving health and wellbeing in Swindon. Understanding Swindon’s changing population, the factors that affect health and wellbeing, the town’s assets and the implications for future services are important in setting priorities and planning future services.

The Swindon Health and Wellbeing Board aims to develop and open up the JSNA process so that it becomes a useful resource for everyone involved in health and wellbeing. A JSNA summary for 2012 has been produced and a range of individual needs assessment documents is already publicly available.

There is an agreed programme of work to produce a series of needs assessments and JSNA bulletins that summarise key points for a range of priority topics in a user-friendly form. There will also be updates on key statistical data such as the 2011 Census results so that health and wellbeing plans can
be based on the most up to date information available. More details of the local JSNA vision and process can be found in Swindon’s JSNA website http://www.swindon.gov.uk/sc/sc-healthmedicaladvice/jsna/Pages/sc-jsna.aspx.

2. Context

2.1 The People of Swindon
Swindon is a large town on the eastern edge of the South West region, midway between Bristol and Reading. The population size of Swindon Borough (which includes the urban areas of Swindon and surrounding villages and rural areas) was 209,156 at the time of the 2011 census. The area and population covered by NHS commissioned services for Swindon is slightly different; it includes people living within Swindon Borough Council and Shireham ward boundaries and is the population that will be served by Swindon’s Clinical Commissioning Group (CCG). It is about 20,000 people greater than the population of Swindon Borough Council. About 5,000 of these additional people live in the Oxfordshire electoral ward of Shireham and most of the remainder live in the counties of Wiltshire and Gloucestershire. The main focus of this needs assessment is Swindon Borough. However some health service data included in the report includes patient data from those living outside the Borough.

Swindon’s population has increased by 12% since 2001, more than either the South West (7.0%) or England (6.3%) as a whole and is expected to continue to grow; the population is forecast to rise by about 5% by mid-year 2015 and by about 15% by mid-year 2022 (ONS 2011).

Swindon’s population is younger than average; the most populous age-groups are those between 35 and 45 years and there are also relatively large numbers of pre-school age children. 15.5% of Swindon’s population is from a minority ethnic population (compared to 17.2% for England as a whole); those from an Asian background make up the largest proportion of this group, with 3.3% of Indian Asian origin.

The health of people in Swindon is mixed compared to the England average. Deprivation is lower than average, however there are areas of significant deprivation; 15 (13%) of Swindon’s 119 Lower Super Output Areas (LSOAs) are ranked among the most deprived 20% in England. Eight of these are among the most deprived 10% in England.

2.2 Health services in Swindon
There are 27 GP Practices serving the community of Swindon. The main acute care provider is the Great Western Hospital. Specialist Hepatitis Treatment Services are commissioned from the John Radcliffe Hospital in Oxford. Before 1st April 2013 (when the majority of data for this needs assessment were collected) health services in Swindon were commissioned by NHS Swindon Primary Care Trust. On the 1st April 2013 commissioning responsibilities moved to Swindon Clinical Commissioning Group and the NHS England Area Team for Gloucestershire, Swindon and Wiltshire. Swindon Borough Council continues to lead the commissioning of drug and alcohol treatment services.

2.3 Hepatitis B & C
Hepatitis is a term used to describe inflammation of the liver. It can occur as a result of a viral infection or because the liver is exposed to harmful substances such as alcohol. Some types of hepatitis will pass without causing permanent damage to the liver. Other types can persist for many years and cause scarring of the liver (cirrhosis) and, in the most serious cases, loss of liver function, which can be fatal. These types of long-lasting hepatitis are known as chronic hepatitis.

The focus of this needs assessment is on the blood borne viruses Hepatitis B and C. Both can cause long-lasting infection which can lead to liver disease. Treatments are available for those diagnosed with Hepatitis B and C; the goal of treatment for chronic Hepatitis B is to suppress viral replication thus reducing the likelihood of serious liver damage whilst Hepatitis C treatment can clear the virus.
However, the number of people treated in the UK is low. People with an untreated infection are not only at high risk of developing liver disease but remain infectious and are therefore a risk to others.

Whilst the epidemiology of the infections is different, there are parallels between the two and routes into treatment are similar. Both infections are known to affect vulnerable population groups (intravenous drug users, some minority ethnic groups, and men who have sex with men) who tend to have less contact with health services than the general population. Paired with the fact that both Hepatitis B and C infections are largely asymptomatic, this means that many individuals remain undiagnosed and only a small proportion of those infected come into contact with treatment services.

Further details about the epidemiology of the infections are presented in Chapters 4-7.

### 2.4 National Policy Context

The incidence and burden of liver disease in the UK is increasing and has become one of the major causes of death. Between 2000 and 2009 deaths from chronic liver disease and cirrhosis in the under 65s increased by around 20 per cent in the UK. This increasing trend is not inevitable; deaths fell by the same amount in most EU countries over the same period (Davies 2012) and reducing deaths is a government priority in the UK.

A striking 90% of people who die from liver disease are under 70 years old. When measured as ‘years of life lost’, liver disease is therefore much more prominent than many other causes of death (National End of Life Care Network 2012). Liver disease is associated with substantial costs to the NHS related to hospital inpatient admissions and liver transplants and these costs are expected to increase.

Yet liver disease is largely preventable. The NHS and Public Health Outcomes Frameworks (DH 2011, DH 2012) both set an ambition for reduction of mortality in people under 75 years from liver disease, and liver disease has recently been highlighted as a priority for action in the Chief Medical Officers Report 2011 (Davies 2012).

The main causes of liver disease are alcohol abuse, obesity and to a smaller but still significant extent viral hepatitis. To-date interventions to prevent and treat viral hepatitis infections have received less attention than those for alcohol and obesity, which are also risk factors for other high profile preventable diseases such as cardiovascular disease. However, there is growing awareness of the need to invest in the prevention and treatment of viral hepatitis.

Hepatitis C has been identified by the Office of National Statistics as an ‘avoidable’ cause of mortality; that is a cause of death for which effective public health and medical interventions are available, and should therefore be rare and ideally, should not occur (ONS 2011).

There has been no national strategy for viral hepatitis since the National Hepatitis Strategy for England was published in 2002 however the Department of Health has set out plans to develop a National Liver Disease Strategy to improve prevention and treatment along the care pathway (DH 2010). Publication is expected soon.

### 2.5 Local Context and Project Drivers

Improving prevention, screening and access to treatment for those with chronic Hepatitis C infection have been the focus of work in Swindon for a number of years. Testing rates have historically been low, and there is no locally provided treatment service in Swindon; services are provided by the John Radcliffe Hospital in Oxford as part of their block contract with NHS Swindon (Swindon Clinical Commissioning Group from April 1st 2013).

Concerns about the accessibility of treatment services have been expressed frequently by local professionals in health care and other support services and by some service users. Hepatitis C disproportionately affects disadvantaged, vulnerable and socially excluded people, particularly homeless people, prisoners and injecting drug users (HCV Action 2012). These groups often lead chaotic lifestyles making travel to treatment outside the town particularly difficult.
In 2007 a Hepatitis C Health Equity Audit was conducted in Swindon (Mayes 2007). This led to the development of a proposal for a nurse led hepatitis service in Swindon. The service was aimed at improving access to treatment and improving the testing and vaccination in drug services. The proposal was approved and the Inclusion Drug Service agreed to recruit a blood borne virus nurse to work within their service but despite numerous attempts was unable to do so. Other providers were unable to provide the service within budget and had concerns about a clinician working in isolation and so the proposal was not implemented.

At a similar time dried blood spot testing was introduced in Swindon to increase the numbers of those identified at risk of Hepatitis C being screened. This was not supported by any increase in treatment services. Subsequently a proposal to develop a local GP led treatment service provided by a GP with Special Interest (GPwSI) together with nursing support was submitted to the PCT. This proposal was not approved and the only treatment option for Swindon patients remains the John Radcliffe Hospital in Oxford.

With the abolition of Primary Care Trusts on 31st March 2013 and the move of Public Health to Local Authorities and much of local NHS commissioning to GP led Clinical Commissioning Groups the NHS Swindon Public Health Directorate identified the need to draw together the learning from previous work in this area in to one document, and to clarify the need for service improvements. Because of the parallels between Hepatitis B and C in terms of risk groups and pathways in to treatment it was felt that the opportunity should be taken to include both infections in this needs assessment.
3. Methods

3.1 What is health needs assessment?
Health needs assessment is a systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities (HDA 2005).

In order to carry out a health needs assessment an understanding of the type of need that it aims to assess is required. In health economics need is usually defined as “capacity to benefit from an intervention”. Need can also be described by the way it is expressed and identified:

- **Felt need**: what people feel and/or say that they need.
- **Expressed need**: needs expressed by action – help seeking, access to services.
- **Normative need**: needs defined by professionals.
- **Comparative need**: needs identified through comparisons between similar populations.

There are a number of approaches to doing a health needs assessment, these can broadly be described as (Stevens & Raftery 1994):

- **Epidemiological**: considers the population affected by the condition, current service provision, and the effectiveness and cost-effectiveness of interventions and services.
- **Comparative**: compares service provision between different populations.
- **Corporate**: based on eliciting the views of stakeholders (these may include professionals, patients and service-users, the public and politicians).

This health needs assessment takes an epidemiological and corporate approach to provide a deeper understanding of the incidence and prevalence of Hepatitis B & C in Swindon, current service provision (prevention, awareness raising and testing, treatment and care) and the extent to which this meets need and where there are gaps, and thus capacity to benefit.

Methods were chosen to capture all types of need:

<table>
<thead>
<tr>
<th>Need</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt need: what people feel and/or say that they need.</td>
<td>Focus group with Hepatitis C service users</td>
</tr>
<tr>
<td>Expressed need: needs expressed by action – help seeking, access to services.</td>
<td>Focus group with Hepatitis C service users Stakeholder engagement.</td>
</tr>
<tr>
<td>Normative need: needs defined by professionals.</td>
<td>Literature review. Consultation with key local professionals</td>
</tr>
<tr>
<td>Comparative need: needs identified through comparisons between similar populations.</td>
<td>Review of population and service data and comparison to regional and national data.</td>
</tr>
</tbody>
</table>

3.2 Review of Literature
The first stage in this needs assessment was to undertake a literature review and desk research to identify relevant publications and guidance relating to Hepatitis B and C. This was done initially by searching the websites of the key relevant national organisations (Department of Health, Health Protection Agency, National Institute for Health and Clinical Excellence and relevant national charities). The reference lists of publications identified from these two organisations were then reviewed and a cascade approach used to identify further relevant publications. Simple Google
searches were used to check for more recent publications, and any references that might have been missed. Systematic literature searches were then undertaken to identify published research on more specific areas using NHS Evidence healthcare databases.

3.3 Epidemiology
Nationally published data on the epidemiology of Hepatitis B and C were identified through the literature review described above, and through a search of the Health Protection Agency website (now Public Health England).

The Health Protection Agency South West Regional Epidemiology Unit was contacted to ask for support in identifying further data. A Senior Epidemiology and Surveillance Analyst from the team provided links and further background to the datasets available through the national website, and also a data extract from Cosurv, the national data system for routine laboratory Communicable Disease Reporting (more detail provided in later sections).

Local service providers were contacted as part of the stakeholder engagement process described below to ask about locally collected data sets.

3.4 Stakeholder Engagement
Stakeholder mapping was undertaken as part of the planning process for the needs assessment. This was done with the support of the project sponsor, a Consultant in Public Health Medicine in NHS Swindon’s Public Health Directorate, and a Senior Public Health Manager. Through this process a number of organisations and named contacts were identified – the organisations are listed below.

- NHS Swindon Public Health Directorate
- NHS Swindon Commissioning
- Swindon Clinical Commissioning Group
- Great Western Hospital - Gastroenterology
- Great Western Hospital – Sexual Health Department
- John Radcliffe Hospital - Hepatology
- Health Protection Agency – South West (North) Health Protection Unit
- Health Protection Agency - South West Regional Epidemiology Unit
- Inclusion Drug Service
- Swindon Drug & Alcohol Action Team
- Hepatitis C Positive
- The Hepatitis C Trust
- Swindon & Wiltshire Alcohol & Drug Service
- Developing Health and Independence (DHI)

Stakeholders were contacted and individual meetings arranged with representatives from key services in the care pathway. Semi-structured interviews were undertaken to explore current service provision and referral patterns, and also to identify data which might help to develop an epidemiological picture of Hepatitis B and C in Swindon.

3.5 Service User Engagement
In order to capture qualitative information to support the quantitative data collected for this needs assessment a focus group with Hepatitis C service users was held.

Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data (Kitzinger 1995); people are encouraged to talk to one another: asking questions, exchanging anecdotes and commenting on each other's' experiences and points of view (Kitzinger 1994). The main purpose of focus group research is to draw upon participants attitudes, feelings, beliefs, experiences and reactions in a way in which would not be feasible using other methods, for example observation, one-to-one interviewing, or questionnaire surveys. They are a useful tool for ascertaining felt and expressed need.
A focus group with Hepatitis C service users was held. The aim of the focus group was to explore the experiences of people in Swindon with Hepatitis C of the treatment and care they have received. It was set-up with the help of the co-ordinator of Swindon's Hepatitis C Positive group, who identified and invited members who he thought would be willing to participate. The group was made-up of six males and two females, seven of whom had been infected with Hepatitis C and were at different stages along the treatment pathway, and one carer.

The focus group was planned following guidance from the National Centre for Public Engagement. It was facilitated by the author of the health needs assessment, and was recorded and transcribed.

A topic guide outlining the areas for discussion during the focus group was planned in advance. This was structured around the key steps on the care pathway.

- **Testing**
  - Where is it available?
  - What do you think would encourage people to be tested?
  - How was the process for you?
  - Hepatitis B – were you offered testing or vaccination?

