Blood Borne Viral Hepatitis Action for Wales
Research Programme –
Developing the evidence base

Findings, Implications and Recommendations
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Abbreviations:
HCV – Hepatitis C
HBV – Hepatitis B
IDU – Injecting drug user
MSM – Men who have sex with men
CSW – Commercial sex worker
NSE – Needle and syringe exchange services

100 person years: The incidence of a disease is the rate at which new infections occur. As it is a rate, incidence is expressed as the number of cases per unit time for a particular population size. This is often expressed as per 100 person years, thus an incidence rate of 10 per 100 person years would mean that if 100 people were followed up for one year then in that year there would be 10 new infections.

95% Confidence Intervals: Whenever a proportion (%) is used to describe the prevalence of a disease in a population it is usual to quote the 95% confidence intervals. Since generally information is only available for a sample drawn from a wider population (e.g. a sample of IDUs drawn from the population of all the IDUs in Wales) the proportion of that sample that is infected is not necessarily the same as the proportion infected in the whole population. Presuming that the sample taken is representative of the wider population, then the 95% CI show a range of values that we can estimate, with a 95% probability, that the ‘true’ population value lies within. The size of the confidence interval is dependent on the size of the population from which the events came and an assumption about the statistical distribution of the data. Generally speaking, rates based on small populations are likely to have wider confidence intervals. Conversely, rates based on large populations are likely to have narrower confidence intervals. For example; a prevalence of 30% with 95% CI of 25% to 35% means there is a 95% probability that the ‘true’ prevalence of the disease in the population from which the sample is drawn lies between 25% and 35%. Beware when a prevalence or proportion is expressed without the confidence intervals, without these one cannot be sure how robust the estimate is, if it was drawn from a very small sample then chance events could mean that that the real prevalence is completely different.

Design and development of the research programme was undertaken by Dr Marion Lyons (Lead - Blood Borne Viral Hepatitis Strategy, ICDS, NPHS), Dr Mark Walker (Consultant Microbiologist, NPHS-Microbiology Wales), Dr Noel Craine and Josie Smith (Research Scientists, ICDS, NPHS), and the South East Health Protection Team comprising Zoë Couzens, Health Protection Specialist, Jackie Murray, Nurse Consultant in Communicable Disease Control and Sam Ray, Health Protection Nurse.

The team recognise that without the support of all services and providers of care this baseline review would not have been achieved. Further support and guidance was offered by the project board.
LAY SUMMARY

- Hepatitis B and Hepatitis C are blood borne viruses that are both preventable and treatable. Vaccination is only available for hepatitis B.

- In the UK most people acquire hepatitis B through sexual intercourse with an infected person or through injecting drug use.

- Individuals may have become infected with hepatitis C through transfusions prior to 1991 (donated blood/blood products have been tested since then) or through unsterilised medical equipment, but by far the most common route of ongoing transmission is injecting drug use. At least nine out of ten people will have acquired the infection this way.

- There are an estimated 12,000 people who carry the hepatitis C virus in Wales – over three quarters of these people are unaware that they have the virus.

- Over time, if untreated around 60% of infected individuals will develop symptoms of liver damage.

- Last year in Wales 67 people were treated for hepatitis C.

- The average total cost of treating one patient with hepatitis C is between £8000 - £16000. The estimated burden of disease on NHS Wales for hepatitis C treatment for those currently infected would amount to £160 million. Failure to treat will cost a great deal more...

- The cost of a liver transplant episode is £75,000. This does not take into account the personal misery that is incurred by the infected individual and their families.

- Today in Wales one in four of our known injecting drug users are already infected with hepatitis C, this rises to two in five injectors in the cities. Of those that are currently not infected, between 3 and 9 in every 100 injectors are likely to become infected each year.

- There is a general lack of awareness of both hepatitis B and hepatitis C in the general population, who may have contracted the virus in the past, and in the current at-risk populations.

- This is both a health and a social issue and needs to be addressed as such.
PRIORITY RECOMMENDATIONS

Use multi-agency partnership working to:

- Increase awareness of blood borne viruses among at-risk populations to encourage testing and treatment.

- Develop a monitoring and evaluation tool such that all partnership agencies understand the contribution their intervention programme makes and understands the evidence that needs to be collected to show effectiveness.

- Strengthen the knowledge and training of staff working with at risk groups on the transmission of infection and safe injecting techniques

- Develop and strengthen peer led prevention/early intervention initiatives to reduce the number of at risk individuals and to provide education early in injecting careers

- Strengthen existing through and aftercare services for offenders utilising robust keyworker systems to address health, social care, housing and substance misuse issues prior, during and after release from prison.

- Continue and strengthen the health care services within prisons including the provision of hepatitis B vaccination, screening for blood borne viruses with appropriate ongoing support and awareness raising of risk factors and routes of transmission and training for prison staff.

- Maximise shared care opportunities and ensure involvement of clients in development of policies and treatment options

- Develop a network of community clinical staff to ensure continuity of care and access to appropriate support at all stages from diagnosis to treatment or otherwise

- Within all areas pertinent to blood borne viruses, ensure there is continual overview of service provision so that the impact of changes in epidemiology, changes in treatment options and changing client needs can be met

- Develop standardised data collection systems and interconnected relational databases across Wales to enable surveillance of both drug use and viral epidemiology and to enable relevant partnership agencies to ensure continuity of care
EXECUTIVE SUMMARY

Introduction

Blood borne virus infection, in particular that associated with injecting drug use, provides great challenges to the health of Wales in terms of prevention of infection, diagnosis of infection and treatment of infection. The research programme outlined here, developed within the National Public Health Service for Wales, seeks to understand the scale of the problem and the issues that need to be addressed. To this end a number of studies were designed and undertaken between December 2004 and May 2006. These studies examined the scale of the existing burden placed on the population by hepatitis blood borne viruses in Wales and the current service provision that supports prevention of transmission, diagnosis and treatment of these viruses.

The report outlines these studies, highlights key findings and makes recommendations based upon the emerging evidence. The outcomes of the research undertaken are intended to inform Welsh Assembly Government and support policy development. All recommendations are designed to build on existing structures and services, to highlight gaps and to support equity of service provision. The recommendations are drawn both from the findings of our research studies and from consultation with substance misuse and health care partnership agencies across Wales.

Summary and recommendations

The scale of the problem

The central role of injecting drug use in the transmission of hepatitis C (HCV) and hepatitis B (HBV) within the UK is well established. Injecting drug use is the probable cause of the majority of reported HCV infections\(^1, 2\) and remains the most commonly reported risk exposure associated with acute HBV infection in the UK\(^1, 3, 4\). Studies suggest that 0.5% of the general population in Wales (approximately 14,700 people) has been infected with hepatitis C\(^5\). About 20% of those infected appear to clear the virus naturally without treatment. Thus 0.4% of the population (some 11,800 people) are chronically infected with hepatitis C. If left untreated, hepatitis C can cause serious liver disease in some patients, including cirrhosis and liver cancer. HBV infection can also cause serious disease.

The hepatitis C epidemic is already well established in Wales. In 2002 the Unlinked Anonymous Prevalence Monitoring Programme of England and Wales (UAPMP)\(^1\) testing injecting drug users, reported an anti-HCV prevalence of 20%. A study in North West Wales\(^6\) indicated an anti-HCV rate of 23% (95% CI 16% - 30%). These same studies reported an anti hepatitis B core (anti HBc) prevalence of 15% for all of Wales\(^1, 2\) and 27% for North Wales respectively\(^2\).

