Chronic Hepatitis C – The Patient’s Perspective
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Executive Summary

The Hepatitis C epidemic is already well established in Wales with an estimated 12,000 chronic hepatitis C positive individuals currently living in Wales. This report represents a summary of the findings to date from an on-going survey of those individuals living in Wales who have been diagnosed with chronic hepatitis C.

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. The findings are drawn from the 25 responses received 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
Introduction and Methodology

The National Public Health Service for Wales (NPHS Wales), in collaboration with Welsh Assembly Government, are responsible for development of the ‘Blood Borne Viral Hepatitis Action Plan for Wales’ to address all aspects of hepatitis B and hepatitis C from prevention through to treatment and support for the population in Wales.

A research programme was designed by NPHS Wales to provide a robust evidence base upon which to draw and implement recommendations. In Wales, there are currently an estimated 12,000 (0.4% of the population) individuals with chronic hepatitis C. If left untreated, hepatitis C can cause serious liver disease in some patients, including cirrhosis and liver cancer. Hepatitis C is transmitted through blood-to-blood contact. To date, the majority of hepatitis C infections in the UK have occurred through the sharing of blood-contaminated needles and injecting equipment among injecting drug users. Contaminated blood or blood products through transfusion prior to 1991 accounted for a further 2.5% of reported infections. Other people may have become infected with hepatitis C through non-sterile medical or dental procedures; non-sterile tattooing, body-piercing or other skin-incision procedures; other forms of blood-to-blood contact. There is around a 6% risk of transmission from mother to child before or during birth if the mother has chronic hepatitis C and detectable viraemia.

To date 1240 people infected with chronic hepatitis C have presented to specialist hospital based hepatitis C clinics across Wales for monitoring or treatment. In 2004 – 2005, 67 patients received treatment. In order to establish a base line of current service provision and to further develop and improve services it is vital to gain an understanding of these and community based support services from the patients’ perspective.

A questionnaire was developed by NPHS Wales designed to achieve the following 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 (appendix 1) 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 research study is on-going and to date 25 patients have responded. We would like to thank all of the respondents and to encourage further participation in order that existing services may be improved upon, and further services developed.

**Findings**

**Sample Characteristics**
Average age = 41.3 years with a range of 28 – 60 years  
Female = 40%, Male = 60%

**Hepatitis B vaccination provision**
Only 40% of respondents had been offered and received hepatitis B vaccination. However, only a half had completed the full course.

**Average age of diagnosis**
Average age = 34 with a range of 17 – 57 years

**Method of infection with hepatitis C**
Previous injecting drug use including the sharing of needles or sharing injecting paraphernalia was the main route of transmission and accounted for 80% of infections, blood transfusions prior to 1991 were cited by 8% of respondents, with the remaining 12% unsure how they became infected with hepatitis C.

**Pre and post test discussion**
Pre and post test discussion represents an important element in the screening process and should be undertaken at every testing event by a trained individual. Within this patient group only 32% stated they had received pre-test discussion on the implications of the blood test. Following testing only 56% of patients stated they received post test discussion. Less than half (48%) of patients undergoing testing stated that they understood what the test result meant. This may have serious negative implications for the patients who receive a positive diagnosis.

**Support networks**
The majority of patients discussed their diagnosis with family, friends and drug support workers (if they were in contact with an agency). 92% had advised the GP of their status.

**Referral to specialist treatment services**
Three quarters (76%) were referred to a specialist treatment centre. The average waiting time from diagnosis to first appointment with a specialist nurse or consultant was between 3 – 4 months but ranged from less than one month to over two years.

**Treatment**
48% had or were currently receiving combination therapy.
Professional and specialist support and advice
None of the respondents had been referred to a dietician or received information regarding changes to diet apart from information gained via the internet. Those who were in contact with substance misuse agencies gained support and advice through drug and alcohol groups established within the agencies. The main sources of information were leaflets, the internet and the specialist nurses based in treatment centres.

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

In what ways and to what degree has hepatitis C impacted on your life?
A number of keys areas were highlighted including health, social circumstances, family relations, employment, lifestyle and psychological well-being. Undergoing treatment had a strong impact on health with fatigue and depression highlighted consistently by the respondents. In addition, employment issues were of particular concern as a number of respondents indicated that they did not wish to advise their employer of their health status due to potential stigma and could not ask for time off work to undergo treatment.

The following comments were made with regard to the impact of hepatitis C:

“ I am always aware that I have hepatitis C especially around the children in my family … I have started looking for employment and feel that if I disclose I have hepatitis C they might not employ me. This is very daunting even down to my personal life – who do I tell? Hep C has totally turned my life upside down and it can get depressing”

“My dentist struck me off a month after I told him I was positive, he also struck my children off”

“My life is amazing now. I cleared the virus and god do I know it. I am no longer tired, my quality of life has improved 100%”

“The diagnosis has given me the motivation to give up alcohol in order to receive treatment”

“Most difficult factors were the impact on family life – partner and child considerations and worries. Treatment was lonely and long lasting… felt so exhausted, support at the out-of-town hospital was not actually that useful-l
needed community based support, from people who know about drug use, not just people who know about medical issues’’

“Considerations around sexual contact with partner... and future children – will they have hep C? Issues of management of condition in protecting other family members / colleagues / general public. Disclosure issues with medical or dental interventions. Restriction of choices within my career. Living with a disease – ‘time-bomb’. Life insurance issues. Family contexts – to disclose or not”

“Stopped drinking totally – lead a celibate lifestyle – eat as healthily as money allows. Psychologically I have just accepted the inevitable consequences, e.g. no children of my own, limitations in life style and much shorter life expectancy”

“The worst impact is when you have to tell someone... had to go to hospital and when I told the nurse I have hep C her attitude towards me totally changed. That happens quite a lot but for a nurse to take that attitude really shocked me”

“Haven’t taken time off work whilst on treatment as I don’t want my manager to know. I’m aware of how judgemental people can be and how misinformed. I also spent years worrying that I may have given it to my children. Even GPs seem poorly informed”

“It drains all my forces – I just want to rest and sleep”

“Initially hep C had little physical impact but became very debilitating with nausea, headaches, arthralgia, exhaustion. Being a one parent family to 5 children the impact was devastating”

“The virus is like an energy zapper. It drains me mentally and physically. My worst fear is the depression, when this comes on it can overwhelm me”
Appendix 1 – Patient Needs Assessment Questionnaire

Please only complete this form once.

