National HCV Patient Satisfaction Survey

2015

Key results
Hepatitis Scotland are very grateful for the hard work and time given up by the volunteer peer researchers, the logistical and personnel support from Waverley Care, including access to their volunteers, and the generous support from MCN coordinators and HCV treatment staff.
Executive summary

One of the key focuses of Outcome 3 of the 2015-2020 update to the Scottish Government’s Sexual Health and Blood-borne Virus Framework (SHBBV) is ensuring that people affected by blood borne viruses can access the best treatment and care. It highlights that in Scotland anyone who needs care and/or support Hepatitis C (HCV) should also be able to access it without financial barriers. Although Scotland has been recognised worldwide as a key leader in developing a systematic countrywide approach to tackling viral hepatitis, there is still a way to go in ensuring easy access to treatment and care for all those who need it.

Over the life of the Framework many people have been cured of their infection. This is partly due to the increase in infrastructure driven by the Scottish Government’s response to viral hepatitis but also by the work of those at the frontline of treatment and care.

A key factor in the success of the national response to viral hepatitis has been measurement, whether that be in monitoring an increase in numbers accessing treatment, numbers of those tested or establishing national indicators of treatment success. This national patient satisfaction survey of treatment services therefore examines this key aspect of the patient pathway.

The survey was completed by 115 patients from across 6 Managed Care Network areas that contain approximately 80% of the known prevalence of HCV. The surveys were administered in treatment settings by trained peer researchers and staff.

There was a high overall level of satisfaction with treatment staff (Figure 3) and care across the healthcare districts, and also potentially a demonstration that there was often a partnership between clinicians, professionals, patients and carers (Figures 8 to 10) to develop understanding of a person’s condition, thereby making informed decisions about the right treatment and care:

- **Nurses are always offering help and support and tell me I can call them anytime. They have also helped me deal with other issues not related to Hep C.**
- **The team first class here. Always approachable and contactable. The Doctor is calm and measured without being patronising.**
- **... were extremely helpful and understood the issues I faced. They waited for my mental health to improve before starting treatment. No pressure was put on me to start. They were very patient**
- **Drug worker offered me testing from day 1. I kept putting it off until I felt ready. It was good they kept offering it. You have to get it done.**
- **Thank God my GP kept persisting for me to get a test done. Liver at quite advanced disease stage.**

Satisfaction with location of the clinics can also support the development of outreach services.

- **Arbroath clinic very convenient. Dundee a bit more of a hassle. Happy for the outreach clinic**
- **Travel to appointments with buses can prove difficult for some. Especially when having 2 get 2 buses and judging the times.**
- **Choose to get a taxi as otherwise would be on a bus for over an hour. 2 or 3 buses to get here.**
Within the small number of people who expressed some disappointment with their treatment it was often with services related to treatment delivery, such as testing in primary care, reception staff and transport or the physical location of clinics as above.

- Car parking can be a problem.
- GP knew nothing about Hep C. Was told it wasn’t curable by one of the nurses. Took a month to have first appointment at clinic to get the right info. If (newly) diagnosed people should be left with information to take away with them. This should be improved.
- Reception staff sometimes asks questions that there is no need for them to ask. I also feel it is not private and other patients can hear what I’m saying.
- Very disappointed by my GP. He told me he didn’t know very much about hep c. They didn’t refer me or anything. My outreach worker who I told about my diagnosis got me to this liver clinic. All the info since has been great.

There were also issues with potential disclosure of status such as being seen at a clinic then meaning others knew they had HCV. This was both in specialist, mixed and outreach clinics in other services and would be difficult to resolve as some patients were in favour of these approaches as well.

- The waiting area, if you know people from drug services, you know they have Hep C. Doesn’t feel confidential when you come from the drugs world.
- Like the fact it’s a mixed clinic. Don’t know why people are here. People don’t assume you are an ex addict
- People know the hep nurses. If they call you through other people know you have Hep C.

**Engagement in care**

Whilst referral to hospital HCV care should be considered for all people diagnosed with hepatitis C, it is important to recognise that many people have other pressing issues that may need to be addressed to enhance numbers engaging with clinical HCV services. With the knowledge that many patients attending services for Hepatitis C have additional complex need it is important to support people differently in their initial engagement with services and subsequently throughout their treatment and care pathway. Tayside MCN developed a testing and referral pathway that “encourages a collaborative approach between health and social care professionals, for example by allowing for non-medical referrals from groups such as drug workers, prison nurses, midwives, social workers and homeless workers”. This has demonstrated a significant increase\(^1\) in access to treatment services.