The size of the injecting drug using population

Whilst an estimate of the total number of serious and injecting drug users across Wales is ongoing, extrapolation of the prevalence estimates from England and data
from the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) suggest that 17,000 people aged between 15–64 living in Wales could be considered as serious drug users with an estimated 5000 of these injecting drugs.\textsuperscript{7}

**The prevalence of blood borne virus infection amongst drug injectors**

- To address the epidemiology of blood borne viral transmission in Wales, a large multi-centre incidence study was carried out between 2004 – 2006. This study, the largest of its kind in Wales, has produced up to date evidence of the prevalence and incidence of HCV, HBV amongst injecting drug users (IDUs) in Wales. The study found prevalence rates of anti-HCV 26\% (95\% CI 23\% – 30\%) and anti-HBc - 9\% (95\% CI 7\%-12\%). 7\% (95\% CI 5\% - 9\%) had markers of exposure to both HCV and HBV. There were marked regional differences in prevalence, for example, in Cardiff anti-HCV prevalence was 35\% (95\% CI 29-43) and anti-HBc was 18\% (95\% CI 13-25), whilst in Merthyr Tydfil respective prevalences were 10\% (95\% CI 4-17) and 0\% (95\% CI 0-4).

- Incidence rates of 6 per 100 person years (95\% CI 3\%-9\%) for hepatitis C were found. This means that in a year, between 3 and 9 in every 100 injectors will become infected with hepatitis C. Incidence rates of 2 per 100 person years (95\% CI 0.8\%-4\%) for hepatitis B were found. This means that within injecting drug user population, in a year between 1 and 4 will become infected with hepatitis B. These figures are not static and may rise due to the year on year increase in those infected and potentially passing on the virus to others.

- Initial analysis of incidence data suggests that the incidence of HCV is at least as great amongst recent initiates to injecting as amongst long term injectors.

- The prevalence of infection was greatest among those who had long injecting careers, however, an anti-HCV prevalence of 5\% was found in those, usually young people, who had been injecting for one year or less.

- Only one quarter of those individuals who tested anti-HCV positive were already aware of their status, the remaining three quarters, over 135 individuals, were unaware of their status.

- Of serious concern was the lack of awareness of hepatitis C and hepatitis B transmission routes and the implications for health among this population despite contact with substance misuse services.
**Who is at risk?**

**Demographics / Drug Use / Risk behaviours**

The multi-centre incidence study shed valuable light on the demographics of injecting drug users in Wales. This background can inform the provision of prevention initiatives.

- Children who had been in local authority care, and those excluded from school were over-represented within the injecting drug using population sampled.

- Over 60% of the sample population were parents however less than one quarter of these had their children living with them. The average number of children per parent was 2.3.

- Heroin was the primary drug within this population, however poly drug use was common with high levels of stimulant use including crack cocaine reported. Over 70% reported using two or more drugs regularly.

- The average age of initiation into injecting was 21 years, however over 40% began injecting aged 18 years or younger.

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**Recommendations**

Use multi-agency partnership working to:

1. Increase awareness of blood borne viruses among at-risk populations to encourage testing and treatment.

2. Develop a monitoring and evaluation tool such that all partnership agencies understand the contribution their intervention programme makes and understands the evidence that needs to be collected to show effectiveness.

3. Strengthen the knowledge and training of staff working with at risk groups on the transmission of infection and safe injecting techniques.

4. Develop and strengthen community based support services for infected individuals who are not readily able to access treatment.

5. Develop and strengthen peer led prevention/early intervention initiatives to reduce the number of at risk individuals and educate early in injecting careers.

6. Develop standardised data collection systems across Wales to enable surveillance of both drug use and viral epidemiology.
Reported sharing rates, both direct (needles and syringes) and indirect (other injecting equipment e.g. spoons, filters, water), were high and are thought to be an underestimation of the actual rates.

The main risk factors associated with hepatitis C infection included homelessness, history of imprisonment, length of injecting career and crack use.

Recommendations

7. Ensure all existing social and youth services are adequately resourced to meet the challenge of serious and injecting drug use in vulnerable young people to include investment in peer education programmes and outreach work for all young people and targeting vulnerable groups.

8. Ensure support services are in place to minimise generational effect with children of parents who substance misuse.

9. Through commissioning networks ensure that services can meet local demand including the provision of rapid access to treatment for young people.

10. Develop treatment approaches to address poly drug use (including alcohol)

11. Increase awareness of blood borne viruses, transmission routes and implications for health for both substance misusers and relevant care providers

12. Assess existing evidence regarding safer injecting environments for homeless populations and young people.

The role of existing service provision

The multi-centre incidence study and the Community Needs Assessment gave an overview of the role of prisons, drug treatment agencies, needle and syringe exchange services, local authority agencies and tertiary health care services in prevention, diagnosis and treatment of blood borne virus infection.

Prisons:

- Clearly prison plays a major role in the lives of many IDUs in Wales; 71% of the sample population had been incarcerated at least once with the majority of these being imprisoned at least four times

- Prisons provided hepatitis B vaccination coverage far in excess of any other service provider

- Prisons do provide a valuable opportunity for detoxification from substance use for many prisoners, either formal or informal (self-imposed). However, perhaps due to
the lack of consistent aftercare, the majority (60%) remained drug free for less than one week following release

- A lack of consistent through and aftercare services for substance-misusing offenders was apparent. Over 80% had disclosed their drug use to prison authorities however only 20% of these reported being offered through care, aftercare or any follow up

### Recommendations

Use multi-agency partnership working to:

13. Continue and strengthen the health care services within prisons including provision of hepatitis B vaccination, screening for blood borne viruses with appropriate ongoing support, awareness raising of risk factors and routes of transmission and training for prison staff.

14. Ensure continuity of care through the development of a shared health database and partnership working between Prisons, GPs and CDTs

15. Strengthen existing through and aftercare services for offenders utilising robust keyworker systems to address health, social care, housing and substance misuse issues prior, during and after release.

16. Ensure appropriate resources to operate demand management systems

### Drug Treatment agencies:

- Around 50% of the study sample had been in or were currently on a substitute drug treatment program

- Current treatment focuses on opiate use however poly-drug use was common. Stimulant use including crack use was widespread

- Waiting times were consistently reported as a barrier to access to treatment although regional variations existed

- Punitive policies were reported with regard to suspension or withdrawal of treatment. Over one third of those currently on treatment had been banned or suspended from treatment for missing an appointment

- Service users reported very low expectation in terms of treatment options
Needle Syringe Exchange (NSE) services:

NSE provide an invaluable service. However a number of issues arose which, if addressed, could lead to an improvement of existing services. The issues raised were:

- Variation in coverage of NSE services leading to inequity in access both geographical and time related
- Regular reuse of own injecting equipment or sharing of equipment due to lack of access to clean equipment when required outside of normal working hours
- Absence of information on safe injecting and related infections and illnesses delivered by pharmacy based NSE
- Inconsistent supply and distribution of sterile injecting equipment
- Barriers to use of NSE included breaches of confidentiality, prejudice and lack of discretion by staff
- Lack of provision of all necessary injecting equipment

Recommendations

17. Ensure substitute drug treatment services meet agreed standards for Wales
18. Improve training for generic substance misuse workers so that poly drug users can be appropriately managed.
19. Address issues of waiting times and treatment options – support services to operate demand management systems
20. Provide for basic drug related health care at point of presentation (e.g. within treatment services) and develop systems for treatment of blood borne virus infections, where appropriate, within drug treatment services
21. Establish standardised recording system for all health related actions and care pathways to ensure continuity of care across treatment providers
22. Maximise shared care opportunities and ensure involvement of clients in development of policies and treatment options
NHS Health Care provision (Primary to Tertiary)

- Over half of the IDU sample reported having been screened for hepatitis C, however pre and post test discussion was inconsistent. Test results were received in 90% of cases however less than 15% of those receiving a positive result were referred on to a specialist clinic

- Around a third of the IDU sample reported recent potentially serious injecting related problems, with the majority attending A&E instead of other health services. 40% had overdosed