Section 1 - Demographic Details

1. Your location (name of Town or City): .........................
2. Age: -------
3. Gender: male female
4. Race / ethnicity
   - White Welsh
   - White British
   - White Irish
   - White Other
   - Mixed
   - Indian
   - Pakistani
   - Bangladeshi
   - Other Asian
   - Black British
   - Black Caribbean
   - Black African
   - Black Other
   - Chinese
   - Other

5. What type of housing do you currently live in?

<table>
<thead>
<tr>
<th>Type of housing</th>
<th>Please tick if applies to you</th>
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<tbody>
<tr>
<td>Owner occupier</td>
<td></td>
</tr>
<tr>
<td>Rent from private landlord</td>
<td></td>
</tr>
<tr>
<td>Rent from housing association</td>
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<tr>
<td>Rent from council</td>
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<tr>
<td>Hostel/B and B</td>
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</tr>
<tr>
<td>Live with family</td>
<td></td>
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<tr>
<td>Live with friends</td>
<td></td>
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<tr>
<td>Homeless / NFA</td>
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### Hepatitis B

6. Have you had any vaccinations for Hepatitis B
   - Yes
   - No

If No – have you been offered vaccinations
   - Yes
   - No
   (Please then go to question 10)

7. If yes. How many have you had?
   - One
   - Two
   - Three
   - Four

8. Where did you receive the vaccinations?

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<tr>
<td>G.P</td>
<td></td>
</tr>
<tr>
<td>Specialist Nurse</td>
<td></td>
</tr>
<tr>
<td>G.U.M</td>
<td></td>
</tr>
<tr>
<td>OTHER e.g. Prison, drug service (Please specify)</td>
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</tbody>
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### Hepatitis C

9. When were you diagnosed with chronic hepatitis C? Year: ******

10. Where were you diagnosed? .....................................................

11. How do you believe you contracted Hepatitis C?

   ........................................................................................................
   ........................................................................................................
   ........................................................................................................
   ........................................................................................................
   ........................................................................................................
   ........................................................................................................
   ........................................................................................................

12. Did you receive discussion and support BEFORE you were tested?
   - Yes
   - No

13. Did you receive discussion and support AFTER you were tested?
   - Yes
   - No

14. If yes, who gave you this support?

<table>
<thead>
<tr>
<th>GP</th>
<th>GUM clinic</th>
<th>Drug worker</th>
<th>Other?</th>
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Authors: Josie Smith, Marion Lyons
15. Did you feel that you understood what the test result meant?  
Yes  No

16. Who have you discussed the result with?  

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<tr>
<th>Family</th>
<th>Friends</th>
<th>GUM clinic</th>
<th>GP</th>
<th>Drug worker</th>
<th>Other?</th>
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17. Is your G.P aware of your hepatitis C status  Yes  No

18. Were you referred for an appointment to a specialist nurse/doctor or hepatitis clinic by whoever organised your test and gave you the result?  
Yes  No

19. If an appointment was made for you, did you attend?  Yes  No

20. If no, please explain the reasons why not?  

21. Did any support or health care workers offer to attend the appointment with you? – if yes, please specify.  

22. If you saw a specialist nurse or consultant – how long did you have to wait before you saw her/him?  

<table>
<thead>
<tr>
<th>Didn’t see a specialist nurse or consultant</th>
<th>Less than two weeks</th>
<th>Two week to a month</th>
<th>One to two months</th>
<th>Two to six months</th>
<th>Six months to a year</th>
<th>A year to eighteen months</th>
<th>eighteen months to two years</th>
<th>Over two years</th>
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23. When did you first attend a specialist clinic?  Month/Year  …………../……

24. How many times have you been to the specialist clinic?  ………………. times
25. Since you have received your test result what other kinds of support have you been given, what other professional or support workers have you been able to see? (including alcohol/drug support services, dietitians, etc?)

26. Have you been given advice on lifestyle changes e.g. diet and reducing alcohol consumption, getting Hep B vaccination, to reduce the impact of hepatitis C? If yes – who gave you the advice/guidance?

27. Have you received any treatment for hepatitis C? (this can be called combination therapy)

   Yes          No

28. Were you aware that there are hepatitis support groups?

   Yes          No

29. If yes, how did you find out about them?

30. Have you seen much information e.g. leaflets, posters, on Hepatitis C? What did you think of it? Who gave it to you / where did you find it?
31. Please describe how you feel about your experiences from initial diagnosis to present day including the treatment and care that you have received so far. What do you think should be improved? What do you feel has been useful and helpful?

32. If there was one thing that could be put in place to improve the service, what would it be?

33. Please describe in what ways and to what degree Hepatitis C has impacted on your life? This may include your health, social circumstances, family, employment, lifestyle and psychological well being.

THANK YOU VERY MUCH FOR YOUR TIME