- **Diagnosis and referral to initial assessment**
  - What happens when you receive a positive result?
  - Support from GP
  - Communication between service providers

- **Initial assessment**
  - Referral process
  - Waiting times
  - Information and care provided

- **Referral for specialist treatment**
  - Referral process
  - Waiting times
  - Information and care provided

- **Specialist treatment**
  - Referral process
  - Waiting times
  - Information and care provided
4. Population – who is affected?
To understand the needs of those with Hepatitis B and C it is important to first understand the natural history of the conditions and their distribution in the population.

KEY TERMS
- Transmission: any mechanism by which an infectious agent is spread from a source or a reservoir to another person.
- Incidence: the number of new infections within a defined population over a specified time period. It may be measured as a frequency count, a rate or a proportion.
- Prevalence: the total number of individuals with an infection at a particular time divided by the population at risk. It is a proportion not a rate.
- Natural History: the course of a disease from pathological onset or inception to resolution.
- Acute infection: sudden onset, often brief. For Hepatitis B & C usually a marker of new infection and therefore incident cases.
- Chronic infection: lasting a long time. For Hepatitis B & C most prevalent cases have a chronic infection.


4.1 Hepatitis B

4.1.1 Transmission
Hepatitis B is transmitted through contact with infected blood or other body fluids.

Transmission occurs:
- through sexual intercourse
- as a result of blood-to-blood contact (e.g. sharing of needles and other equipment by injecting drug users (IDUs), 'needle stick' injuries)
- through perinatal transmission (during pregnancy/at birth) from mother to child.

In the UK, the majority (95%) of chronic Hepatitis B infections are diagnosed in migrant populations, and were acquired at birth, most often outside the UK (NICE 2012, Hahné et al. 2004).

Data on the route of infection for new acute infections are limited. National surveillance of acute Hepatitis B was introduced in 2007; available data on confirmed infections reported from laboratories is matched with epidemiological data collected by Health Protection Units through HPZone (HPA 2012a) however associated exposure information is often not recorded (50% in 2011).

Findings from the Acute Hepatitis B (England): Annual Report for 2011 (HPA 2012a) suggest that most infections in England are acquired through adult risk behaviour; injecting drug use and sexual contact. The most common transmission route was heterosexual exposure, implicated as the probable route of exposure in 172 (58%) of cases where exposure data was available, followed by homosexual exposure in 59 (20%). Only thirteen (4.4%) of the cases with known exposure were attributed to injecting drug use although a further five of those with sexual exposure also reported injecting.
4.1.2 Natural History
Hepatitis B does not cause any symptoms in most people who acquire the virus. In fact only 30% of adults and fewer than 10% of children who are infected experience an acute symptomatic disease. Those with symptoms experience nausea, abdominal pain, inflammation of the liver (hepatitis) and jaundice.

There is a high clearance rate for the virus, and most infected people clear the virus naturally without medical help. However, a proportion will go on to develop chronic infection leading to cirrhosis and hepatocellular carcinoma. The risk of developing chronic hepatitis B infection depends on the age at which infection is acquired. Chronic infection occurs in 85-90% of those infected perinatally but is less frequent in those infected as children (e.g. 20 to 50% in children between one and five years of age) and adults. 5% or less of previously healthy people, infected as adults, become chronically infected. The risk is increased in those whose immunity is impaired (DH 2009, NICE 2013, HPA 2012b).

4.1.3 Incidence
Hepatitis B is relatively uncommon in the population in England. Laboratory reports of acute Hepatitis B diagnoses provide some indication of the number of new infections, but as discussed above most infections are asymptomatic and therefore go undiagnosed.

Annual laboratory reports of acute Hepatitis B decreased from 729 in 2000 to 512 in 2010; there was a slight increase to 589 in 2011 (Davies 2012, HPA 2012a). This decrease was accompanied by a decline in injecting drug use as the main reported risk factor from 46% (214) to 2% (10). The number of cases reporting heterosexual sex as their main risk factor has remained relatively stable (113 cases in 2000, 132 in 2010) but as transmission through injecting drug use has declined the proportion of all cases acquired through heterosexual sex has increased from 24% to 55%.

The annual incidence of laboratory reported acute Hepatitis B in 2011 was 1.13 per 100,000 population, slightly higher than the incidence of 0.99 per 100,000 reported for 2010. In 2011 61 cases were reported from the South West; giving an annual incidence of 1.16; the highest in the country outside London. Since many people have no symptoms only a small proportion of those with an acute infection are likely to present for testing; this dataset is therefore likely to underestimate infection rates.
This is incidence rate which is based only on identified cases and is thought to be significantly lower than the true incidence rate. The most recent study to estimate the annual incidence of Hepatitis B in England and Wales was conducted between 1995 and 2000 (HPA 2012b, Hahné et al. 2004). It estimated the annual incidence of hepatitis B, from laboratory reports, to be around 7.4 per 100,000 people. This translates into around 3700 acute infections per year and around 270 cases of chronic hepatitis B per year.

In 2011 only 26% of laboratory identified acute cases reported had their ethnicity recorded. The data give an indication of the disproportionate burden of disease on minority ethnic groups; cases identifying as Black or Black British accounted for 19% and those Asian or Asian British origin 10%. Whilst the majority of cases were White (56%) this compares to 83% of the UK population.

The majority of cases were in men (71%) who had an overall incidence of 1.63 per 100,000, an increase from 1.38 per 100,000 in 2010. The corresponding incidence in women in 2011 was 0.64 per 100,000. Men aged 25-34 years had the highest incidence of acute Hepatitis B at 3.11 per 100,000, an increase from 2.07 in 2010. This excess of male cases is partly explained by cases in men who have sex with men. The incidence in children remains very low.

4.1.4 Prevalence

Information on the prevalence of Hepatitis B in England and Wales is derived from a number of sources (NICE 2013):

- laboratory reports of confirmed acute and chronic infections
- serological studies of populations covered by screening programmes (pregnant women and blood donors)
- serological studies of populations at high risk (for example, people who inject drugs)
- sentinel laboratory surveillance of people being tested
- estimates of the size of the migrant population.

The prevalence of chronic Hepatitis B infection is estimated to be 0.3% (approximately 180,000 people). Prevalence is higher for residents born in Asia and Africa (Davies 2012; HPA 2012b; NHS Evidence 2012). The prevalence of people with antibodies to Hepatitis B core antigen (anti-HBc) — a marker of current or previous infection is 1–2% in the UK.

4.1.5 High Risk Groups

- People born or brought up in a country with an intermediate or high prevalence (2% or greater) of chronic hepatitis B. This includes all countries in Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands.
- Babies born to mothers infected with hepatitis B.
- People who have ever injected drugs.
- Men who have sex with men.

4.1.6 Hepatitis B in Swindon

Understanding the incidence and prevalence of Hepatitis B infections in Swindon is difficult because of limitations associated with small numbers and the way in which laboratory data are collected.

If the nationally estimated incidence of acute Hepatitis B infection 1.13 per 100,000 population in 2011 (HPA 2012a) derived from laboratory reports is applied to the Swindon population it can be predicted that in Swindon (which has a population of 209,156 (ONS 2011) 2-3 new acute infections might have been reported in 2011. If the estimated overall annual incidence of Hepatitis B in England and Wales (HPA 2012b, Hahné et al. 2004) (7.4 per 100,000 people) which takes account of both diagnosed and undiagnosed cases is applied to the population then 16 new cases of Hepatitis B would be expected in Swindon each year. Applying the national estimated prevalence of 0.3% for chronic Hepatitis B infection, suggests that there are around 627 people living with chronic Hepatitis B in Swindon.
Table 2: Estimated Hepatitis B incidence and prevalence in Swindon

<table>
<thead>
<tr>
<th>National Estimate</th>
<th>Expected number of cases in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Hepatitis B infection incidence derived from laboratory reports (2011)</td>
<td>1.13 per 100,000 population 2 per annum</td>
</tr>
<tr>
<td>Estimated annual Hepatitis B incidence (diagnosed and undiagnosed cases)</td>
<td>7.4 per 100,000 population 16 per annum</td>
</tr>
<tr>
<td>Prevalence of chronic Hepatitis B infection</td>
<td>0.3% 627</td>
</tr>
<tr>
<td>Current or previous Hepatitis B infection</td>
<td>1-2% 2092-4183</td>
</tr>
</tbody>
</table>

Numbers of new acute infections are therefore very small and the data, if available, would provide little information about the demographics of the population affected. Data for new diagnoses of infections (chronic and acute) diagnosed in Swindon are available from CoSurv, the national data system for routine laboratory Communicable Disease Reporting (CDR) to the Health Protection Agency and provide more insight.

The data show that in 2011 40 cases of Hepatitis B were diagnosed in Swindon residents. This is higher than the previous year (29) but lower than in 2009, and overall the data shows no clear trend, increasing or decreasing, in number of diagnoses over recent years in Swindon or the South West as a whole.

![Number of cases of Hepatitis B in Swindon by year, 2007 to 2011](image)

Figure 3: Number of cases of Hepatitis B (acute and chronic) diagnosed in Swindon by year, 2007 to 2011.

Source: Health Protection Agency - extracted from CoSurv on 23/11/2012

In 2011 in Swindon there was a significantly larger proportion (65%) of diagnoses in men than women; this mirrors the national picture seen for acute cases, and may be explained at least in part by cases in men who have sex with men. However, this was the first time in 4 years that the gender split was significant. With such small numbers it is difficult to explain the reasons behind this.
Figure 4: Hepatitis B cases (acute and chronic) diagnosed in Swindon, 2008 – 2011, % male and female.
Source: Health Protection Agency - extracted from CoSurv on 23/11/2012

Number of diagnoses is greater in young adults than older adults. In 2011 the age group with the highest number (19 (48%)) of diagnoses was 20-29 year olds. Again, this is similar to the national picture for acute cases.

Table 3: Number of cases of Hepatitis B in Swindon by age group, 2008 - 2011

<table>
<thead>
<tr>
<th>Age Group</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-19</td>
<td>0</td>
<td>0</td>
<td>&lt;5</td>
<td>&lt;5</td>
</tr>
<tr>
<td>20-29</td>
<td>7</td>
<td>22</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>30-39</td>
<td>5</td>
<td>17</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>40-49</td>
<td>5</td>
<td>9</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>50-59</td>
<td>0</td>
<td>&lt;5</td>
<td>&lt;5</td>
<td>&lt;5</td>
</tr>
<tr>
<td>60+</td>
<td>0</td>
<td>&lt;5</td>
<td>0</td>
<td>&lt;5</td>
</tr>
<tr>
<td>Total</td>
<td>17</td>
<td>51</td>
<td>29</td>
<td>40</td>
</tr>
</tbody>
</table>

Source: Health Protection Agency - extracted from CoSurv on 23/11/2012

Unpicking what proportion of these diagnoses were new acute infections rather than chronic cases is difficult. Extrapolating data from the South West as a whole where 61 acute Hepatitis B cases were reported in 2011 and the Cosurv data which identified 630 new diagnoses over the same period suggests that ~10% of new diagnoses may have been reported as acute – 4 in Swindon. This is not dissimilar to the incidence calculated from national data above.
4.2 Hepatitis C

4.2.1 Transmission
Hepatitis C transmission is mainly through contaminated blood. Injecting drug use is the most important risk factor for infection in the UK. It is also possible for Hepatitis C to be transmitted through sharing a pipe or snorting drugs through a straw. Data from the Unlinked Anonymous Monitoring survey of people who inject drugs (HPA 2013) suggest that levels of infection in this group are 45% in England.

Hepatitis C can also be transmitted through contaminated blood in other ways, for example by sharing razors or toothbrushes, or where tattooing or other procedures are carried out without sterilised needles. Before blood donations were screened in the UK, this was also another method of transmission. Vertical transmission from mother to newborn baby is thought to occur in less than 10% of cases, although this is more likely if the mother has high levels of virus circulating in her blood or is also infected with HIV.

![Risk factor information in laboratory reports of Hepatitis C infection from England: 1996-2011](HPA 2012c)

4.2.2 Natural History
Hepatitis C is often asymptomatic, and symptoms may not appear until the liver is severely damaged. Around 15-20% of infected people clear their infection naturally within the first 6 months of infection. For the remainder, Hepatitis C is a chronic infection that can span several decades and can be life-long. The rate of progression of the disease is slow but variable, usually taking about 20–50 years from the time of infection. About 30% of those who are infected develop cirrhosis within 20–30 years, and a small percentage of these people are at a high risk of developing hepatocellular carcinoma (HPA 2012b)

4.2.3 Incidence
Over nearly two decades, there has been a steady increase in the number of laboratory confirmed reports of Hepatitis C in England with a seven-fold increase between 1995 and 2011 to 9,908 cases. It should be noted that the increased incidence observed is likely to be due, at least in part, to increased awareness of infection and increased testing; statutory notification by diagnostic laboratories was introduced in October 2010 and there was a 25.5% increase in diagnoses between 2010 and 2011 (HPA 2012c).
Like Hepatitis B men are affected more than women, as are young adults. In 2011 more than two-thirds of laboratory reports (69%) were in men; almost 50% of all reports received were in individuals aged between 25 and 39 years.

4.2.4 Prevalence
The overall prevalence of chronic Hepatitis C infection in the UK is estimated be around 0.4% (around 216,000) (Davies 2012; HPA 2012c). Of these, around 160,000 live in England (Harris 2012a).