Recommendations

23. There is a need for continual overview of geographic distribution of needle/syringe exchange services including pharmacy, community and statutory based services to ensure fail safes can be implemented when services can no longer provide for the population and to ensure adequate coverage and equity of service provision over time

24. There is an urgent need to address the deficiency in needle/syringe exchange and drug related equipment provision in areas of poor coverage

25. Develop a standardised data collection system for all NSE services in Wales

26. Establish an All Wales Needle Exchange Forum to maximise opportunities for sharing experiences of quality services.

27. Develop further mobile/outreach NSE services outside of normal working hours

28. Consider the implications of alternatives such as vending machines in certain high-use areas alongside provision of secure disposal units

29. Ensure services are adequately resourced to provide consistent supply of all injecting equipment to meet demand with a contingency supply available

30. Provide appropriate and consistent training to all NSE workers to ensure issues of prejudice and confidentiality are addressed

31. Develop and strengthen appropriate information systems on safe injecting and blood borne viral transmission
Within the general population there is a lack of active identification of patients at risk of hepatitis C by GPs due to an expressed lack of awareness and of standardised protocols relating to hepatitis C. Only half of GPs reported offering hepatitis B vaccination or testing to identified hepatitis C positive patients.

Levels of shared care between GPs and relevant organisations (Community Drug Teams, GUMs, hospital specialists) grossly inadequate and subject to regional variation.

1240 chronic HCV patients have been referred to hepatitis C specialist treatment services to date and are being monitored or treated by services across Wales. In 2005 a total of 106 patients were eligible and ready for treatment, as identified by 10 of the 11 tertiary services, and 67 received treatment according to NICE guidelines. This would indicate that of all those ready for treatment, at most only 63% received it.

No identified budget for management of hepatitis C in any of the specialist services.

Interim support for patients diagnosed with chronic hepatitis C is only provided in 4 of the 11 specialist treatment services.
Recommendations

32. Provide basic health care within voluntary and statutory drug services, redefining the role and contribution of staff in order to provide HBV vaccinations supported by generic Patient Group Direction in addition to wound care and prescribing of antibiotics for abscesses.

33. Explore opportunities for developing a training programme for generic drug workers to provide counselling and testing for blood borne viruses to their clients.

34. Through the National Framework, consider how best to support primary care in encouraging GPs to actively identify those patients who may have put themselves at risk of infection with blood borne viruses, and to initiate the appropriate referral process if required.

35. Develop and implement increased levels of shared care with drug treatment services and other relevant voluntary agencies including alcohol services. Explore opportunities for sharing experiences of services who participate in quality shared care. Liaise with clients groups to ensure patient needs are understood.

36. Produce a standardised protocol for pre and post-test discussion for use with blood borne viral testing. Distribute with appropriate training.

37. Provide specific information and support to GP practices in order to provide improved service to those with a positive HCV diagnosis.

38. Develop and strengthen appropriate community support services for those diagnosed with blood borne viruses including alcohol services.

39. Quantify both current and future unmet need for treatment and care. Identify resources required to implement NICE guidance in full.

40. Implement patient care pathways to ensure that resources are targeted appropriately with adequate support for community management and delivery of care and patients are provided with a seamless service.

41. Develop a network of community clinical staff to ensure continuity of care and access to appropriate support at all stages from diagnosis to treatment or otherwise.

42. Within all areas pertinent to blood borne viruses, ensure there is continual overview of service provision so that the impact of changes in epidemiology, changes in treatment options and changing client needs can be met.
References


SECTION 1 – SERVICE USER RESEARCH PROGRAMME

1. Incidence of blood borne viral hepatitis in injecting drug users in South Wales; a de-linked prospective cohort study

STATUS – data collection and analysis complete

Project co-ordinated by Dr Marion Lyons, Dr Mark Walker, Dr Noel Craine and Josie Smith, ICDS, Dr Mathew Hickman Centre for Research on Drugs and Health Behaviour, Imperial College London, Dr John Parry, Health Protection Agency Specialist and Reference Microbiology Division, Sexually Transmitted and Blood Borne Virus Laboratory, Hidden Populations Research (HPR).

Study design/overview: Estimates of the prevalence and incidence of HCV, HBV and HIV infection amongst injecting drug users (IDUs) in South Wales have been obtained from a de-linked prospective cohort study. 700 current IDUs were recruited into the study from treatment services, low threshold needle and syringe exchange services and via community recruitment during December 2004 – January 2005. Dried blood spot samples were taken and a risk factor questionnaire completed for each of the study subjects providing a baseline. During the follow up phase, December 2005 – January 2006, following attempts to re-contact all of the original cohort, a total of 407 study subjects were retested and a second dried blood spot sample was taken, and questionnaire completed. All blood samples were tested on both occasions for the presence of anti-HCV and HBc, HIV was included at follow up. The incidence of HCV and HBV infection is estimated from the number of individuals negative at baseline who are sero-positive at follow up, calculated as the number of sero-conversions divided by the person years at risk. Data collection was de-linked; neither study subjects nor the research team have access to identifiable test results. The results will prove invaluable in enabling a clear estimation of the prevalence and the level of incidence of these diseases as well as significant risk factors related to transmission of disease.
### Findings

#### 1.1 Overall findings:

For Study Period 1 (Dec 2004 to Jan 2005)

**Prevalence rates:**
- anti-HCV 26% (95% CI 23% – 30%)
- anti-HBc - 9% (95% CI 7% -12%).
- 7% (95% CI 5% - 9%) had both markers.

The two main cities Cardiff (35%) and Swansea (43%) had the highest prevalence rates.


**Incidence rates:**
- Anti-HCV 6 per 100 person years (95% CI 3%-9%)
- Anti-HBc 2 per 100 person years (95% CI 0.8% - 4%)

A previous study in North West Wales (2003) (N=153) indicated anti-HCV rates of 23% (95% CI 16% - 30%) and anti-HBc 27% (95% CI 20%-34%).
- 16% of sample had both markers.

25% of those anti-HCV positive were already aware of their status, with the remaining 75% (n = 138) anti-HCV positive individuals who were unaware of their status.

### Implications

- Prevalence rates of anti-HCV and anti-HBc vary greatly by geographic area and by size of town or city.

- Prevalence rates lower than those in England and Scotland for 2004 – 2005

- Population in need of health care for blood borne viral infection now identified

- Large numbers of current injecting drug users exist who have chronic HCV but are unaware of this and therefore may continue to practice risk behaviours thereby potentially transmitting infection to others and worsening their own potential health outcomes

### Recommendations

Use multi-agency partnership working to address the following issues:

- Increase needle/syringe exchange and drug related equipment provision in areas of poor coverage.

- Strengthen the knowledge and training of drug support staff re. transmission of infection and safe injecting techniques

- Strengthen HBV vaccination services in Drug Services both statutory and non-statutory including GPs

- Establish standardised data collection systems for HBV vaccinations, needle/syringe exchange provision etc

- Provide peer led education intervention and prevention initiatives to reduce the number of individuals at risk including vulnerable groups e.g. young offenders, sex workers, excluded children.

- Increase awareness of blood borne viruses among general and at-risk populations to encourage testing and treatment. Awareness raising should follow the French awareness campaign approach
<table>
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<tr>
<th>1.2</th>
<th><strong>New injectors</strong></th>
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<td>There was evidence of exposure to HCV early in individuals' injecting careers with an anti-HCV prevalence of 5% (95% CI 1%-12%) amongst those who had been injecting for one year or less (76/700)</td>
<td>Ongoing risk of transmission of blood borne viruses to new injectors</td>
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<th><strong>Risk factors</strong></th>
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<td>Factors significant in anti-HCV infection risk include: homelessness; history of incarceration; duration of injecting and crack use, however,</td>
<td>Socially excluded and marginalised individuals at increased risk of HCV and HBV</td>
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**HBV vaccination**

Vaccination coverage 44%. 71% (495/700) of the study cohort had been to prison, of these 40% (200/495) had received at least one inoculation whilst incarcerated, this represented 65% (200/307) of the individuals reporting vaccination in the whole study cohort.

Vaccination coverage remains poor. Prison vaccination programs offer the opportunity to increase vaccination coverage. Scottish Prison Service experience provides evidence of efficacy of enhanced program.

Support and further develop prison based vaccination program. With the Local Health Boards assuming responsibility for Prison health care since April 2006, there is an opportunity to develop meaningful programmes.

Vaccination needs to be carried out early in injectors careers or prior to injecting in high risk groups.
more in-depth analysis of the data is required to assess the relative contribution of these factors to transmission of HCV and HBV within this population.  

50% (351/700) of the sample reported ever sharing needles and syringes

Existing interventions within housing/homelessness and prison services are insufficient to address the specific needs of the homeless and drug using inmates in relation to prevention / intervention initiatives relating to transmission of blood borne viruses

Develop/strengthen range of through/after care services following prison including referral pathways to drug treatment and including incarcerated individuals on waiting lists. Prior to exit from prison each individual to be nominated a keyworker who will coordinate health and care needs on an individual need basis.

| 1.4 | Poly drug use the norm – crack use widespread:  
Smoked crack ever = 91.8% (643/700)  
Smoked crack in last four weeks = 58% (405/700)  
Injected crack ever = 34.7% (243/700)  
Injected crack in last four weeks = 8.6% (60/700)  
Injected heroin & crack together ever = 33.2%  
Injected heroin & crack together in the last four weeks = 8.6% (60/700) | Further treatment options required to address crack, cocaine and other poly drug use. | Ensure optimum substitute drug treatment services  
Need to strengthen treatment and community based drug services to ensure sufficient specialist stimulant workers and to further develop support / advice and treatment approach for poly drug use. |
2. Needs Assessment of harm reduction and health care services for substance misusers across Wales

STATUS: data collection and analysis complete

Project co-ordinated by ICDS and carried out by HPR

Little research data is available to date as to the efficacy of the main pillars of the HCV prevention strategy, namely needle and syringe exchange, substitution treatment and education in preventing HCV transmission. The high prevalence of HCV reported from a range of settings across the UK would suggest that current service provision is insufficient to prevent transmission. This however may be due not to the suitability of these approaches in preventing transmission but rather to their quality and coverage on the ground. Experiences gained during the incidence study would suggest that in South Wales the quality and coverage of these services varies greatly. The purpose of the needs assessment study was thus:

i) to evaluate needle and syringe exchange provision, including communication and education on wider health issues;

ii) to evaluate access to substitution treatment including current waiting list;

iii) to assess knowledge of risk from the perspective of current injecting drug users in a range of settings across Wales.

iv) to assess provision of vaccinations against other blood borne viruses e.g. Hepatitis B

v) to assess current care pathways for those wishing to be tested for HCV, or those who are confirmed HCV sero-positive, including pre and post test counselling services, referral pathways to Clinicians and existing community support - availability and quality.

The evaluation is drawn from 500 structured interviews with a purposive sample of IDUs accessed in NON service based settings. The study sample will be stratified by age, gender, injecting experience and from a range of predetermined geographical areas. The key elements of focus involve spatial and temporal indicators of needle and syringe availability; waiting list time to access substitution treatment as experienced by client and predicted by service; range of methadone and buprenorphine dose; self reported risk behaviour in month prior to interview and health service provision.
<table>
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<th>FINDINGS</th>
<th>IMPLICATIONS</th>
<th>RECOMMENDATIONS</th>
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<tr>
<td><strong>2.1 NSE Services</strong>&lt;br&gt; Inequity of coverage of needle/syringe exchange: in some areas very good coverage and in other more outlying areas services are poor or non-existent service. Regular re-use of own needle/syringes widespread. Of current injectors (injected in last four weeks), 65% reported regular re-use of own needle/syringes. Of these 67% reported reuse of each needle/syringe between 2 – 4 times. Of the 322 IDUs who reported using pharmacy based needle exchange services, only 9% reported receiving any information on infections / illnesses related to injecting.</td>
<td>Overall:&lt;br&gt; This is a vulnerable, marginalised and socially excluded population whose perception and expectation of services are very poor compounded by inequity in service provision, long waiting times for treatment (depending on geographical area) and a punitive approach to care. The needs of poly-drug users are not met.</td>
<td>Overall recommendation:&lt;br&gt; Develop a framework for demand management. In partnership with primary care, rethink the caseloads of CDTs to maximise their contribution to the challenge and ensure that those with the most complex or dual diagnosis cases have access to their expertise. Long standing, stable individuals could be supported by less intensive services. On-going (annual) audit of geographic distribution of pharmacy and other needle exchanges in each area (by needle exchange co-ordinators?) to establish gaps where users known to reside and further work with pharmacies in outlying areas to encourage development of services. Also need to work on retaining existing services as several pharmacies have dropped out from providing this service and there is need to identify the support they require. Strengthen pharmacy NSE in terms of harm reduction info / safer injecting techniques / infection info etc</td>
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| 2.2 | Supply and distribution of clean needles/syringes to NSE services inconsistent | Shortage of supplies for clean needles and syringes, sharps bins and other equipment occurs leading to an unnecessary reduction in the efficacy of harm reduction services | Provide adequate supplies of ALL clean injecting equipment to be available 7 days per week and outside of normal 9 – 5 hours 
Ensure supply meets demand with adequate contingency supply. |
| 2.3 | Social and Educational: | In 2004, 1.3% (n = 4,315) of the general population in South Wales, aged between 0-19 year old, were in local authority care. Potential at-risk individuals may be identified early on and specific support given. ‘Having been in care’ and ‘exclusion from school’ represent risk factors to future problem drug use | Develop and invest in peer education programmes and outreach work with young people specific targeting of vulnerable groups including excluded children. Need to ensure support services are in place to prevent generational effect. 
A proposal has been submitted to WORD [http://www.homeoffice.gov.uk/rds/pdfs2/hors260.pdf](http://www.homeoffice.gov.uk/rds/pdfs2/hors260.pdf) |