As discussed above, prevalence is much higher in injecting drug users; data from the Unlinked Anonymous Monitoring survey of people who inject drugs (HPA 2013) suggest that levels of infection in this group are 45% in England.
4.2.5 High Risk Groups

- People who have ever injected drugs.
- People who received a blood transfusion before 1991 or blood products before 1986, when screening of blood donors for hepatitis C infection, or heat treatment for inactivation of viruses were introduced.
- People born or brought up in a country with an intermediate or high prevalence (2% or greater) of chronic hepatitis C. Although data are not available for all countries, for practical purposes this includes all countries in Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands.
- Babies born to mothers infected with Hepatitis C.
- Prisoners, including young offenders.

4.2.6 Hepatitis C in Swindon

As with Hepatitis B understanding the incidence and prevalence of Hepatitis C infections in Swindon is difficult because of limitations associated with small numbers and the way in which laboratory data are collected.

Laboratory data are available from Cosurv on the number of new cases of Hepatitis C diagnosed in Swindon annually. These diagnoses are most likely to be of prevalent chronic infections rather than new infections, and it should be noted that it is likely that they underestimate the number of people diagnosed as other laboratories will also be diagnosing cases, in particular providers of dried blood spot testing. This is discussed further in a later section of this report.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-19</td>
<td>&lt;5</td>
<td>&lt;5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>20-29</td>
<td>8</td>
<td>12</td>
<td>&lt;5</td>
<td>&lt;5</td>
</tr>
<tr>
<td>30-39</td>
<td>8</td>
<td>20</td>
<td>&lt;5</td>
<td>12</td>
</tr>
<tr>
<td>40-49</td>
<td>&lt;5</td>
<td>18</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>50-59</td>
<td>&lt;5</td>
<td>&lt;5</td>
<td>&lt;5</td>
<td>0</td>
</tr>
<tr>
<td>60+</td>
<td>0</td>
<td>&lt;5</td>
<td>&lt;5</td>
<td>&lt;5</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>60</td>
<td>15</td>
<td>29</td>
</tr>
</tbody>
</table>

Source: Health Protection Agency - extracted from CoSurv on 23/11/2012

The data from Swindon do not show the clear increasing trend seen nationally, nor is this seen in the South West as a whole. There are a number of possible explanations for this; it may be that interventions to prevent infection have been more successful in the South West than other areas and therefore incidence and prevalence is truly lower, however it might also be that testing is not being targeted at those people most at risk and therefore a large proportion of cases remain undiagnosed. It is not possible to draw any conclusions from this data alone.
In 2008 and 2009 proportion of cases diagnosed in males significantly higher than in females, however this was not the case in 2010 and 2011.

Applying the nationally estimated Hepatitis C prevalence of 0.4% would suggest that there are around 836 living with the infection.

The Health Protection Agency has produced a template (HPA 2011a) to help local areas estimate the prevalence of Hepatitis C in their local population. The template uses population data from 2009 rather than 2011 census data which was used in the calculation above. It takes account of the estimated number of intravenous drug users in the population and also ethnic mix. It should be noted that local estimates are naturally less accurate than national estimates due to limited data available at a local level; however they are helpful in providing an indicator of the scale of the problem. From this it can be estimated that there are 519 people in Swindon infected with Hepatitis C. This is a much lower than the very crude estimate of 836; the true value is likely to lie somewhere between the two.
### Table 5: Estimated number of Hepatitis C cases in Swindon

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Estimated number of cases in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infected current intravenous drug users (15-64y)</td>
<td>208</td>
</tr>
<tr>
<td>Infected ex-intravenous drug users (15-64y)</td>
<td>232</td>
</tr>
<tr>
<td>Infected non-IDUs (16-59y)</td>
<td>47</td>
</tr>
<tr>
<td>Infected Asian/Asian-British (16-59+y)</td>
<td>28</td>
</tr>
<tr>
<td>Infected Asian/Asian-British (60+y)</td>
<td>5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>519</td>
</tr>
</tbody>
</table>

Assuming that around 15-20% of infected people clear their infection naturally within the first 6 months of infection, 415-441 of these 519 will have or will go on to develop a chronic infection.

### 4.2.7 Hepatitis C among people who inject drugs: estimated prevalence in Swindon

The Health Protection Agency (HPA) currently monitors the prevalence of Hepatitis C antibodies among people who inject drugs across England through the national Unlinked Anonymous Monitoring Survey of people who inject drugs attending specialist drug services (HPA 2013). This survey provides both national and regional data on the prevalence of Hepatitis C among people who inject drugs. Using data from this survey, the HPA, with assistance from the National Treatment Agency, has recently developed a means of estimating Hepatitis C prevalence among intravenous drug users in each local partnership (Drug Action Team) area. This method is very new and the HPA recommends that estimates should be used cautiously, but they can be viewed as being indicative of the likely prevalence of Hepatitis C.

The estimates indicate that the prevalence of antibodies to Hepatitis C at the local level vary considerably across England, ranging from 17% to 82%. The chart below shows all areas in the South of England including Swindon.
Figure 10: Estimates and 80% credible intervals* for the prevalence of antibodies to Hepatitis C among people who inject drugs in the South of England

Source: HPA (HPA 2013)

* Credible interval similar to confidence interval, based on Bayesian probability.

The chart shows that Swindon is a lower prevalence area, where Hepatitis C antibody prevalence is less than 40%. The HPA state that in these areas most people who inject drugs will be uninfected. However, it is likely that among longer term injectors (those injecting for more than 15 years) the majority will be infected.

It should be noted that the number of people tested to calculate this estimate was very small (56) and that as the estimates are based on prevalence data obtained from the UAM Survey, they only reflect the prevalence among people who inject drugs in contact with specialist services, such as, needle and syringe programmes and drug treatment services. The prevalence among those who are not in contact with such services might be different.
5. Prevention and Vaccination

5.1 Prevention of Hepatitis B and C
Actions required to prevent Hepatitis B and C infection include (Davies 2012; HPA 2012b; NHS Evidence 2012):

- increasing awareness of infection
- promoting safer sex and condom use,
- reducing injecting drug use,
- safer injecting services
- universal precautions in health care settings
- Hepatitis B vaccination
- increasing testing and diagnosis
- getting diagnosed individuals into treatment and care.

They span a wide range of agencies and areas of commissioning and healthcare delivery including sexual health services, drug and alcohol services, child and maternity services and healthcare infection control. Although it is recognised that primary prevention of infection is important, a detailed investigation of community based initiatives (sexual health promotion, drug education, needle exchange) was beyond the scope of this needs assessment. Areas of prevention relating directly to healthcare (Hepatitis B vaccination, increasing testing and diagnosis, getting diagnosed individuals into treatment and care) are discussed).

5.2 Hepatitis B Vaccination in Swindon
Hepatitis B is a vaccine preventable disease. There is no universal Hepatitis B vaccination programme in the UK. Immunisation is recommended for ‘at risk’ groups including those who change sexual partners frequently (particularly men who have sex with men and male and female commercial sex workers), injecting drug users, family contacts of those known to be infected and healthcare workers.

There are no specific services commissioned to provide Hepatitis B vaccination in Swindon other than services for injecting drug users and as part of the antenatal screening pathway. Vaccination is available locally through Primary Care, and Sexual Health services.

There is no central data collection point for Hepatitis B vaccination and it is therefore difficult to get an overall picture of the number of vaccines given annually in Swindon, or the proportion of those in ‘at risk groups’ who have been vaccinated.

Injecting Drug Users have been a particular target group for Hepatitis B vaccination. The Swindon Drug Needs Assessment 2012 (SBC DAAT 2012) recommended improved uptake of Hepatitis B vaccination through current service providers both specialist and GP shared care services. Data collected through the National Drug Treatment Monitoring System and included in the Swindon Drugs Needs Assessment 2012 provide an indicator of uptake in those accessing drug users.

Table 6: Hepatitis B Vaccination in Swindon Drug Services 2010/11

<table>
<thead>
<tr>
<th>2010/11</th>
<th>Inclusion</th>
<th>DHI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Immunised already</td>
<td>22</td>
<td>19.1</td>
</tr>
<tr>
<td>Acquired immunity</td>
<td>&gt;5</td>
<td>1.7</td>
</tr>
<tr>
<td>Offered and accepted</td>
<td>40</td>
<td>34.8</td>
</tr>
<tr>
<td>Missing</td>
<td>6</td>
<td>5.2</td>
</tr>
<tr>
<td>Not offered</td>
<td>11</td>
<td>9.6</td>
</tr>
<tr>
<td>Offered and refused</td>
<td>34</td>
<td>29.6</td>
</tr>
<tr>
<td>TOTAL</td>
<td>115</td>
<td>100</td>
</tr>
</tbody>
</table>
The data show variability in uptake between the services and a significantly higher uptake of vaccinations in DHI than in Inclusion.

Inclusion does not currently provide Hepatitis B vaccinations directly to its users, whilst there is a monthly outreach clinic provided by a GUM Nurse in DHI where vaccination and testing are provided. Discussions with service providers indicate that this clinic provides vaccines to up to 5 service users each month. The difference in uptake rates between the two services may be an indicator of the effectiveness of having vaccines provided on-site. Interviews with stakeholders in Inclusion indicated that this is a service they would also like to be able to provide if funding were available.

A new service provider, CRI, has been commissioned to take over delivery of services currently provided by DHI and Inclusion from 1st April 2013. This provides an opportunity to review current vaccination provision and ensure that it is easily accessible to all those accessing drug services in Swindon. Early indications are that the service plan to train all nurses in the service to provide Hepatitis B vaccinations, and that the outreach clinic provided by the Sexual Health service will also continue.

**RECOMMENDED ACTION**

Work with new drug service provider, CRI, to ensure that Hepatitis B vaccination is offered to all service users and that it is easily accessible to all those accessing drug services in Swindon.

5.3 Antenatal Screening – Hepatitis B

There is a national antenatal screening programme for Hepatitis B in place to identify infections and ensure that babies born to Hepatitis B positive mothers are fully immunised (DH 2009). National uptake of screening during pregnancy has increased over time (up to 97% in 2011), but the proportion of women who test positive has remained stable (0.42% in 2011).

Adherence to the vaccination schedule provides an opportunity to prevent chronic infection in babies. There is evidence nationally that current systems may be failing to ensure babies receive a full course of vaccination and are tested for hepatitis B surface antigen (HBsAg) at 12 months to exclude infection (NICE 2012).

A pathway for Hepatitis B vaccination for babies born to mothers screened Hepatitis B positive in pregnancy has recently been developed in Swindon. The stakeholders involved with delivering this pathway are Maternity Services at Great Western Hospital NHS Foundation Trust (GWH), the Child Health Team in Swindon Borough Council and General Practices within NHS Swindon.

An audit was undertaken in 2012 before the implementation of this pathway. Babies born to mothers screened Hepatitis B positive antenatally who reached their second birthday during the audit period (2011/2012) were included. These babies should have received four doses of vaccine during the evaluation period. 9 babies were included; all had received four doses of the Hepatitis B vaccine however after the initial dose at birth few received vaccines at the recommended age and only 5 babies has had a blood test to ascertain infectivity status. It is hoped that the introduction of the care pathway will improve timeliness in vaccination. A repeat audit is planned for June 2013. This will be the responsibility of Public Health England.

**RECOMMENDED ACTION**

Ensure that a repeat audit of the Hepatitis B vaccination programme for babies in Swindon is carried out in June 2013.
5.4 Contact Tracing

Identification of acute cases of Hepatitis B and tracing of sexual contacts offers an opportunity to offer post-exposure immunisation to those exposed to the virus, thus reducing the risk of secondary cases and is recommended in health protection guidelines (HPA 2011c) and by NICE (NICE 2012). Whilst active contact tracing for people who test positive for Hepatitis C is not routinely recommended, given low transmission rates to both sexual and household contacts and the absence of a vaccine, NICE Guidelines (NICE 2012) recommend that it is sensible to discuss with people who test positive whether any of their contacts may have been exposed to infection.

Local Public Health England health protection teams have responsibility for contact tracing for acute Hepatitis B and C and chronic Hepatitis B infections. The team which supports Swindon is based in the South West (North) Health Protection Unit in Bristol. Their role is to work alongside the NHS, local authorities and emergency services to provide specialist support in communicable disease, infection control and emergency planning.

For Hepatitis B & C contact tracing this includes ensuring patients are referred for clinical assessment, and identification of contacts followed by advice, screening and vaccination and ensuring information is given to prevent onward transmission. How this role is discharged by the Health Protection Unit is a local decision and in some cases will depend on the particular circumstances of a patient. The South West (North) Health Protection Unit will contact patients diagnosed with an acute infection of Hepatitis B or C to carry out contact tracing, or support a health professional to do this where appropriate. They also write to the patient’s GP to advise on public health action to take.

Health Protection Units can only carry out contact tracing when they are notified of an infection. The database HPZone used by the units allows activity data to be explored. However, its use was only introduced at the end of 2010 and only 2 years of complete data are available so few conclusions can be drawn from it.

<table>
<thead>
<tr>
<th>Health Protection Unit Activity</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notifications of acute Hepatitis B infection in Swindon patients</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Notifications of chronic Hepatitis B infection in Swindon patients</td>
<td>23</td>
<td>15</td>
</tr>
<tr>
<td>Notifications of acute Hepatitis C infection in Swindon patients</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Notifications of chronic Hepatitis C infection in Swindon patients</td>
<td>11</td>
<td>18</td>
</tr>
</tbody>
</table>

Looking at data from 2011 suggests that some notifications from laboratories are missed; in total 24 Hepatitis B cases were notified to the Unit in 2011; this compares to 29 diagnoses identified through Cosurv. Over the same period 11 Hepatitis C infections were notified to the Unit compared with 15 on Cosurv. It is difficult to draw and conclusions from this data, however it is important that all health professionals and laboratories are aware of the role of Health Protection Units in contact tracing and wider public health action in response to linked cases and outbreaks, and are encouraged to notify them of all new infections.