32% (160/500) of the sample had been in local authority care as a child. 
Overall, 57% (284/500) had been excluded from school, with 81% (130/160) of those in care also excluded from school. 
63% (318/500) of the study group were parents however of these, only 24% had their children living with them. Average number of children per parent participant was 2.3
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<th>2.4</th>
<th>Drug use:</th>
<th>There are a great number of young injectors who may not be accessing NSE services following initiation into injecting thereby relying on others to provide clean needles for them or using other peoples equipment</th>
<th>Develop and strengthen existing harm reduction and prevention services specifically aimed at reaching young people</th>
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<tr>
<td>44.1% of sample started injecting aged 18 or younger. Range of age of first injection: 9 – 50 years old</td>
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<td>2.5</td>
<td>Treatment focuses on heroin use however poly-drug use is the norm. 78% (390/500) of sample were using two or more drugs regularly. There is increased and regular use of stimulants including crack cocaine, amphetamine etc as well as other drugs.</td>
<td>Existing substitute drug treatment options (methadone, subutex etc) focus on opiate use.</td>
<td>Ensure optimum substitute drug treatment services</td>
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<td>Focus treatment to address poly drug use not just primary drug use to ensure services provide the support required to combat all addiction</td>
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<td>2.6</td>
<td>Of those that had injected in the last 4 weeks, 45% (164/361) had shared injecting equipment in the last month and 12% (43/361) reported sharing needles and syringes in the last month. 42% reported direct sharing in the past.</td>
<td>Ongoing risk of transmission of blood borne viruses</td>
<td>Adequate provision of and accessibility to clean injecting equipment</td>
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<td>Increase awareness of blood borne viruses and transmission routes</td>
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<td>2.7</td>
<td>Hepatitis:</td>
<td>Prevalence of infection within this sample equivalent to the overall rates observed from the prospective cohort study</td>
<td>Standardise protocol and training for pre and post test discussion and agree an all Wales approach</td>
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<tr>
<td>47% (237/500) of sample reported having had a test for hepatitis C.</td>
<td>Not all individuals coming forward for testing are given the appropriate pre and post test discussion</td>
<td>Provide dedicated support for those contacting testing services to ensure follow through of results, dealing with positive result and ensuring appropriate referral and advice.</td>
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<td>62% (147/237) of these reported being given pre and post test discussion</td>
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<td>25% (51/204) received a positive result</td>
<td>Failure to follow appropriate referral pathways for positive patients.</td>
<td>Only eight positive individuals were referred to a specialist clinic.</td>
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<td>2.8 Use of health services:</td>
<td>IDUs may experience a range of problems relating to poor injecting technique or poor hygiene. Delay in approaching primary health care results in more serious infection.</td>
<td>Develop or strengthen basic health care provision within voluntary and statutory drug services by redefining role and the contribution of staff in order to provide HBV vaccinations supported by generic PGDs / wound care / prescribing anti-biotics for abscesses etc / support for getting tested for BBV’s / referrals etc.</td>
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<td>Majority of IDUs go to hospital (A&amp;E) for drug related health problems instead of G.P or Drug Service.</td>
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<td>Increase overdose and CPR training to clients of drug services</td>
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<td>32% (159/500) had suffered from a potentially serious injecting related problem (Abscess, DVT or septicaemia) in last 3 years, and sought medical attention via A&amp;E.</td>
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<td>40% (202/500) had overdosed</td>
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<td>2.9 Drug Treatment:</td>
<td>Substitute drug treatment is perceived as difficult to access, hard to remain on and the service criteria for discontinuation of treatment seen as punitive and unrealistic.</td>
<td>Focus efforts to develop and encourage G.P involvement in treatment provision and basic health care for stable users – those on substitute drugs including methadone and buprenorphine thereby leaving the more specialist drug services to work with the more complex and chaotic drug users</td>
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<td>Waiting times barrier to access – regional differences in waiting times. Majority felt it was a difficult and slow process to get on to treatment – regional differences in waiting times and perception of ease of access</td>
<td>The sample population generally perceived substitute drug treatment as the only option in a care package.</td>
<td>Development and strengthen drug treatment services reducing waiting times for treatment</td>
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<td>Service users felt that policy with regard to suspension/withdrawn of script were punitive making it difficult to get into and stay on treatment</td>
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<td>Very low expectations in terms of treatment options</td>
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### 2.10 Prisons:

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<th>Prisons:</th>
<th>Drug use ongoing in prison – suspected under-reporting of injecting behaviour within prisons</th>
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<tr>
<td>70% (347/500) had been in prison with 68% being imprisoned at least 4 times.</td>
<td>There is a failure in partnership working with other organisations to ensure that a care pathway is established for those drug using offenders to avoid repeat imprisonment.</td>
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<td>For those who had been in prison 39% (135/347) reported continuing to use heroin but did not inject</td>
<td>Multi-agency work is required – the care pathway must include the necessary partnership working between drug misuse agencies, prisons and GPs etc to ensure continuity of care. It is not supportable to the client to continue to disrupt treatment and it is counterproductive to the services</td>
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<td>5% reported injecting last time they were in prison</td>
<td>Develop and strengthen existing detox / harm reduction services within prisons.</td>
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<td>82% (285/347) disclosed drug use to prison authorities however only 21% (61/285) were offered through/aftercare or follow up treatment</td>
<td>Examine evidence based harm reduction options within prisons</td>
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<td>Strengthen links between prescribing drug agencies and prisons.</td>
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<td></td>
<td>See point 1.3</td>
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3. **Prevalence estimate of serious and injecting drug use across Wales**

   **STATUS:** Ongoing

   Project co-ordinated by ICDS

**Aim**
The study aims to provide a robust estimate of the prevalence of heroin, crack/cocaine and injecting drug use across Wales. Estimates will be provided for different regions and areas, defined by Police Divisions, NHS Trusts and LHB’s across Wales. Estimates will be produced using capture-recapture techniques applied to available data sets.

**Background**
A robust estimate of serious (non-injecting heroin, crack, cocaine, amphetamine) use and injecting drug use across Wales is needed for a number of reasons:

- To inform estimates of the burden of disease from blood borne viral infection including hepatitis B, hepatitis C and HIV
- To inform the planning of treatment service provision
- To standardise recorded information relating to serious non-injecting and injecting drug users in contact with relevant services.
- To provide a baseline from which to monitor any trends / changes in the population size of drug injectors and serious drug users in line with the strategic aims outlined in ‘Tackling Substance Misuse in Wales, A partnership approach’ 2000.

**Findings:** Serious issues have arisen with regard to data collection procedures throughout Wales. The Welsh National Database, which provides data relating to persons treated at drug treatment agencies within Wales, provides far more comprehensive information for the period 2005 than for previous years as it has only recently been established. Needle Exchanges including Pharmacy, Voluntary and Statutory agencies have tended to record different information with only Gwent collecting comprehensive information for the period 2004. There is great regional variation in data collection and processing systems.

**Recommendations:**
That NPHS establish an All Wales Needle Exchange Forum with terms of reference: To oversee and support uniformity in data collection; to provide a forum for debate; to support a best practice database; for NPHS to develop centralised database in conjunction with HSW and WAG. The forum will be open to all relevant LHB Commissioners, NEX Pharmacy co-ordinators, NEX Managers and project staff etc. MREC have granted ethical approval for the prevalence estimate to cover the year 2005.
4. **A qualitative study on access to injecting equipment for injecting drug users in South Wales**

**STATUS data collection and final analysis complete**

Co-ordinated by Dr Tim Rhodes, Centre for Research on Drugs and Health Behaviour, Imperial College London. Collaborating partners - Professor David Clark, Department of Psychology, Swansea University, Hidden Populations Research (HPR), and ICDS

Needle and syringe exchange provision is one of the key components in the prevention of blood borne viral transmission in Wales. It became apparent from current work undertaken by the ICDS and from talking to providers of such services, that the provision of clean needles and syringes across Wales is varied and at times problematic. Furthermore, barriers exist in the ability of individual injectors to access services. A greater understanding of both these barriers and of current provision was thus needed.

**Aims/overview:** To provide a qualitative insight into current provision of clean needles and syringes and other injecting paraphernalia to injecting drug users (IDUs) in South Wales and the barriers to its uptake. The key components addressed were coverage of different exchange schemes, the quality of these schemes and personal barriers to their use. The study explored both areas of good practice and areas where provision is limited. Coverage included accessibility, opening times and barriers to access. Quality will include the depth of the service offered and appropriate nature of schemes in relation to needs of IDUs in the area. The study also looked at access to education about blood borne viruses, vaccination and testing.