**RECOMMENDED ACTION**

Promote the role of the Health Protection Unit in contact tracing and specialist health protection and infection control to services in Swindon, and encourage all services to notify the Health Protection Unit of Hepatitis B and C infections.
6. Burden of Disease

6.1 Liver Disease - Mortality
Liver disease causes approximately 2% of all deaths in the UK; viral liver disease accounts for less than 0.1% of all deaths in England (191 deaths annually) (National End of Life Care Intelligence Network 2011). In Swindon there were 16 deaths from chronic liver disease in 2010 out of a total of 1538 deaths from all causes.

![Graph](image.png)

Figure 11: Cause of death (underlying cause): average annual number and proportion of all deaths, England, 2001–09. Source: Deaths from liver disease: End of Life Care Report

Death rates from viral hepatitis are higher for men than women, which mirrors incidence and prevalence. There is wide variation in the percentage of all deaths attributed to liver disease by age and also in the contribution of viral liver disease to total deaths; they both make up the largest proportion of deaths in 40-49 year olds (11.4% of all deaths, 0.3% of which are caused by viral hepatitis) (National End of Life Care Intelligence Network 2011).

![Graph](image.png)

Figure 12: Cause of death (underlying cause) by age: proportion of all deaths in each age group in England, 2001–09. Source: Deaths from liver disease: End of Life Care Report
The data presented above come from a recent report from the End of Life Care Network on deaths from liver disease (National End of Life Care Intelligence Network 2011). This report highlights that people dying with liver disease are likely to have specific end of life care needs related to their condition and personal circumstances. This is particularly true of viral hepatitis; drug and alcohol use and homelessness are common amongst those with Hepatitis C, and co-infection with HIV is an issue for those with both viruses. A review of the end of life care needs of people with Hepatitis B and C was beyond the scope of this needs assessment but should be considered by commissioners in service planning.

**RECOMMENDED ACTION**
Commissioners should ensure that the needs of those dying with Hepatitis B and C are considered in service planning.

6.2 Liver Disease - Morbidity
Hospital episodes for liver disease increased by 8.3% each year from 1998-2008. In the UK in 2005 there were 43,694 episodes coded with liver disease as the primary diagnosis, and 6,798 deaths – a mortality rate of 15.5% per episode. Unlike most general medical conditions, 66% of these admissions were under the age of 60 (BASL & BSG 2009). A small proportion of these will have been due to viral hepatitis.

The NHS Atlas of Variation 2011 (HPA & NHS User Care 2013) highlighted huge inconsistencies between Primary Care Trusts in the percentage of hospital emergency admissions that are attributed to liver disease (3.4% to 54.1%). Rates were in the lowest quintile for Swindon, but higher for neighbouring Oxfordshire which provides specialist hepatology services for some Swindon patients. Again numbers will be small but a proportion of these will have been due to viral hepatitis. The report concluded that this degree of variation probably includes unwarranted variation due to differences in the organisation and management of care for people with liver disease in local health services although there are other explanations related to distribution of risk factors for liver disease and the coding of cases.

The hospital admissions and mortality data presented above reflect the severity of liver disease when patients with liver disease present to hospital whatever the cause. Although viral hepatitis currently causes a relatively small number of hospital admissions, these numbers are expected to rise substantially over the next few years, particularly in minority ethnic communities (HPA 2011b).

Limited data on hospital admissions were available for Swindon. The table below shows the number of patients admitted to the Great Western Hospital in Swindon between 2010 and 2012 who had a diagnosis of Hepatitis B or C, not necessarily as the primary diagnosis or cause of admission:

**Table 7: Patients admitted to the Great Western Hospital in Swindon between 2010 and 2012 who had a diagnosis of Hepatitis B or C (not necessarily primary diagnosis or cause of admission).**

<table>
<thead>
<tr>
<th>Arrival Month</th>
<th>Number of patients with Hepatitis B/C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jan-Dec 2010</td>
<td>45</td>
</tr>
<tr>
<td>Jan-Dec 2011</td>
<td>44</td>
</tr>
<tr>
<td>Jan-Dec 2012</td>
<td>47</td>
</tr>
</tbody>
</table>

The data show very similar numbers for each year, but without further information about cause of admission or treatment received it is difficult to draw any conclusions from this data.

6.3 Hepatitis B - Morbidity and Mortality
The development of chronic Hepatitis B in those exposed to the virus varies with age; 85-90% of those infected perinatally go on to develop a chronic infection whilst 5% or less of previously healthy people...
infected as adults do. The progression of liver disease is associated with virus DNA levels in the blood. Without antiviral treatment, the 5-year cumulative incidence of cirrhosis ranges from 8 to 20%. People with cirrhosis face a significant risk of decompensated liver disease if they remain untreated. Five-year survival rates among people with untreated decompensated cirrhosis can be as low as 15% (NICE 2013). The annual cost of care for a person with decompensated cirrhosis is £12,432 and of someone with hepatocellular carcinoma £11,0784 (HCV Action 2012).

Estimating the burden of disease progression at a local level is very difficult because of underdiagnosis and the lack of demographic information about those diagnosed. Since the majority of new chronic Hepatitis B infections in the UK occur in migrant populations (NICE 2012) the largest burden of disease is likely to fall on the Asian communities in Swindon. Many will have acquired their infection perinatally in the country of birth where antenatal screening and vaccination programmes were not in place, and will therefore be at substantial risk of going on to develop liver cirrhosis.

Crude estimates of morbidity and mortality (NICE 2013), can be made based on the estimate of 627 people currently living with chronic Hepatitis B infection in Swindon (Table 2), and published estimates of previous progression are presented below.

Table 8: Estimates of Hepatitis B Burden of Disease in Swindon

<table>
<thead>
<tr>
<th>Published Estimate</th>
<th>Expected number of cases in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of chronic Hepatitis B infection</td>
<td>0.3%</td>
</tr>
<tr>
<td>Life time progression of chronic infection to cirrhosis</td>
<td>20%-30%</td>
</tr>
<tr>
<td>5-year cumulative incidence of cirrhosis in those with chronic infection</td>
<td>8% to 20%</td>
</tr>
<tr>
<td>Progression of chronic infection to hepatocellular carcinoma</td>
<td>5-10%</td>
</tr>
</tbody>
</table>

The implications and costs associated with treating Hepatitis B and therefore preventing disease progression are discussed below.

6.4 Hepatitis C - Morbidity and Mortality

About 80% of those exposed to the Hepatitis C virus go on to develop chronic hepatitis. The rate of progression of the disease is slow but variable, usually taking about 20–50 years from the time of infection. About 30% of those who are infected develop cirrhosis within 20–30 years, and a small percentage of these people are at a high risk of developing hepatocellular carcinoma. A third may never progress to cirrhosis or will not progress for at least 50 years. Some people with end-stage liver disease or hepatocellular carcinoma may need liver transplantation. (NICE 2010).

The group most affected by Hepatitis C is a very different group to that affected by Hepatitis B; it is predominantly made up of ex and current injecting drug users. Of the estimated number of people who are chronically infected, around 87% are current or past injection drug users. Of the remaining 13%, 6% are of South Asian descent and the other 7% are of white/other ethnicity (HPA 2011b)

Ethnic minority populations have been shown to be more likely than white populations to experience an admission or to die from severe liver disease as a result of Hepatitis C infection (HPA 2011b). This may be due to poorer access to services, longer duration of infection before diagnosis or the prevalence of co-morbidities.

High alcohol consumption, an age over 40 years at the time of infection, male gender and smoking are associated with more rapid progression to severe liver disease, as is co-infection with other blood borne viruses, in particular HIV(RCGP 2007).
Factors associated with faster progression include:
- Male sex
- Alcohol consumption of >50g per day
- Aged over 40 years at time of infection
- Co-infection with human immunodeficiency virus (HIV) or Hepatitis B

6.5 Mental Health Needs of those with Hepatitis B and C
Mental illness and Hepatitis B and C frequently co-occur. The infections often affect those in socially isolated groups and those with a history of substance misuse. People who have mental illness are at greater risk than the general public for exposure to infectious diseases, including viral hepatitis. The infections themselves, as well as the treatment, can have debilitating effects on mental health and quality of life. This is particularly true for Hepatitis C. This comorbidity can be a significant barrier to accessing care and initiating antiviral treatment and it is essential that services are in place to support the mental health needs of those diagnosed with Hepatitis B and C, including prescribing of antidepressants to those entering treatment where appropriate. This was a gap highlighted by some stakeholders interviewed as part of this needs assessment.

**RECOMMENDED ACTION**
Ensure services are in place to support the mental health needs of those diagnosed with Hepatitis B and C, including prescribing of antidepressants to those entering treatment when required.
7. Treatment
Treatments are available for those diagnosed with Hepatitis B or C. Management consists of infection control and lifestyle advice and support, assessment and monitoring of liver function and consideration for antiviral treatment.

7.1 Hepatitis B
The goal of treatment for chronic Hepatitis B is to prevent cirrhosis, hepatocellular carcinoma and liver failure. There are a number of treatments available, including adefovir dipivoxil and peginterferon alfa-2a, lamivudine, entecavir, and tenofovir (NICE 2013). These treatments suppress viral replication and decrease hepatic inflammation and fibrosis, thereby reducing the likelihood of serious clinical disease, but do not eradicate the virus. Long term and perhaps lifelong treatment is therefore required.

One of the main challenges in Hepatitis B treatment is determining who is suitable for and when treatment should be commenced. Hepatitis B is often asymptomatic, however patients can move between disease phases in a short space of time which means that once diagnosed watchful monitoring of patients is an essential part of treatment. Cultural misconceptions of chronic Hepatitis B in some minority ethnic groups in UK can hinder this, particularly those with links to countries in which the disease is endemic.

RECOMMENDED ACTION
Develop awareness campaigns and education programmes for public and professionals which overcome social and cultural barriers and improve access to testing and treatment for people at increased risk of Hepatitis B (and C) infection.

The number of patients being treated in the UK is low. It is estimated that only 26% of those with chronic Hepatitis B have had their infection diagnosed and of these 5% receive antiviral treatment each year (NICE 2008). The average cost of treating people identified with Hepatitis B is £3474 in the first year. There are also likely to be ongoing costs for treatment since people may require treatment for Hepatitis B for several years (NICE 2013).

There are currently National Institute for Health and Clinical Excellence (NICE) Technology Appraisals available for the treatments available for the management of Hepatitis B. The National Institute for Health and Clinical Excellence (NICE) have recently circulated draft guidelines on the diagnosis and management of chronic Hepatitis B in children, young people and adults (NICE 2013). Final guidelines are expected to be published in June 2013 along with a costing template which will enable health service commissioners to calculate the financial implications of implementing the guidelines.

The guidelines set out the recommendations on patient information; assessment and referral of those diagnosed with Hepatitis B; assessment of liver disease in secondary specialist care; thresholds for treatment and recommended treatment regimens; and monitoring for people who do not meet criteria for antiviral treatment. These guidelines are still in draft form and therefore an audit of how Hepatitis B treatment services in Swindon meet them would not have been appropriate, or indeed feasible within the scope of this needs assessment. However key principles are reflected on in the sections below.

RECOMMENDED ACTION
Commissioners should audit services currently available for the management and treatment of Hepatitis B in Swindon and ensure compliance with NICE Guidelines when they are published in June 2013.
7.2 Hepatitis C

Early diagnosis and treatment can clear Hepatitis C infection and reduce the risk of long-term complications, such as cirrhosis and liver cancer. For people with chronic Hepatitis C, early therapy is associated with increased and sustained virological response rates (Foster et al. 2010).

Similarly to Hepatitis B there are National Institute for Health and Clinical Excellence (NICE) Technology Appraisals available for the antiviral treatments available for the management of Hepatitis C (NICE 2012b, NICE 2012c, NICE 2010). Overarching guidelines on the diagnosis and management of chronic Hepatitis C are currently under development and it will be important to reflect on compliance to these in Swindon when they are published.

**RECOMMENDED ACTION**

Commissioners should audit services currently available for the management and treatment of Hepatitis C in Swindon and ensure compliance with NICE Guidelines when they are published.

Treatment with combined antiviral therapy is recommended for those with chronic infection. Length of treatment course is long (12-48 weeks) and is determined by the genotype of the virus (HPA 2012c). The average cost of treating people identified with Hepatitis C is £9,085 in the first year (Martin et al., 2012, Miners et al. 2012 NICE 2012, NICE 2012b).

The effectiveness of treatment for chronic Hepatitis C is related to the genotype of the virus. Six major genetic types of have been found. In England, sentinel surveillance data from 2002-2011 show genotypes 1 (45%) and 3 (45%) predominating, with other genotypes comprising only 10% of infections (HPA 2012c).

Standard treatment for chronic Hepatitis C is to use antiviral combination therapy for varying times according to genotype (NICE 2012b, 2012c, 2010, 2008):

- Treatment of genotypes 1, 4, 5, and 6 requires 48 weeks of pegylated interferon and ribavirin and leads to sustained viral response rates of between 38-50%.
- Treatment of genotype 2 and 3 requires 24 weeks of pegylated interferon and ribavirin and leads to sustained viral response rates of between 75-80%.

As can be seen from the data above treatment is not always successful at clearing the virus. Viral load is monitored closely in those undergoing treatment; a minimum of a 100-fold drop in viral load is required to continue treatment beyond 12 weeks. If this is not achieved then treatment is stopped early as further therapy is likely to be futile. More recently NICE have recommended boceprevir or telaprevir with peginterferon alfa and ribavirin as a possible treatment for genotype 1 chronic Hepatitis C in adults with the earlier stages of liver disease (known as compensated liver disease) and for those in whom standard treatment did not work.

Studies have shown that only a proportion of those testing positive for Hepatitis C will go on to have further investigations, attend appointments at specialist services and eventually be treated (HPA 2012c, Irving et al 2006). Feedback from stakeholders in this needs assessment was that this is also the case in Swindon. There are a number of possible reasons for this.