Semi-structured recorded interviews were carried out with 49 current IDUs drawn from 5 different sites across South Wales. The study used purposive sampling and ensure inclusion of both women and men, younger injectors (<25 years old) and recent onset injectors (<3 years injecting) and, when appropriate, different ethnic groups. Study sites were selected to represent the range of provision scenarios across the region. They include a) inner city homeless IUDs - Cardiff; b) City housed - Newport; c) smaller town based IUDs - sites within Rhondda Cynon Taff and Gwent. Recruitment was achieved by snowballing from initial contacts. Interviews were taped and transcribed and subject to thematic analysis.
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<td>4.1</td>
<td>Accessibility and availability issues- restrictive opening times and lack of advertising of services impacted specifically on new injectors</td>
<td>Perceived inflexibility in existing NSE provision in pharmacies, voluntary and statutory drug agencies. New injectors not aware of where to go to obtain free needles and syringes. Reliance on more experienced injectors for information.</td>
<td>Develop further mobile / outreach in addition to existing NES services to ensure equity of service provision across Wales. Consider implications of alternatives such as vending machines.</td>
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<td>4.2</td>
<td>Geographic location of NSE services focused in central locations. Inadequate coverage in outlying estates etc</td>
<td>Higher levels of sharing and re-using behaviour in outlying estates or more rural areas due to inability to access NSE services.</td>
<td>On-going (annual) audit of geographic distribution of pharmacy and other needle exchanges in each area to establish gaps where users reside and further work with pharmacies in outlying areas to encourage development of services. Also need to work on retaining services as several pharmacies have dropped out from providing this service.</td>
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<td>4.3</td>
<td>Lack of adequate provision of all injecting equipment/paraphernalia across services.</td>
<td>Indirect sharing levels higher due lack of availability of injecting equipment (filters, water, cookers etc)</td>
<td>Ensure adequate resources to provide sufficient good quality needles/syringes and all other injecting equipment to prevent sharing and try to maintain good hygiene</td>
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<td>4.4</td>
<td>Barriers to use of pharmacy NEX include issues of prejudice, lack of discretion and breaches of confidentiality, lack of free needle exchange, lack of equipment provided, and staff being particular about who they will serve.</td>
<td>Increased levels of direct and indirect sharing due to reluctance to approach pharmacy NSE services.</td>
<td>Provide appropriate and consistent training of pharmacy NSE workers to ensure issues of prejudice, confidentiality and privacy are addressed.</td>
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### 4.5 Importance of injecting environment – for the homeless there is very little choice about where they inject – being surrounded by other users led to increase or lack of control of use and increase in sharing behaviour. Hostels enforcing no-drug policies. Those users stable and housed indicated better control of drug use, the ability to reduce intake and also inject more hygienically.

Type of housing (particularly stable or temporary) has direct impact on drug use and risk behaviours. Vulnerable people, especially the young, who are in temporary accommodation / hostels are more likely to encounter cohorts of regular serious and injecting drug users. IDUs are more likely to be evicted from temporary housing if drug injecting equipment found due to no-drug policies.

Investigate / assess existing European research on options such as safer injecting environments for homeless IDUs. Strengthen links between drug services and homeless agencies.

### 4.6 Within the study group, injecting initiation usually took place within a group of peers where someone else (more experienced but not necessarily using good technique) would inject others. Individuals already using drugs via non-injecting route are initiated into injecting without education on safe injecting techniques and practices.

Target those individuals / groups who are already using drugs but not yet injecting. Provide information to inform of potential risks, injecting technique etc.

A research proposal has been submitted to WORD addressing these issues.

### 4.7 Lack of awareness of risks of sharing paraphernalia

Ongoing indirect sharing and potential transmission of blood borne viruses.

Develop peer led interventions. Raise awareness of risks of sharing ANY injecting equipment (alongside provision and adequate resourcing of NSE to provide all equipment required as standard).

### 4.8 Groups more likely to share equipment and needles including young people and homeless.

Need to ensure that availability of all clean equipment meets specific high risk groups through mobile and outreach services.
| 4.9 | Long waiting lists viewed as major barrier to accessing treatment, other barriers included lack of communication from services, being dropped from lists due to prison term or missing an appointment. | Drug users not approaching treatment services due to barriers in process re. dropping clients from drug treatment programmes, the opportunity costs need to be quantified both for the services and the clients. | Address the issues of waiting lists and barriers to accessing treatment via drug agencies. Develop and strengthen GP involvement in prescribing. |
| 4.10 | Drug Treatment & Testing order (DTTO) perceived to be a quicker way of rapid access to substitute drug treatment, as well as providing assistance with relevant travel expenses to go to centre each day and help with housing. Although this perception was tempered as it was felt unfair that in order to access these services, it was first necessary to get a criminal record. | IDUs may see committing more crime as a means of accessing substitute drug treatment more rapidly. | Ensure optimum substitute drug treatment services Ensure parity of services between those IDUs committing crimes and those with no criminal record / not committing crime. |
| 4.11 | Experiences of prejudice and negative attitudes from health services including GPs and hospital staff. | IDUs not receiving equity of health care and may be less inclined to approach health services when required, to the further detriment of their health. | Raise awareness and understanding of drug related issues aimed at schools, doctors, pharmacy workers and health care professionals. |
5. Chronic hepatitis C – A Patients Perspective

STATUS: Ongoing

Project co-ordinated by Research Team, ICDS

Aim
A questionnaire was designed for use by any person living in Wales who has received a confirmed diagnosis for hepatitis C. The questionnaire aims:

Key Aims:
- to provide evidence on extent of advice, support and protective measures to reduce the potential morbidity of the infection e.g. Hepatitis B vaccination, information on diet and alcohol reduction
- to assess the type and level of support and discussion involved in the early stages of diagnosis and assessment for that individual
- to describe, from the patients perspective, the specialist HCV services currently available including waiting times, treatment experience and access to information
- to gain a deeper understanding of the extent to which hepatitis C impacts on different elements of an individuals life including health, social circumstances, family, employment, and psychological well-being.

The questionnaire was distributed to: all Hepatitis C treatment clinics; via drug agencies both voluntary and statutory; and, through established hepatitis C support groups within agencies. This project is ongoing and the findings outlined below are based on the 25 completed questionnaires that have been returned to date.

Key Findings:
- 40% of the individuals diagnosed with chronic hepatitis C had received any vaccinations for hepatitis B, only half of these had received a full course.
- Average age of diagnosis was 34 years, range 17 – 57 years
- 80% had contracted the disease through injecting drug use, 8% through blood transfusion prior to 1991, the remaining individuals were unsure or did not state how they became infected
Less than one third received pre-test discussion prior to screening for hepatitis C. 56% received post-test discussion following positive diagnosis. Less than 50% stated that they understood what the results of the blood test meant.

Average waiting times from diagnosis to first appointment with a specialist nurse or consultant was between 3 – 4 months.

Identified as in need for improvement were: levels of community support, clearer information on treatment from hospitals; waiting times to treatment; protocols for pre and post test discussion; and GP awareness of hepatitis C.

What could be improved?
The following recommendations were identified as potential ways of improving existing services along the care pathway:

- More information required from hospital on the treatment available
- Better communication between relevant agencies
- Development of local community support groups or networks is important as it helps to recognise that others have the disease and to reduce the stigma attached
- Reduction in the waiting time for treatment
- Better care before and after the diagnostic tests
- More information and training to be available to GPs
SECTION 2 – SERVICE PROVIDERS

6. Community Drug Teams (CDTs) in Wales: Provision of Hepatitis B and Hepatitis C services

STATUS: Data collection completed, analysis complete

Project co-ordinated by Research Team, ICDS

A questionnaire sent to each CDT in Wales, responses received from 8 of the services: N.E. Wales, N.W. Wales, Powys, West Wales Substance Misuse Service, Swansea, Cardiff & the Vale, Pontypridd & Rhondda, Merthyr (MIDAS).
No response received from Gwent (GSSMS) or Bridgend

Aims/Overview:

The questionnaire was designed to assess the level of health care provision within community drug services in particular: the provision of information and education; provision of hepatitis B vaccination; and screening processes for blood borne viruses. The following areas were included:
• General health including wound care, mental health, blood borne viruses and use of other substances e.g. alcohol.
• HBV vaccination provision and data collection systems
• HCV information, screening, pre and post test discussion procedures, referral processes and specific ongoing support to those testing positive
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<td>6.1 All CDTs apart from one addressed general health issues with service users, usually at initial assessment and at ongoing attendances. Services did not address wound care and infections in-house instead referring to G.P or A&amp;E.</td>
<td>Basic health assessment is being undertaken in-house. It is a missed opportunity to not to provide wound care in-house at the same time as providing information on safer injecting technique and infection prevention.</td>
<td>Provide basic drug related health care on site e.g. treatment of abscesses and verbal/visual instruction and information on safer injecting practices to avoid future abscesses and other bacterial infections.</td>
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<td>6.2 All CDTs provided information about Hepatitis B and Hepatitis C and routes of transmission in the form of leaflets and/or verbal discussion. However, no evaluation or evidence is collected on its value or benefit. During interviews in the previously mentioned studies, even those individuals who had been attending drug services (statutory or voluntary sector) for some time displayed very poor (if any) knowledge and understanding about blood borne virus transmission</td>
<td>Written information in the form of leaflets and posters relies on clients motivation and ability to read and understand the information. Verbal discussion requires time and appropriate levels of knowledge re BBVs. However neither existing route appears to have been effective enough at raising awareness re. blood borne virus transmission and risk behaviour.</td>
<td>Develop training package for use with all relevant staff.</td>
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<td>6.3</td>
<td>50% of CDTs provided hepatitis B vaccination on site and indicated that procedures were in place to facilitate client receiving full course. Of those that did not provide the service, referral was made to local GUM or G.P.</td>
<td>IDUs in contact with specialist drug agencies may remain at risk of acquiring and transmitting hepatitis B either through lack of availability of this service on site or through failure to follow up referrals and track patient care between prisons, CDTs and GPs</td>
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<td>6.4</td>
<td>50% of CDTs provided HCV testing on site. The remaining services refer to GUM or G.P. Of those CDTs providing the HCV testing service, only one had protocol or guidelines in place for Hepatitis C testing.</td>
<td>Lack of consistent approach to hepatitis C testing. Referring on to other agencies misses an opportunity to provide Continuity of care and relies on good relationship with GPs (not always present) and reasonable waiting lists in GUMs</td>
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<td>6.5</td>
<td>86% of CDTs provided pre and post test discussion service. This is undertaken by range of staff members including Nurses, CPNs, Doctors, Keyworkers or NEX Co-ordinators.</td>
<td>On site testing for blood borne viruses with clear protocol, standardised operating procedures, guidelines and training where appropriate</td>
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<td>6.6</td>
<td>All services indicated that a positive result would not affect drug treatment decisions. One service indicated that pregnant women and women with vulnerable children, if found to be hepatitis C positive, would be fast-tracked.</td>
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6.7  Counselling support was indicated in 37.5\% (3 of 8) services, the remaining services indicated no additional support.  
Lack of counselling support available

6.8  Only two CDTs implemented any kind of data collection or recording system for HBV vaccinations to new clients or on the number of people screened for blood borne viruses in a given year.  
Lack of health related recording system may lead to incomplete packages of health care provided by service  
Establish standardised recording system for all tests for blood borne viruses and vaccinations.  
Establish database for all health related actions undertaken and care pathways described.
7. Hepatitis B vaccinations in GUM clinics across Wales

STATUS: Data collection and analysis complete

Project co-ordinated by Research Team, ICDS

**Aims/Overview**
All of the nine main GUM Centres completed a questionnaire covering issues specific to screening for blood borne viruses and the provision of hepatitis B vaccination.

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| **7.1 Policies / Protocols / Guidelines**  
Of the 9 main centres (which serve the satellite clinics):  
One has a written policy for hepatitis B immunisation  
All of the centres follow the National BASHH guidelines | | To continue to follow national guidelines.  
### 7.2 Screening and tests
All offer screening prior to hepatitis B immunisation to high risk groups.

- The groups screened are:
  - MSM and CSW in all centres
  - Individuals from countries of high prevalence in all but one
  - Injecting drug users in all but one
  - Bisexuals in all but one
  - Sexual partners of the above groups in all but one
  - HIV positive individuals not included in the above groups in all
  - In three centres screening is routinely offered to all patients.

### 7.3 Vaccination
All clinics offer vaccination to:
- MSM, CSW, Bisexuals, HIV positive individuals not included in the other groups.
  - Two clinics offer vaccination to injecting drug users whilst 1 confirmed that this group were dealt with by their drug service.
  - In one clinic, vaccination is given to any patient requesting it.
8. Provision of accelerated hepatitis B vaccination schedule to babies born to hepatitis B positive mothers within Wales
STATUS: Information gathering and audit complete

Project co-ordinated by Research Team, ICDS

Aims/Overview:
Perinatal transmission of HBV is a significant risk for the infant of an infected mother; with babies infected at birth or soon after having a 90% risk of chronic carriage. Early identification of hepatitis B positive mothers through antenatal screening, and provision of protection through the timely delivery of passive and active immunisation can significantly reduce the risk of infection to the baby.

Aims to provide:
- An examination of the current process by which these babies are identified and notified to the NPHS co-ordinator for follow up in the 3 regions
- An audit on the delivery and completeness of hepatitis B vaccination schedules for babies delivered throughout Wales for 2002/3
- Recommendations for strengthening links with related health care personnel.

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<tr>
<td><strong>8.1</strong> Systems for the identification and follow up of babies born to hepatitis B mothers are in place in the South East Region area and Dyfed Powys. Until recently these systems were not in place in other regions however:- As of 2004, North Wales have put in place an effective system of notification thus ensuring the identified NPHS co-ordinator responsible for the follow up of identified babies and their families through Primary Care is undertaken.</td>
<td>Increased identification for at risk babies. Follow-up, vaccination and testing of those identified at-risk babies leading to prevention of chronic HBV carriage in babies born to hepatitis B positive mothers. Increased involvement of other health care disciplines regarding follow up for babies born to HBV positive mothers.</td>
<td>Regular audit of the number of women offered ante-natal screening for hepatitis B and the number uptake. There is still no single identifier which denotes a blood sample as being antenatal thus making the process of accessing this data time consuming and cumbersome. It is intended that a project board be established to take this forward.</td>
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<td>8.2</td>
<td>Uptake of serology tests within the Cardiff area was low over the audited period of 2002/3. The principle problem was and remains the lack of easy access to a facility for these young infants to be bled, the only two options being the Paediatric Outpatients Department at University Hospital of Wales and St David’s Hospital.</td>
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<td>There are babies who have not responded to the course of vaccinations or who are unidentified HBV chronic carriers. These individuals will not have access to the appropriate referrals / care pathways and remain a potential source of infection to others.</td>
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<td>Continue to improve uptake of the serology tests in the Cardiff area.</td>
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9. **Primary care services for blood borne viral hepatitis prevention, treatment and care**

**STATUS:** Data collection and analysis complete

Project co-ordinated by Research Team, ICDS

**Aims / Overview**

A questionnaire was designed by the research team, ICDS, to obtain information from GPs across Wales covering three main areas:

- Provision of Hepatitis B vaccination to specific vulnerable groups, awareness of guidelines for dealing with hepatitis C and perceived support for the management / treatment of hepatitis C patients.
- Testing for hepatitis C including pre and post test counselling discussion and referral processes
- Positive patients – referral for treatment, arrangement for range of confirmatory tests, involvement in shared care and information/support available to patients.

The questionnaire was sent to all 512 G.P practices across Wales and a response rate of 45% (n = 230) was achieved.