Patients may be deterred from undertaking a year-long course of treatment because they perceive efficacy rates to be low relative to the likely side effects. However, there was strong evidence identified in the development of NICE Guidelines (NICE 2012) and through discussions with service providers and patients as part of this needs assessment that patients are willing to accept these negative aspects of therapy for the possibility of experiencing a sustained virological response.

The treatment does however require strong commitment. It can be difficult to take for some patients; the drugs are toxic with severe and unpleasant side effects including flu-like illness, debilitating fatigue and psychological issues. Those currently on treatment or who had been treated in the past who were
consulted as part of this needs assessment reported treatment being life consuming with feelings of “ribo rage” and “living in a daze” throughout their treatment.

“It was really hard for me. I was very unwell. I was not sleeping at night. I’d get up in the morning and put on leggings, jeans, thermal socks – because I’d lost so much weight the cold would go straight through me.” (Service User, Hepatitis C)

“I was very very breathless. Shaking all the time. Passing out. It was really really difficult” (Service User, Hepatitis C)

Encouraging those with Hepatitis C to take up treatment is important to reduce the number of those developing serious liver disease, and to prevent onward transmission of infection. Modelling work is underway to examine the potential impact of an increase in the rate of treatment uptake on the predicted future burden of Hepatitis C over the next 30 years (HPA 2012c). Analyses suggest that approximately 3% of the chronically infected population are currently treated each year. Initial results show that increasing treatment to 10% in those with moderate Hepatitis C and to 20% in those with compensated cirrhosis annually could reduce the number of new cirrhosis and hepatocellular carcinoma cases by around 2,060 (95% credible interval 1,750 – 2,430) over the next 10 years (HPA 2012c).

RECOMMENDED ACTION
Commissioners and service providers should ensure mechanisms are in place for following up patients who defer treatment.

One of the challenges for health professionals is determining who is suitable for treatment. Evidence presented to those developing NICE Guidance highlighted that patients who have been diagnosed and seek medical advice about managing their condition generally take a high level of responsibility for its management. However, many patients remain undiagnosed or do not prioritise treatment. In particular, few active injectors are treated. This is often because health professionals have concerns over compliance and reinfection; a number of focus group participants spoke about the lack of encouragement to access treatment they encountered, particularly for those working in drug services,

“I felt I was being semi talked out of it. They kept saying “Do you think you’re ready?” “You know it’s really hard treatment?”” (Service User, Hepatitis C)

However, there is increasing evidence that injectors can exhibit similar compliance and response rates to non- or ex-injecting drug users, and that treating current drug users can be cost effective (Martin et al., 2012).

RECOMMENDED ACTION
Develop the knowledge and skills of healthcare professionals and others providing services for people at increased risk of Hepatitis C (and B) infection, particularly those in drug treatment services to ensure they have up-to-date knowledge of testing, diagnosis and treatment.

The Health Protection Agency Hepatitis C prevalence template allows estimates of the numbers of people at each stage of the treatment pathway to be made at a local level and the associated treatment costs.
Table 9: Prevalence of Hepatitis C in Swindon, and estimated numbers of patients receiving treatment.

<table>
<thead>
<tr>
<th>Treatment stage</th>
<th>Estimated number in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of people with Hepatitis C infection</td>
<td>519</td>
</tr>
<tr>
<td>Number eligible for treatment (RNA positive)</td>
<td>358</td>
</tr>
<tr>
<td>Number already diagnosed</td>
<td>215</td>
</tr>
<tr>
<td>Number referred appropriately</td>
<td>150</td>
</tr>
<tr>
<td>Number who attend clinic</td>
<td>107</td>
</tr>
<tr>
<td>Number indicated for treatment</td>
<td>94</td>
</tr>
<tr>
<td>Number accepting treatment</td>
<td>66</td>
</tr>
<tr>
<td>Number already treated</td>
<td>40</td>
</tr>
<tr>
<td>Remaining number identified requiring treatment</td>
<td>26</td>
</tr>
</tbody>
</table>

Source: estimates from HPA Hepatitis C Prevalence template (HPA 2011a)

Table 10: Future estimates of Hepatitis C diagnoses in Swindon and estimated numbers of patients entering treatment.

<table>
<thead>
<tr>
<th>Treatment stage/cost</th>
<th>Estimated number in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number currently being identified with Hepatitis C annually</td>
<td>18</td>
</tr>
<tr>
<td>Number referred appropriately</td>
<td>13</td>
</tr>
<tr>
<td>Number who attend clinic</td>
<td>9</td>
</tr>
<tr>
<td>Number indicated for treatment</td>
<td>8</td>
</tr>
<tr>
<td>Number accepting treatment</td>
<td>6</td>
</tr>
<tr>
<td>Number requiring 48 weeks treatment</td>
<td>3</td>
</tr>
<tr>
<td>Number requiring 24 weeks treatment</td>
<td>3</td>
</tr>
<tr>
<td>Cost of 48 weeks treatment</td>
<td>£33,670</td>
</tr>
<tr>
<td>Cost of 24 weeks treatment</td>
<td>£17,705</td>
</tr>
<tr>
<td>Annual costs of treating cases identified who accept treatment</td>
<td>£51,376</td>
</tr>
</tbody>
</table>

Source: estimates from HPA Hepatitis C Prevalence template (HPA 2011a)
8. What Services do People Use?

8.1.1 Swindon Care Pathways

There is currently no formal pathway for Hepatitis B or C in Swindon that covers the whole patient journey from testing through to specialist treatment, although specific pathways for antenatal screening and vaccination of babies born to Hepatitis B positive mothers are in place.

A key aim of this needs assessment was to map the patient pathways for Hepatitis B & C in Swindon from testing and diagnosis through to specialist care and management and treatment. Figure 13 below shows the key services offering testing and referral routes in to specialist treatment identified.

Discussions with stakeholders and service users identified problems with a lack of communication between services along the pathway, and wide variety in practice and referral routes to specialist

![Diagram showing routes in to testing and treatment for Hepatitis B & C in Swindon](image-url)

**Figure 13**: Diagram showing routes in to testing and treatment for Hepatitis B & C in Swindon (From 1st April 2013 services provided by the drug services Inclusion and DHI have moved to the new service provider CRI).

Discussions with stakeholders and service users identified problems with a lack of communication between services along the pathway, and wide variety in practice and referral routes to specialist
services. The need for clear and agreed pathways and co-ordination of care between services was highlighted by many of those consulted as part of this needs assessment.

“What I’ve learned is that you’ve just got to keep on knocking down the door. If I sat around waiting for letters and phone calls then I would never have been treated.”
(Service User, Hepatitis C)

RECOMMENDED ACTION
Development of a viral hepatitis (or blood borne viruses) stakeholder group which facilitates networking, information sharing and collaborative working and learning between commissioners and providers at all stages of the care pathway.

Map of Medicine care pathways (MoM 2013) provide a useful tool for reflecting on what a local care pathway based on evidence and best practice might look like; they present practice-informed care maps which connect all the knowledge and services around a clinical condition. Pathways for Hepatitis B and C are shown in Appendix A.

The care maps can be customised to reflect local needs and practices and could therefore be used in Swindon to devise a care pathway for the area.

RECOMMENDED ACTION
Develop a care pathway that covers whole patient journey from testing through to specialist treatment for patients with Hepatitis B and C in Swindon.

The sections below describe the steps on the patient journey for those with Hepatitis B or C in Swindon and the services people use.

8.2 Testing
One of the main challenges with viral hepatitis is the substantial number of people who are unaware of their infection. In order to identify those who are infected and would benefit from treatment a diagnosis is required so that a referral to specialist care can be made. Testing also has an important role in prevention; the process of testing, including pre and post-test counselling, can be used to raise awareness of hepatitis infection, educate individuals about transmission and how to prevent infection including promoting Hepatitis B vaccination.

Testing for Hepatitis B and C is done through blood testing. Testing for Hepatitis B usually involves testing for Hepatitis B surface antigen (HBsAg) or for anti-hepatitis B core antigen. Results require careful interpretation by a clinician to determine Hepatitis B status.

Hepatitis C is diagnosed using two tests; firstly a Hepatitis C virus antibody test which will detect whether a person has ever been exposed to the virus. This will not be positive until some months after infection, so may need repeating. If this is positive, a second blood test to detect Hepatitis C RNA, will determine whether there is current infection.

Dried blood spot testing can be used to test for Hepatitis B and C in non-clinical settings. This is discussed further in Section 8.2.3 below.
8.2.1 NICE Guidance- Hepatitis Testing

In December 2012 NICE published Public Health Guidance on ways to promote and offer testing to people at increased risk of Hepatitis B and C infection (NICE 2012).

The recommendations cover:
- Awareness-raising among:
  - the general population
  - people at increased risk of hepatitis B and C infection.
- Developing the knowledge and skills of healthcare professionals and others providing services for people at increased risk of hepatitis B or C infection.
- Testing:
  - in primary care
  - in prisons and youth offender institutions
  - in immigration removal centres
  - in drugs services
  - in genitourinary medicine and sexual health clinics.
- Contact tracing.
- Providing and auditing neonatal hepatitis B vaccination.
- Commissioning hepatitis B and C testing and treatment services.
- Laboratory services for hepatitis B and C testing.

Table 11: NICE Guidance - key areas to consider when offering a test for Hepatitis B or C

<table>
<thead>
<tr>
<th>NICE Guidance highlights key areas to consider when offering a test for Hepatitis B or C:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Have issues of confidentiality and anxiety been addressed?</td>
</tr>
<tr>
<td>• Has the offer been accompanied by an agreed mechanism for providing the result to the person being tested?</td>
</tr>
<tr>
<td>• Has the offer been phrased in a way that suits the person’s age, culture and literacy level and is respectful and non-judgemental?</td>
</tr>
<tr>
<td>• Has the offer taken into account potential barriers to testing such as the stigma associated with Hepatitis B and C or lack of access to services?</td>
</tr>
<tr>
<td>• Has the offer included information to enable people to make informed choices about their care should they test positive, and to reduce their risk of Hepatitis B and C infection should they test negative?</td>
</tr>
<tr>
<td>• Has the offer been accompanied by details of support available for clinical and non-clinical needs, both while waiting for test results and following diagnosis?</td>
</tr>
</tbody>
</table>

These recommendations are reflected on throughout the sections on testing in Swindon.
8.2.2 Testing by Service Type
Venous blood sampling is the standard method of testing for Hepatitis B and C in most services, particularly in health led services. The charts below show the number of individuals tested and testing positive by service type in the sentinel laboratory in South West between 2006 and 2010.

Number of individuals tested and testing positive for HBsAg by service type in the sentinel laboratory in South West (excluding antenatal screening, April 2006 - December 2010)*

SW * Excludes dried blood spot, oral fluid, reference testing, and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. All data are provisional.
SW † Other ward types includes cardiology, dermatology haematology, ultrasound, x-ray
SW ‡ This refers to infectious disease services, hepatology departments and gastroenterology departments.
SW ^ These are hospital services which are currently being investigated to identify specific service type, and may include any of the secondary care services mentioned above.
SW § These services are currently being investigated to identify specific service type, where possible.

Figure 14: Number of individuals tested and testing positive for HBsAg by service type in the sentinel laboratory in South West (excluding antenatal screening, April 2006 - December 2010)
Source: Health Protection Agency - extracted from CoSurv on 23/11/2012
Number of individuals tested for anti-HCV by service type in the sentinel laboratory in the South West (April 2006 - December 2010)*

The charts show that for both infections the largest proportion of tests was done in General Practice. However, for both infections the percentage testing positive in General Practice was lower than in many other services, perhaps suggesting a lack of targeted testing.

Genitourinary Medicine clinics tested the second largest number of patients for Hepatitis B; this is encouraging since sexual contact is the greatest risk factor for transmission, however similarly to General Practice the percentage testing positive is relatively low (in fact lower than in General Practice) which may be an indicator that Hepatitis B tests are offered as part of routine screening and so tests are offered to those at lower risk as well as those likely to be at higher risk such as men who have sex with men. Positivity rates were highest in specialist liver services, which is perhaps unsurprising, and also in specialist HIV services providing an indicator of the problem of co-infection.

A quick glance at the difference in the scale for positivity rates between the two charts provides an indicator of the way in which Hepatitis C testing can be targeted to specific services and groups to identify infection in those most at risk; whilst only a small proportion of tests were from drug dependency services positivity rates are 35-40%. The reason for the small number of tests from drug services is likely to be due in part to the use of dried blood spot testing, rather than simply low testing rates. This is discussed further later on in this section.

Data was not available on numbers of tests done by service type for services in Swindon; however questions about the provision and accessibility of testing were included in consultation with service providers and service users as part of this needs assessment. Feedback highlighted variability in provision and rather disjointed services with a lack of communication between them about positive results.
8.2.3 Dried Blood Spot Testing

NICE Guidelines on testing for Hepatitis B and C (NICE 2012) state that whilst venepuncture samples remain the gold standard for testing, dried blood spot tests can be useful in certain settings for people with poor venous access and where there may be no facilities or expertise to take venous blood samples (for example, in specialist drug treatment services or prisons). The cost of a basic antibody dried blood spot for Hepatitis C test is around £15.

Dried blood spot testing for Hepatitis C is available in some drug services in Swindon, but there is currently no provision of dried blood spot testing for Hepatitis B. Further details of service providers are presented in the sections below.

**RECOMMENDED ACTION**
Ensure that dried blood spot testing for Hepatitis B and C is available in appropriate settings such as drug services in Swindon to improve access to testing.

**RECOMMENDED ACTION**
Ensure staff who undertake pre- and post-test discussions and dried blood spot testing are trained and competent to do so.

One of the issues highlighted as part of this needs assessment is that the results of these dried blood spot tests are not notified to the Health Protection Agency and therefore do not feature in the statistics about incidence and prevalence presented. This also means that Health Protection Practitioners in the South West (North) Health Protection Unit are unable to take any public health action such as contact tracing and providing patient information for those found to be positive.

8.3 Services Providing Testing in Swindon

Testing for Hepatitis B and C is available in Swindon in a range of settings, including:
- Primary Care including Shared Care Services for drug users
- Genitourinary Medicine (GUM)/Sexual Health Services
- Drug and Alcohol Services
- Antenatal screening

8.3.1 Primary Care

NICE Guidance (NICE 2012) recommends that GPs and Practice Nurses should offer testing for Hepatitis B and C to adults and children at increased risk of infection, particularly migrants from medium- or high-prevalence countries and people who inject or have injected drugs.

No systematic review of the level of testing in Primary Care in Swindon was undertaken as part of this needs assessment, however discussions with stakeholders suggested that there is little targeted screening of high risk groups carried out in the Borough, and low awareness amongst GPs of Hepatitis B or C. This is supported by evidence from the literature review and NICE Guidance, and the charts above which show that significant numbers of patients are tested in General Practice in the South West, but that positivity rates are relatively low, and findings from stakeholder interviews and the Hepatitis C Patient Focus Group in which many highlighted the need for GP training to increase their knowledge and awareness of Hepatitis B and C, and a GP Clinical Champion to lead the work.

**RECOMMENDED ACTION**
Develop and deliver a programme of education and training for Primary Care staff to raise their awareness of Hepatitis B and C and encourage testing of people at increased risk of Hepatitis B and C infection.
RECOMMENDED ACTION
GPs and Practice Nurses should offer testing for Hepatitis B and C to adults and children at increased risk of infection in-line with NICE Guidance.

“I see most of the surgeries in Swindon and a lot of them have other priorities like diabetes and heart disease, depending on who their patients are.” (Service Provider)

“A lot of GPs don’t want to know about it – it’s not a fashionable infection to have.” (Service User)

“GPs are often not aware (of Hepatitis B and C). There’s a real need for a clinical champion locally.” (Service Provider)

8.3.2 Sexual Health Services
NICE recommendations (NICE 2012) are that sexual health and genitourinary medicine clinics should:
- offer Hepatitis B vaccination to all service users in line with the Green book
- offer and promote Hepatitis B and C testing to all service users, including people younger than 18
- ensure people diagnosed with Hepatitis B or C are referred for specialist care
- ensure staff have the knowledge and skills to promote Hepatitis B and C testing and treatment
- ensure staff who undertake pre- and post-test discussions are trained and competent to do so.

Sexual Health Services in Swindon are provided by Great Western Hospitals NHS Foundation Trust which provides daily clinics (Monday to Saturday) at the hospital and drop-in clinics at Swindon Health Centre, Carfax Street. Staff in these clinics undertake a risk assessment of all patients and offer viral hepatitis testing where appropriate, including to those under 18. The Sexual Health Service also provides a monthly outreach clinic in the drug service DHI (now CRI) where screening for Hepatitis B and C, and Hepatitis B immunisations are available.

“They have a clause asking you if you’ve ever used needles and then they will test you for Hepatitis C and I just ticked it and they tested me.” (Service User)

An interview with a GUM Consultant carried out as part of this needs assessment highlighted that testing provided by Sexual Health Services is particularly targeted at men who have sex with men, and sex workers (groups known to be particularly at risk of sexually transmitted Hepatitis B infection). The Consultant interviewed reported seeing low numbers of patients with Hepatitis B in Swindon, but that co-infection with HIV was found in a number of those diagnosed positive. This is a particular problem because co-infection with HIV and either Hepatitis B and/or C is associated with more rapid development of severe liver disease. Liver disease caused by Hepatitis B and/or C is a leading cause of serious illness and death in people with HIV.

Those identified as Hepatitis B or C positive are referred to Gastroenterology in the Great Western Hospital for assessment. The patient’s GP is copied in to the referral.

Overall, no issues were identified in this health needs assessment about access to testing through sexual health services. However, concerns were raised about the lack of information sharing, particularly between Sexual Health and Drug Services. Sexual Health clinics provide anonymous testing for individuals; results are not automatically shared with any other health service, nor are they entered on to a patient’s record. This can present challenges for a patient such as a drug user receiving care from multiple agencies; in interviews with stakeholders from the drug services it was clear that they felt that they should have access to their clients’ hepatitis test results to ensure appropriate care and avoid unnecessary repeat testing. Ways in which this could appropriately be achieved are currently being explored by the Sexual Health Service and the new drug service provider CRI.
RECOMMENDED ACTION
Ensure that information about drug service users diagnosed with Hepatitis C (and B) through Sexual Health services is shared with Drug Services and Primary Care in an appropriate way which supports their access to treatment and care.

8.3.3 Drug Services

Drug Services in Swindon
Data collection for this needs assessment was carried out in the financial year 2012-13. At the time there were a number of providers of Drug Services in Swindon. Stakeholders from these were consulted as part of the needs assessment. Swindon Borough Council has recently been through a tendering process for these services and on 1st April a new Provider, CRI took over provision of Tier 2 and 3 services. The introduction of a new Provider presents opportunities for exploring service improvement, and the findings of this needs assessment will be used to inform this.

- Tier 2 services (open access treatment and brief interventions) provided by DHI which was the first point of contact for all drug users in Swindon who are looking for help. DHI undertake an initial assessment and then refer drug users into appropriate services run by DHI or other organisations.
- Tier 3 services (community based structured treatment) for people with opiate dependency were provided by Inclusion, often in partnership with the patients GP Practice as part of a Shared Care Programme. The majority of clients accessing Inclusion services are referred to them by DHI.
- There are also Tier 4 services (residential structured drug treatment) provided in Swindon.

Dried Blood Spot Testing
Commissioners for Drug and Alcohol Services are required to include plans for testing for blood borne viruses and onward referral for those identified as positive as well as prevention and harm reduction measures in the services that they commission. In 2009-10 it was identified that Swindon was performing poorly on these indicators and as a result funding was identified for investment in to improve Hepatitis C testing using dried blood spot testing. This was targeted at Tier 2 and 3 treatment services and homeless hostels in Swindon; training, testing kits and lab time were commissioned from a laboratory in Manchester and 35 Practitioners were trained to provide testing. The drug service Inclusion has also provided training to peer mentors to make testing more accessible. In the following 14-15 months more than 200 people were tested and dried blood spot testing continues to be offered by some services.

RECOMMENDED ACTION
Ensure drug services staff, including peer mentors, who undertake pre- and post-test discussions and dried blood spot testing are trained and competent to do so.

Testing in Inclusion
The main provider of dried blood spot testing in Swindon was Inclusion. The provision sat outside the main contract and commissioners provided funding for testing kits as required. Staff at DHI were also trained to provide the tests but as discussed above their service users are encouraged to access testing through the monthly outreach clinic provided by the Sexual Health Service.

All Inclusion service users were encouraged to be tested and the services estimates that about 50% took up the offer. However, testing was not offered in a systematic way; rather the service orders 100 tests at a time and runs a targeted screening programme, often alongside anonymous testing carried out for the Unlinked Anonymous Monitoring Survey of people who inject drugs attending specialist drug services (HPA 2013).
**Recommended Action**

Develop systems to ensure that all service users entering drug treatment are routinely offered Hepatitis B and C testing at their initial assessment and that annual testing for Hepatitis C is offered to people who test negative but remain at risk of infection.

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**Table 12: Inclusion Dried Blood Spot Testing – service activity and test results**

<table>
<thead>
<tr>
<th>Number tested (2010-12)</th>
<th>154</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Hepatitis C positive</td>
<td>25</td>
</tr>
<tr>
<td>• Genotype 1</td>
<td>11</td>
</tr>
<tr>
<td>• Genotype 2</td>
<td>5</td>
</tr>
<tr>
<td>• Genotype 3</td>
<td>10</td>
</tr>
</tbody>
</table>

When the service receives a positive result for one of their clients they:
- Inform the client of their result
- Write to the client’s GP to inform them of their positive result
- Encourage client to take up treatment and support them where possible

The service does not have a standard letter to send to GPs when a positive result is received, and has no process for notifying the Health Protection Unit of the infection.

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**Recommended Action**

Develop a clear care pathway and data sharing protocols which support drug service users receiving positive dried blood spot test results for Hepatitis C to access support from their GP and move along the treatment care pathway as appropriate.

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Of the 25 who tested positive between 2010-12 Inclusion recorded 12 patients as having been referred for treatment; this means that they will have gone to their GP for further tests and been referred on to more specialist services if appropriate. The remaining 13 clients either refused treatment, are no longer engaged in drug treatment with Inclusion or were either pregnant or drinking and so suited for active treatment when tested, although they may have gone on to treatment at a later date.

**Challenges and Service Improvements**

Discussions with stakeholders and service users as part of the focus group highlighted a number of challenges to the current system of testing in drug services, and improvements which could be made. These were related to the lack of consistency in the way in which testing is offered and data sharing between services.

"*We could do a lot more – more testing and vaccination. We have the staff, we just need the resources.*" (Service Provider)

"*There are real opportunities – like working with Shared Care Providers – we could use them a lot more.*" (Service Provider)

"*We need better information sharing; we don’t want to waste resources repeat testing, but we don’t want to miss people.*" (Service Provider)

Some of those consulted expressed concerns about the way in which drug services support their clients to seek further medical advice, and the number moving on in to treatment. This is discussed further in section 7.2 below.
8.3.4 Antenatal screening
The NHS Infectious Diseases in Pregnancy screening programme is responsible for ensuring that women with Hepatitis B infection, (and HIV, Syphilis and susceptibility to Rubella) are identified in pregnancy. All women are offered screening by their midwife in early pregnancy and uptake in Swindon is high. The national standard is that any mother identified as Hepatitis B positive should have an appointment with an appropriate specialist (e.g. a hepatologist, gastroenterologist or infectious diseases specialist) within 6 weeks of the screening test result being issued to maternity services.

In 2011 it was identified that this standard was not being achieved in Swindon, and as a result the Screening Lead has been working with clinical colleagues in Maternity Services and Gastroenterology at the Great Western Hospital to ensure this target is met. A local pathway has been developed. A key barrier identified was the waiting time for first appointments in the Gastroenterology Department; this problem is not unique to pregnant women and is discussed in further detail below.

**RECOMMENDED ACTION**
Commissioners should audit current pathway for mothers identified as Hepatitis B positive to ensure all receive and appointment with an appropriate specialist within 6 weeks of the screening test result and take action if this standard is not being met.

8.3.5 Testing for Ethnic Minority and Migrant Populations
NICE Guidance recommends that local community services serving migrant populations should work in partnership with primary care practitioners to promote testing of adults and children at increased risk of infection. This should include raising awareness of Hepatitis B and C, promoting the availability of primary care testing facilities and providing support to access these services (NICE 2012).

A key weakness of this needs assessment is the lack of information identified about support available to black and ethnic minority groups. No groups or services offering targeted work around Hepatitis were identified, however that is not to say that no work is being undertaken. The Public Health Team in Swindon has a Public Health Programme Manager post specifically for work around Equality and Diversity and working with the black and ethnic minority communities in Swindon. This post became vacant during the time in which the needs assessment was undertaken and so the planned stakeholder interview did not take place, and it proved difficult to find other links in to the communities. Planning for recruitment to this post may present opportunities for developing work around Hepatitis with ethnic minority and migrant populations.

**RECOMMENDED ACTION**
Public Health to provide information and support to local community services serving migrant populations to raise awareness of Hepatitis B and C, promote the availability of primary care testing facilities and provide support to access these services.

8.4 Diagnosis
Diagnosis of Hepatitis B and C, and assessment of appropriateness for onward referral cannot be achieved through one test alone; as can be seen in the Map of Medicine care pathways in Figures 13-15 a number of biochemical, virological and haematological parameters are needed. For most patients in Swindon these tests will be done in Primary Care, although investigations for those identified in Sexual Health Services remain within that service. Those identified as Hepatitis C positive through dried
blood spot testing must be referred to their GP to arrange confirmatory venous blood testing and onward referral to gastroenterology for initial assessment.

Those who were part of the focus group reported having received their diagnosis of Hepatitis C in a variety of locations; two through their GP, two through drug services, one in prison, one as a result of sexual health screening and one following admission to hospital with acute Hepatitis C infection. Many reported delays in receiving their result and most felt that the health professionals giving the diagnosis could have handled the situation better.

"When I was diagnosed no-one even bothered to get back to me to tell me I was positive. I had to go back and ask." (GP diagnosis)

"First they cocked the blood results up and told me I didn’t have it. Then the doctor phoned me up and all I got was a message saying they were trying to get hold of me. First thing they said was "you’ve got hepatitis"." (GP diagnosis)

"A man came round and told me I had it. I was there on my own because it wasn’t visiting time. I was really ill and he just come in and sat with me for five minutes and just said we’ve tested your blood and you’ve got Hepatitis C. He went off and I was just left there." (Hospital diagnosis)

"I got a phone call from them about 4 weeks later and they said “it looks like you might have the Hepatitis C virus and we need to do some more tests” (Sexual Health Service diagnosis)

As shown in Table 11 one of the prerequisites for Hepatitis B and C testing highlighted by NICE (NICE 2012) is that testing is accompanied by details of support available for patients while waiting for test results and following diagnosis. Many of those in the focus group felt that this support and information was lacking in Swindon. A key problem highlighted was a lack of knowledge amongst healthcare staff about the condition, and therefore the limited information they were given.

“I asked the nurse for more information but she didn’t know anything. One of them went off to the computer and she googled a lot of stuff for me and printed it out but it wasn’t very user friendly.” (Service User, Hepatitis C)

Service users also talked about feeling very alone following diagnosis.