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<td><strong>9.1</strong></td>
<td>60% of GPs provided Hepatitis B vaccination to babies of positive mums, IDUs and MSMs</td>
<td>GPs are offering hepatitis B vaccination when requested to do so (e.g. babies of hepatitis B positive mothers) but difficulties in vaccine provision continue to exist when high risk groups do not wish to identify themselves to GPs</td>
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<td><strong>9.2</strong></td>
<td>30% GPs state they are actively identifying patients at risk of Hepatitis C with 66% offering Hepatitis C testing. If the test is not offered within the practice referrals are made either to drug service or GUM.</td>
<td>GPs may not be fully aware of the signs / symptoms of hepatitis C and therefore may not consider this as a potential diagnosis / element of differential diagnosis.</td>
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<tr>
<td>9.3</td>
<td>In response to questions regarding which groups are offered testing: 55% of responding GPs reported offering HCV testing to self-reporting ‘ever or current IDUs’; 25% of GPs reported offering test to patients who have had blood transfusions / products or transplants; around 41-48% GPs offered test to partners or children of hepatitis C positive patients and 54% offered the test to patients with abnormal LFTs.</td>
<td>There is a proportion of the population whose needs are not met by primary care.</td>
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| 9.4 | Only 54% GPs offered hepatitis B Vaccination to identified hepatitis C positive patients | The reasons for this unmet need is unclear but may possibly be due to:  
- Lack of communication between services providing hepatitis C test (if not GP) and GP.  
- Lack of awareness of necessity for vaccinating HCV positive patients  
- Reliance on others to undertake hepatitis B vaccination | Raise awareness of standard guidelines for provision of Hepatitis B vaccination to high risk populations.  
Develop and strengthen recording system between GPs and specialist clinics to ensure Hepatitis B vaccination administered to all relevant patients. |
<p>| 9.5 | Only 4.4% have a protocol for pre and post test counselling for HCV testing although 50% state that pre and post test counselling is undertaken. 71% of respondents stated they would like a standardised protocol. | Existing system (or lack thereof) for provision of professional and consistent pre and post test discussion is inadequate. | Produce standard protocol for pre and post test discussion for use with BBV testing. Distribute with appropriate training. |</p>
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<tbody>
<tr>
<td>9.6</td>
<td>Only 32% of GPs involved with shared care. Shared care is undertaken with the following: 9% with GUM; 7% with CDT; 25% with hospital specialist. There were regional variations in the levels of GP involvement with shared care. Levels of shared care with relevant partners is grossly inadequate placing specialist treatment services under stress. Develop and implement increased levels of shared care with CDTs and other relevant voluntary agencies including alcohol services. Explore opportunities for sharing experiences of services who participate in quality shared care.</td>
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<td>9.7</td>
<td>52% of GPs referred positive patients to Gastroenterology department, 22% referred to Hepatologist and 10.6% referred to ID specialist. 26% of GPs had no identified referral pathway. Ensure that GPs aware of clear referral pathway to specialist services.</td>
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<td>9.8</td>
<td>Only 35.4% of GPs stated they had access to information for patients awaiting HCV treatment and only 32% provided support to patients waiting to be treated. Lack of support available to patients diagnosed with hepatitis C potentially compounding damage to liver. GPs reliant on presence of community support. Provide specific information and support structure package to GP practices in order to provide improved service to those with HCV diagnosis. Develop and strengthen appropriate community support services including alcohol services.</td>
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### 10. Secondary and Tertiary service provision for chronic hepatitis C across Wales

**STATUS:** Data collection and analysis complete

Project co-ordinated by Research Team, ICDS

**Aims / Overview:**
Completed questionnaire received from all 11 trust based specialist services. The questionnaire was designed to assess provision of existing specialist treatment and support for hepatitis C positive patients. The following areas were addressed: Staffing structure, referral for first testing, referral for patients already tested positive, treatment and care (first visit), and antiviral treatment. Correspondence is ongoing with specialist services to ascertain efficacy of treatment.

<table>
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<tr>
<th>FINDINGS</th>
<th>IMPLICATIONS</th>
<th>RECOMMENDATIONS</th>
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<tbody>
<tr>
<td><strong>10.1</strong> 10 of the 11 services have Gastroenterologist as Clinical Lead. Six of the 11 services have clinical nurse specialist – hours varying from 0.6 to 1.5 WTE</td>
<td>Paucity of service provision. Considerable unmet need No identified budget making demand management impossible</td>
<td>To quantify unmet need and identify resources required to implement NICE guidance in full</td>
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<td><strong>10.2</strong> 1240 chronic HCV patients currently being monitored or treated by services across Wales, however in 2005 only 67 patients received treatment according to NICE guidelines</td>
<td></td>
<td>Standardise data collection and develop a register to monitor achieving compliance with NICE and outcome of patient care</td>
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<td><strong>10.3</strong> Five of 11 services operate a database</td>
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<tr>
<td><strong>10.4</strong></td>
<td>No identified budget for management of hepatitis C in any of the services</td>
<td>Establish dedicated budget based on HCV modelling of populations in Wales to ensure NICE guidance is implemented.</td>
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<td><strong>10.5</strong></td>
<td>Referral to specialist services received from GPs, GUM, CDTs, Prisons, inpatients and Welsh Blood Service. However, only 3 specialist clinics have established criteria for referral and only one has produced a proforma for referral.</td>
<td>To expand the referral protocols across Wales</td>
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<td><strong>10.6</strong></td>
<td>Waiting times to be seen by a specialist vary from 2 months to one year.</td>
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<td><strong>10.7</strong></td>
<td>Interim support for those waiting for treatment is only provided in 4 of the 11 services. The range of interim support services highlighted included HCV related information, emotional, financial, employment and housing support, alcohol services and detox treatment. Current interim support services are inadequate to provide the appropriate care, advice and ongoing support to patients diagnosed with chronic hepatitis C either before during or after treatment.</td>
<td>Develop the patient care pathway to ensure that resources are targeted appropriately with adequate support for community management and delivery of care. Develop network of community and clinical staff to ensure continuity of care and access to appropriate support at all stages from diagnosis to treatment or otherwise</td>
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<tr>
<td><strong>10.8</strong></td>
<td>Only one centre has vaccinations for Hep A &amp; B arranged prior to seeing the specialist</td>
<td>Inadequate system for the provision of vaccinations to those diagnosed with chronic hepatitis C Develop the shared vaccination and system to ensure that appropriate vaccinations are given to patients</td>
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<td>10.9</td>
<td>Nine of 11 centres undertook shared care with GPs, CDTs and GUM clinics</td>
<td>Ensure all centres have shared care</td>
</tr>
<tr>
<td>10.10</td>
<td>Six of 11 centres use NICE guidelines for treatment eligibility criteria. For those patients not eligible for treatment, follow up would occur once or twice a year.</td>
<td>5 centres not using NICE guidelines</td>
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<td>10.11</td>
<td>Average number of visits to determine need for treatment was 4 (ranged between 3 and 8 visits)</td>
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<td>10.12</td>
<td>Currently there are at least 106 patients, identified by tertiary services, who are eligible for treatment now of which 67 (63%) are receiving treatment (13 of these are part of a research project) as per NICE guidelines.</td>
<td>Considerable unmet need. Local Health Boards need to identify resources to implement NICE guidance</td>
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<td>10.13</td>
<td>Waiting times once eligibility for treatment has been established varied from no waiting to 8 months (attributed to lack of funding)</td>
<td>Need to assess demand clinic by clinic and quantify resources required.</td>
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<td>10.14</td>
<td>Cumulatively 255 patients have started treatment, of which 26 or (10%) did not complete the course. Whilst on treatment, patients were seen weekly in six of the centres with the remaining centres seeing their patients monthly.</td>
<td>Inconsistencies in the level of support currently provided by tertiary services across Wales Establish agreed standardised level of support provided by tertiary services for patients with adequate resources to meet demand.</td>
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<td>10.15</td>
<td>Clear lack of community based support for patients undergoing treatment.</td>
<td>Links with the lack of shared care with primary care and other relevant agencies</td>
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