“You’re told you’ve got this life threatening illness that’s blown your whole world but no-one seems to notice.” (Service User, Hepatitis C)

“I didn’t know anyone else with Hep C. So for me…I was petrified…I thought I was going to be dead in 10 years because I’d read through the bumph and it said that within 10 years it can progress. I was lying in my hospital bed and I was breaking my heart…my head was going on overdrive.” (Service User, Hepatitis C)

When asked how services in Swindon could be improved all felt that there was a need for a support service which all those receiving a new diagnosis of Hepatitis C or other blood borne virus are referred to.
There needs to be some sort of level of counselling for when people are told they’ve got Hep C. There’s is sort of stigmatism that Hep C is lethal, there’s no treatment”
(Service User, Hepatitis C)

“If you get a blood test for what it a really serious disease someone needs to run through it with you. How you feel - the psychological side.”
(Service User, Hepatitis C)

“You’re in that half-way stage. You’ve got this disease. You don’t know much about it. You can go on the internet and that frightens you to death reading about liver damage and all those kind of things.” (Service User, Hepatitis C)

RECOMMENDED ACTION
Commissioners of primary and secondary care services should work together to commission a fully integrated care pathway for those who test positive for Hepatitis B or C infection from the point of diagnosis. This should take account of the patient’s psychosocial and support needs as well as treatment for their infection.

8.5 Referral and Initial Assessment (Gastroenterology, Great Western Hospital)
After diagnosis the first step on the treatment pathway for most patients with Hepatitis B and C in Swindon is a referral to the Gastroenterology Department at the Great Western Hospital. All GP Practices in Swindon are able to refer their patients to this service. The Sexual Health Service refers patients directly.

The service has four General Gastroenterology Consultants and a Specialty Doctor but no Hepatologist. The service provides an initial assessment of patients including antibody testing and liver biopsy when appropriate. It does not provide specialist viral hepatitis services. Waiting times for a first appointment were 2-3 months at the time stakeholder interviews were held (January 2013).

A Consultant and a General Manager from the service were interviewed as part of this needs assessment in order to find out more about service provision and identify relevant data available. The interview with the Consultant identified that the service receives referrals from Primary Care, Midwifery and Sexual Health Services but that the department does not have any system for recording the number or route of referrals. This was explored further with the General Manager and an Information Specialist from the Trust who confirmed this lack of data. Anecdotally, the Consultant felt that the majority of patients he saw were referred from Midwifery and Sexual Health Services rather than Primary Care.

One of the objectives of this needs assessment was to collect and analyse data which would enable an understanding of the number of individuals progressing through the care pathway to be developed and points on the pathway where patients ‘drop off’ to be identified. This lack of data collection in Gastroenterology makes this very difficult.

RECOMMENDED ACTION
Commissioners should work with the Gastroenterology Service to develop data collection systems which enable the number and source of referrals for Hepatitis B and C; appointment attendance; treatment and discharge or onward referral to specialist services to be monitored.

Not all those diagnosed will seek treatment for their infection immediately. Some of the focus group participants had lived with the knowledge of their infection for 15 years or more before taking action. For those who immediately wanting treatment the feeling of being unsupported can be exacerbated by the long waiting time between diagnosis and their first hospital appointment.
“It’s a long path. First off you get tested. Then they do a blood test to confirm it. That takes a month. Then you get a referral to the hospital but they don’t have to see you for 18 weeks and then they do all the testing again. Then you have to go back to be referred to Oxford which means another long wait so it takes about 6 months to see a specialist who can actually deal with it. In that time you’re completely alone. What it needs is a nurse or someone in Swindon.”

(Service User, Hepatitis C)

“One of the problems in Swindon is that you get diagnosed with Hepatitis C…and that’s a shock in itself…and then you see someone at the hospital and they discuss it with you and then that’s it. Then you’re in a 3 or 4 month limbo period where there’s nowhere to go and no-one you can talk to about it. There’s nobody coming to you telling you what the procedure will be. You just have to wait.”

(Service User, Hepatitis C)

**RECOMMENDED ACTION**
Commissioners of primary and secondary care services should work together to commission a fully integrated care pathway for those who test positive for Hepatitis B or C infection from the point of diagnosis. This should take account of the patient’s psychosocial and support needs as well as treatment for their infection.

**8.6 Hepatitis C Specialist Treatment John Radcliffe Hospital – Hepatology**

After initial assessment the Gastroenterology Department refer those with Hepatitis C on to the John Radcliffe Hospital in Oxford for specialist care. Those with Hepatitis B are treated for liver inflammation. Hepatitis B carriers are discharged.

The Gastroenterology Department therefore play an important role in assessing patient’s readiness for treatment and encouraging them to access specialist services. Health professionals caring for patients with Hepatitis C and those who had been through the process and took part in the focus group reported mixed experiences.

“It seems like treatment is different for everyone – there’s no set pattern.”

(Service User)

“It took me 18 months of visits to GWH. I had to take the NICE Guidelines along with me and demand to be referred.”

(Service User)

“I just gave them a call and I had one [appointment at Oxford] within a month.”

(Service User)

“GWH – it’s like a black hole. My clients get referred there and then I don’t hear anything. And you don’t know who to call.”

(Service Provider)

Despite this the number of referrals the John Radcliffe Hospital has received from Swindon has increased over the past few years, and the service has in the past expressed some concerns that it may not be able to continue to meet increased demand for treatment.

**Number of Hepatitis C Patients Treated in John Radcliffe Hospital, Oxford (2007-2011)**

<table>
<thead>
<tr>
<th>Year</th>
<th>Genotype 1</th>
<th>Genotype 2</th>
<th>Genotype 3</th>
<th>Total Number of Swindon Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007/2008</td>
<td>5</td>
<td>0</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>2008/2009</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>2009/2010</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>2010/2011</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>13</td>
</tr>
</tbody>
</table>
These numbers are higher than those predicted by the Health Protection Agency template and set out in Table 10, however as discussed in Section 7.2 this may be an underestimate of true numbers.

Stakeholders and service users consulted as part of this needs assessment provided universal positive feedback about the care received from the John Radcliffe Hospital. The only concerns expressed were about the location of the service and the travel required to reach it which many felt made accessing treatment difficult.

“I know one person locally – he’s got Hep C, had it for quite a while. He said – what’s the point – I can’t get treatment anyway – I can’t get to Oxford all the time.” (Service User, Hepatitis C)

“One of the biggest fags with treatment is trawling all the way over to Oxford to be monitored and have your bloods taken” (Service User, Hepatitis C)

“Having to travel to Oxford when you’re feeling really rubbish – it’s a real grind.” (Service User, Hepatitis C)

Feedback from participants in the focus group was that treatment would be made much easier if there were facilities for those being treated at Oxford to have some appointments and blood tests available.

“If there was something in Swindon whereby where a nurse could take your blood a monitor you that would take so much stress out of the treatment.” (Service User, Hepatitis C)

This is not a new finding; it is a problem that has been explored before in Swindon with commissioners and service providers. The Hepatitis C Health Equity Audit carried out in 2007 (Mayes 2007) led to the development of a proposal for a nurse led hepatitis service in Swindon and funding was secured however the drug service Inclusion which was initially identified to host the service was not able to recruit and other providers were unable to provide the service within budget and had concerns about a clinician working in isolation. Subsequently a proposal to develop a local GP led treatment service provided by a GP with Special Interest (GPwSI) together with nursing support was submitted to the PCT. This proposal was not approved.

There is a clear need for investment in to a local service for those with Hepatitis C which provides co-ordination of care and support from the point of diagnosis onwards, and routine check-ups and blood tests for patients in treatment without the need for travel to Oxford.

**RECOMMENDED ACTION**

Develop an options appraisal for commissioners outlining a model of care which would support access to specialist treatment services at the John Radcliffe Hospital in Oxford for patients in Swindon.

**8.7 Other Hepatitis Services Available in Swindon**

**8.7.1 Hepatitis C Positive**

In September 2011 the Hepatitis C Positive support group was launched in Swindon. The group provides peer support to those directly or indirectly affected by the Hepatitis C and other blood borne viruses. It meets weekly and is facilitated by former service users.

In February 2012 the Swindon treatment system employed a Blood Borne Virus Co-ordinator to run a project with the principal aim of ‘following up’ service users who had agreed to a dried blood spot test.
for Hepatitis C. The role of the co-ordinator is to work with those people who have not acted upon their test results through counselling and/or involvement in the Hepatitis C Positive support group, and to improve links with health care and drug service providers to ensure that drug service users are provided every opportunity to gain supportive advice and interventions commensurate with blood borne virus status.

The role of the Co-ordinator, working in partnership with Hepatitis C Positive group has provided a highly valued source of support to many people living with Hepatitis C in Swindon. It also supports some people affected by HIV.

“It was only when the Hep C Positive group…it was the first time I’d ever met anyone with Hep C. I wish I’d had that when I first found out. I had 3 years counting my life down. I just kept thinking “what’s the point?” – I’m going to be dead in 10 years. (Service User, Hepatitis C)

“One of the reasons why the support is so successful is because we tell everybody that the treatment is hard…but at the end of it it’s beneficial.” (Service User, Hepatitis C)

The Blood Borne Virus Co-ordinator post was initially recruited to as a pilot. Data collected in the first 12 months of the project suggest that the Co-ordinator has been successful at identifying people in Swindon needing support and helping them to come to terms with their diagnosis and move in to treatment. It would be helpful to formally evaluate this service, and early discussions about how this might be achieved have been held as a result of this needs assessment.

RECOMMENDED ACTION
Evaluate the role of the Blood Borne Virus Co-ordinator (and Hepatitis C Positive group). This will involve defining clear outcome measures and data collection systems.

RECOMMENDED ACTION
Secure ongoing funding for the Blood Borne Virus Co-ordinator post Hepatitis C Positive group.

8.7.2 GP with a Special Interest
As part of its commitment to supporting people with Hepatitis C in Swindon the drug service Inclusion provided funding for a Swindon GP to undertake training to become a GP with a Special Interest. The GP has completed this training and would be able to take on prescribing and treatment for Hepatitis C with appropriate governance structures and nursing support.

A proposal to develop this role in Swindon has been developed in the past but it was not supported by Commissioners in the Primary Care Trust.

This approach would enable people requiring treatment would initiate their treatment through the consultant at John Radcliffe Hospital and receive on-going treatment and monitoring by a Swindon GP.

RECOMMENDED ACTION
Review and revise options appraisal for commissioners outlining a model of care led by a GP with a Special Interest in Hepatitis C which would support access to specialist treatment services for patients in Swindon.

8.7.3 Shared Care Services
Substitute prescribing services are available from the 27 GP surgeries across Swindon. This care is commissioned through the Drug and Alcohol Action Team in Swindon Borough Council and provides
funding for GPs to work alongside qualified drug workers to offer prescribing and support services. Some stakeholders interviewed as part of this needs assessment felt that the role of these GPs could be developed further to improve testing, treatment and co-ordination of care for drug users with Hepatitis C (and B).

9. Models of Care in Neighbouring Areas
A brief review of models of care in neighbouring areas was undertaken as part of this needs assessment in order to identify examples of good practice and possible alternative scenarios for Swindon. More details about Hepatitis C services are available in a needs assessment of Hepatitis C testing and treatment in the South West undertaken by the Health Protection Agency (Gobin 2012).

The majority of services are led by Consultants in Gastroenterology or Hepatology and most have developed models of care which include a Blood Borne Virus or Hepatitis Nurses to support ongoing patient care. Some services, such as the Bristol Royal Infirmary have developed care models which include nurse led outreach clinics in the community to avoid patients having to regularly travel long distances for treatment.

In Gloucestershire treatment is provided by a nurse led county wide Viral Hepatitis Service which is hosted by the Sexual Health department in Gloucestershire Hospitals NHS Trust and runs in parallel with the HIV care service. Clinical supervision is provided on a monthly basis by a Consultant Gastroenterologist. The service is commissioned by the Sexual Health Commissioning team and provides hospital based clinics across the county. Patients with Hepatitis B and C are referred directly to Gastroenterology.

RECOMMENDED ACTION
Develop an options appraisal for commissioners outlining alternative models of care for patients with viral hepatitis based on evidence and examples of best practice.

10. Commissioning
Before 1st April 2013 (when the majority of data for this needs assessment were collected) health services in Swindon were commissioned by NHS Swindon Primary Care Trust. On the 1st April 2013 commissioning responsibilities moved to Swindon Clinical Commissioning Group and the NHS England Area Team for Gloucestershire, Swindon and Wiltshire. Swindon Borough Council continues to lead the commissioning of drug and alcohol treatment services. There was no named commissioner within Swindon Primary Care Trust for viral hepatitis, and no hepatitis or liver strategy.

From the 1st April 2013 the majority of responsibility for commissioning related to Hepatitis B and C moved to the Local Authority and Clinical Commissioning Groups in Swindon, with some elements of specialist treatment will managed by the NHS Commissioning Board through specialised commissioning.

There are strong drivers for effective commissioning for hepatitis within the NHS and Public Health Outcomes Frameworks

NHS Outcomes Framework (DH 2011):
- Potential years of Life Lost (PYLL) from causes amenable to healthcare
- Mortality rate from liver disease, ages under 75, per 100,000 population

Public Health Outcomes Framework (DH 2012):
- Mortality from liver disease
- Age standardised mortality rate from liver disease for persons aged under 75 per 100,000 population
It will be important for all those involved in commissioning across the care pathway to work collaboratively to achieve cost-effective and sustainable services with good outcomes for patients.

**RECOMMENDED ACTION**
Identify named commissioning leads for viral hepatitis in the Swindon Clinical Commissioning Group, NHS Commissioning Board Local Area Team and Swindon Borough Council and agree ways to work together to ensure effective integrated commissioning in Swindon.

**11. Role of Public Health**
Public Health has a vital role to play in addressing the needs identified in this report. As public health resources and responsibility move from the NHS to Local Authority Swindon Borough Council will take on responsibilities for:

- Monitoring the health status of the community and identify health needs
- Developing programmes to reduce risk and screen for early signs of disease
- Planning and evaluating the provision of healthcare
- Improving health and wellbeing in the population.
- Preventing disease and minimise its consequences.

For Hepatitis B and C, a first step will be to communicate the findings of this needs assessment to all those involved in commissioning through the Joint Strategic Needs Assessment and presentation to strategic groups such as the Health and Wellbeing Board. In the longer term health needs assessment, health equity audit and an audit of Hepatitis B and C services as part of an agreed local care pathway should be regularly undertaken to ensure testing and treatment services are commissioned accordingly.

**RECOMMENDED ACTION**
Swindon Borough Council leads for Public Health should work with the Joint Strategic Needs Assessment steering group to incorporate the findings of this needs assessment into the Joint Strategic Needs Assessment for Swindon and health needs assessment, health equity audit and an audit of Hepatitis B and C services as part of an agreed local care pathway should be regularly undertaken to ensure testing and treatment services are commissioned according to population need.
12. What Does the Future Look Like?

12.1 Hepatitis B

There is little published data on future population projections for the incidence and prevalence of Hepatitis B in England. The reducing incidence of acute infection observed nationally is encouraging, and is likely to be due to interventions to prevent transmission in intravenous drug users such as needle exchanges; antenatal screening; and improved vaccine uptake amongst high risk groups.

However, since most cases of chronic Hepatitis B are diagnosed in immigrant populations prevalence is dependent on global immunisation policy as well as national efforts and there is evidence that the prevalence of chronic Hepatitis B in the UK is increasing as a result of migration. Most existing and newly arriving cases remain undiagnosed (BASL & BSG 2009).

Predicting the likely burden of disease associated with Hepatitis B for Swindon would be complex and beyond the scope of this needs assessment.

12.2 Hepatitis C

The Hepatitis C Trust recently commissioned research into the projected burden of Hepatitis C in the UK (Patruni & Nolte 2013). Using a cohort simulation model, researchers projected that, under current treatment patterns, the overall prevalence of infection would increase from 0.4% in 2010 to 0.61% in 2035. This equates to an increase in the number of persons in the UK living with Hepatitis C infection from around 265,000 in 2010 to 370,000 in 2035.

ONS Population Estimates are only available up until 2021 for Swindon. A crude calculation based on the estimated population size in 2021 of 239,528 and a mid-point prevalence of 0.5% suggests that there would be 1198 people in Swindon living with Hepatitis C infection in 2021. This does not take account of the number of intravenous drug users and ethnic mix that the HPA template does.

Both hospital admissions and deaths from Hepatitis C-related end stage liver disease and hepatocellular carcinoma are continuing to rise in the UK. Hospital admissions have risen from 612 in 1998 to 1,979 in 2010, while deaths have risen from 98 in 1996 to 323 in 2010. An overall increase in registrations for liver transplants with a code of post-hepatitis C cirrhosis has been observed from 45 in 1996 to 101 in 2011. In England, statistical modelling predicts that 15,840 individuals will be living with HCV-related cirrhosis or hepatocellular carcinoma in England in 2020 if left untreated (HPA 2012c).

The Health Protection Agency Hepatitis C Commissioning template enables some estimates of future Hepatitis C disease state in Swindon to be made. As discussed in Section 4.2.6 these figures may be an underestimate of true numbers in Swindon, and numbers based on the crude estimate of 836 Hepatitis C cases in Swindon are also presented.

<table>
<thead>
<tr>
<th>Table 13: Estimates of future Hepatitis C disease state in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HPA Prevalence template</strong></td>
</tr>
<tr>
<td>Estimated number of Hepatitis C cases</td>
</tr>
<tr>
<td><strong>Proportion in disease state at 2015:</strong></td>
</tr>
<tr>
<td>Mild</td>
</tr>
<tr>
<td>Moderate</td>
</tr>
<tr>
<td>Cirrhotic</td>
</tr>
<tr>
<td>End stage disease</td>
</tr>
<tr>
<td>Died (all causes)</td>
</tr>
</tbody>
</table>
12.3 Alternative Scenarios: Improving Uptake of Testing

Whilst interventions to prevent Hepatitis B and C infection are important, the main focus of this needs assessment has been on health care. In order to improve access to care and treatment all those infected must be tested and diagnosed. Therefore when considering what the future might look like and alternative scenarios the most important intervention would be to improve uptake of testing.

Improving uptake of testing in those at increased risk of Hepatitis B and C would have wide ranging benefits, and is considered to be cost effective by NICE (NICE 2012). Detecting people with either disease will allow them to be treated if appropriate. This will subsequently lead to a reduction in the severity of adverse events associated with untreated disease. It should also increase the number of people who are vaccinated against Hepatitis B. Successful completion of treatment and subsequent clearance of the virus will also reduce the risk of onward transmission.

There are significant barriers to testing for viral hepatitis, many of which are similar for both infections.

NICE Guidance (NICE 2012) identifies these as including
- Fear of being stigmatised, whether by healthcare professionals, sexual partners, family or friends.
- Knowledge and awareness in relation to the transmission of infection and the treatments available.
- A general lack of knowledge about Hepatitis B and C, including among people promoting tests for these infections.
- Parental fears that they will not be able to cope with the issues their child may face if the child is found to have Hepatitis B or C.
- People who have injected drugs not wanting to disclose drug-using history.
- Personal circumstances; economic, social or other health needs may be a higher priority for some people.
- Lack of awareness of mother to baby transmission of Hepatitis B and prevention and vaccination.
- Acceptance of infection; transmission of Hepatitis B from mother to child may be considered normal among some minority ethnic communities.
- Poor venous access, particularly in current and ex drug users.

Discussions with stakeholders and service users in Swindon highlighted that the barriers described above are also true for Swindon. The recommendations set out below describe ways in which these might be overcome.

NICE have developed guidelines for improving the uptake of testing; these have been referred to throughout this document and have informed the recommendations set out below. NICE also provide a costing template which allows local areas to estimate the financial implications of implementing the guidelines.
Table 14: Cost and implications of implementing the NICE Guidance on improving Hepatitis B & C Testing in Swindon - modelling a period of 5 years only and based on the approach presented.

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>Number of people in Swindon</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hepatitis B</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased number of people identified as a result of the increased tests</td>
<td>2.70%</td>
<td>22</td>
</tr>
<tr>
<td>Proportion needing treatment</td>
<td>20%</td>
<td>4</td>
</tr>
<tr>
<td>Take-up rate of treatment</td>
<td>80%</td>
<td>4</td>
</tr>
<tr>
<td>People remaining at increased risk of hepatitis B offered vaccination</td>
<td>4.9%</td>
<td>40</td>
</tr>
<tr>
<td>Take-up rate when offered hepatitis B vaccination</td>
<td>89%</td>
<td>36</td>
</tr>
<tr>
<td>Increased cost of tests and treatment: hepatitis B</td>
<td>£51.5k</td>
<td></td>
</tr>
<tr>
<td><strong>Increased cost of vaccination: Hepatitis B</strong></td>
<td>£1.3k</td>
<td></td>
</tr>
<tr>
<td><strong>Hepatitis C</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased number of people identified as a result of the increased tests: Hepatitis C</td>
<td>2.60%</td>
<td>19</td>
</tr>
<tr>
<td>Proportion needing treatment</td>
<td>74%</td>
<td>14</td>
</tr>
<tr>
<td>Take-up rate of treatment</td>
<td>80%</td>
<td>12</td>
</tr>
<tr>
<td><strong>Increased cost of tests and treatment: Hepatitis C</strong></td>
<td>£115.5k</td>
<td></td>
</tr>
</tbody>
</table>

13. Conclusion
The findings of this needs assessment show that whilst only a small proportion of the Swindon population are affected by Hepatitis B (0.3% - estimated 627 people) and Hepatitis C (0.4% - estimated 836 people (HPA adjusted estimate taking account of Swindon demography 519)) numbers are expected to grow. In order to prevent further infections and unnecessary liver disease and deaths testing and diagnosis needs to expand and access to treatment improved.

There are strong arguments for investing in prevention and treatment for hepatitis.
- To prevent further infections
- To reduce under-75 mortality from liver disease
- To reduce costs to the NHS
- To reduce health inequalities

Recommend actions to achieve this have been highlighted throughout this document. These have been summarised in to a set of recommendations based on evidence of best practice and NICE Public Health and Clinical Guidelines and are set out below.

It should be noted that a whole system approach to implementing these is required, with collaboration between commissioners and service providers at all stages of the care pathway. Whilst raising awareness of the viruses and increasing the number of people being tested is important it is also essential that there is adequate capacity within secondary care and specialist treatment services to manage the increased demand this creates. Consultation should take place regarding the capacity of treatment services to deal safely and effectively with increased numbers resulting from any planned expansion of testing.
14. Recommendations

1. Local service providers and community and voluntary groups including the Blood Borne Virus Co-ordinator should work together with support from Swindon Borough Council Public Health leads to develop and deliver evidence based campaigns, materials and resources to raise awareness about Hepatitis B and C among the general population and those at increased risk of infection. This should build on existing nationally produced materials wherever possible and include up-to-date information on:
   - The main routes of infection and transmission
   - Local services providing testing and Hepatitis B vaccination
   - The potential for infection to be asymptomatic
   - The benefits of early testing and treatment
   - Overcoming social and cultural barriers and improve access to testing and treatment

2. Swindon Borough Council Public Health leads should work with local commissioners and service providers to develop and deliver education programmes to improve the knowledge and skills of healthcare professionals and others providing services for people at increased risk of Hepatitis B or C infection. This should build on existing nationally produced materials wherever possible and include up-to-date information on:
   - Epidemiology of Hepatitis B and C – local prevalence, at risk groups
   - Testing and diagnosis
   - Treatment
   - National guidance on testing and delivery of care
   - Skills to overcome social and cultural barriers and improve access to testing and treatment

3. Commissioners in the Local Authority, Clinical Commissioning Group and NHS Commissioning Board should ensure testing for Hepatitis B and C (venous and/or dried blood spot as appropriate) and Hepatitis B vaccination is available in-line with NICE Guidance in:
   - Primary Care
   - Drug and Alcohol Services
   - Sexual Health Services

4. Swindon Borough Council Drug and Alcohol Treatment Commissioners should work with the new Swindon drug service provider, CRI, to ensure that all service users entering drug treatment are routinely offered Hepatitis B and C testing and Hepatitis B vaccination at their initial assessment, and that annual testing for Hepatitis C is offered to people who test negative but remain at risk of infection. Commissioners should routinely audit data collected.

5. Services providing testing should ensure that all those who undertake testing are trained and competent to provide appropriate pre- and post-test discussions and that testing is accompanied by appropriate information resources and support while waiting for test results and following diagnosis.

6. A named commissioning lead for viral hepatitis should be identified in the Swindon Clinical Commissioning Group, NHS Commissioning Board Local Area Team and Swindon Borough Council who should agree ways to work together to ensure effective commissioning of a fully integrated care pathway for those who test positive for Hepatitis B or C infection from the point of diagnosis. This should take account of the patient’s psychosocial and support needs as well as treatment for their infection and include mechanisms for following up patients who defer treatment.
7. Swindon Borough Council Public Health leads should work with Commissioners and Service Providers to develop clear data recording and sharing protocols which support those receiving positive results for Hepatitis B or C to access support and move along the treatment care pathway as appropriate, and which enable the number and source of referrals for Hepatitis B and C; appointment attendance; treatment and discharge or onward referral to specialist services to be monitored.

8. Swindon Clinical Commissioning Group Commissioners should audit services available for the management and treatment of Hepatitis B and C in Swindon and ensure compliance with NICE Guidelines when they are published.

9. Swindon Borough Council Public Health leads should work with Antenatal Screening Commissioners in the NHS England Local Area Team to undertake regular audit of the Hepatitis B vaccination programme for babies in Swindon and pathways for mothers identified as Hepatitis B positive and take action if standards are not being met.

10. Findings of this needs assessment should be used by the Clinical Commissioning Group to consider redesign of current treatment pathways. This should include development of an options appraisal outlining models of care which would support and improve access to specialist Hepatitis B & C treatment services for patients in Swindon. Options might include:
   a. A nurse led in-reach service from the John Radcliffe Hospital in Oxford for Hepatitis C treatment.
   b. A nurse led service providing co-ordinated care and support hosted by the Great Western Hospital (Gastroenterology or Sexual Health Department).
   c. A community based Blood Borne Virus or Hepatitis Nurse (possible hosting organisations suggested by stakeholders in this needs assessment include Carfax Medical Centre or CRI).
   d. Development of the Blood Borne Virus Co-ordinator pilot and the Hepatitis C Positive group to provide non-clinical community based support for all those diagnosed with Hepatitis B and C.
   e. Development of a GP with a Special Interest role in Swindon.

11. Swindon Borough Council Public Health and Drug and Alcohol Commissioners should work together to evaluate the role of the Blood Borne Virus Co-ordinator (and Hepatitis C Positive group) and secure ongoing funding for the projects.
15. References


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16. Appendices

16.1 Appendix A – Map of Medicine Care Pathways for Hepatitis B and C

Figure 16: Hepatitis B Care Pathway – Diagnosis and Assessment (Map of Medicine)
Figure 17: Hepatitis C Care Pathway – Diagnosis (Map of Medicine)
Figure 18: Hepatitis C Care Pathway – Assessment (Map of Medicine)