Engagement in care can also be enhanced by patient “activation”. Identifying people who could benefit from additional support in making positive choices in regards to their life and health can be challenging. Although certain groups of patients are at far higher risk of ill health there is often considerable variation within these groups. Therefore even when interventions are targeted at a specific group of patients, a proportion will not benefit – either because they will not engage with the information they are given, or because they lack the skills and motivation to do so.

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Patient Activation Measures (PAM)\(^2\) can be used to reduce health inequalities and improve outcomes, quality care and lower costs. PAM measures an individual's knowledge, skill, and confidence for self-management and can be a predictor of health outcomes

- People who are more activated are significantly more likely to attend appointments
- Patients who are less activated are significantly less likely to prepare questions for a medical visit, know about treatment guidelines or be persistent in clarifying advice
- People with the lowest levels of activation may be less likely to engage and less capable of doing so, meaning that they do not benefit from health support interventions. Tailoring interventions to this group to raise their levels of activation can improve access, support engagement and, most importantly, provide long-term improvements in health behaviours.

**Recommendations**

With the very good overall satisfaction with treatment services recommendations are therefore aimed at enhancing access to the services for those currently outside treatment pathways.

1. With the high numbers of those patients surveyed noting they felt involved in decisions regarding their care (Figure 8) it would be useful to measure patient activation on a wider scale amongst those referred to, but not attending clinics.
2. Consideration of different approaches to enhance GP knowledge and practice e.g. professional awareness raising, development of packs/information sheets for people with a new diagnosis (these could be automatically generated by a computer algorithm whenever a positive result is sent electronically)
3. Benchmark local care pathways against identified best practice examples of patient engagement

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Policy Context
The project was aimed at adjudging patient satisfaction with HCV treatment services in a cross section of viral hepatitis MCN areas across Scotland. It is based on the commitment in the Sexual Health and Blood Borne Framework (SHBBV) 2011-2015 for the Scottish Government to examine options for regular surveys to determine public satisfaction with sexual health and blood borne virus related services in Scotland. Hepatitis Scotland took this forward in relation to satisfaction with Hepatitis C treatment services.

Methodology
The aim was to carry out the surveys in treatment settings, drawing on patients currently undergoing care in treatment services. The targeted Managed Care Network districts were based on a recruiting a mix of urban, urban/rural and rural areas so as to cover as wide a range of patient experience as possible within the confines of a limited survey workforce resource.

The location of patient interviews were decided after negotiation with local coordinators/treatment staff regarding access to clinics that had a range of patients (Figure 2) and timings and were undertaken from late March to August, 2015. Patients were recruited at clinics on the day by treatment staff who gave all clinic attendees an overview of the survey and the option of taking part. An information sheet was given to, and consent forms were signed by, all participants. A voucher was also given to all who then completed the survey.

The survey was administered by trained peer researchers, Waverley Care staff and Hepatitis Scotland’s Patient Involvement Officer in one to one interviews by way of a short electronic survey on a tablet device. All peer researchers took part in initial two day training workshops.

The questionnaire was developed from two validated surveys, the Whittall St Sexual Health Services Patient Satisfaction Survey and the Scottish Health and Care Experience Survey. The survey and patient recruitment process was also informed by previous correspondence with West of Scotland Research Ethics which indicated that a survey did not require ethical approval if:

- It is an opinion survey seeking the views of patients on treatment options and delivery
- Recruitment is invitational and responses to the questionnaire fully anonymous so that the respondent’s identity is fully protected
- It will not be possible to identify the individual from any direct quotation used in the reporting of the project.
Survey results

- 115 surveys completed across the 6 MCN areas.

![Figure 1: Total Number of Responses](image1)

- Ethnicity was approximately in line with national prevalence figures.

![Figure 2: Self Identified Ethnicity](image2)
• Overall satisfaction with treatment services was high.

![Figure 3: Overall Rating of Service](image)

• Most patients felt their needs were met when booking treatment appointments.

![Figure 4: Were your needs taken into account when booking this appointment](image)
- Those with the furthest to travel generally felt their needs were met when booking appointments.

\[\text{Figure 5: Time to travel to appointment and Needs taken into account}\]

- Most patients felt reception staff were polite and approachable, with a small number having had negative experiences.

\[\text{Figure 6: Were reception staff polite}\]
• Reception area confidentiality was highlighted as an issue in all types of clinics. At the same time all clinics also received many positive ratings.

![Figure 7: Was the Reception Area Confidential](image)

• Patients felt engaged in their care and decisions about it. About a third were accompanied when attending clinic.  (Fig 8,9,10)

![Figure 8: Did you feel involved in decisions made about your care?](image)
Figure 9: Did you have someone accompany you to your appointment?

Figure 10: Are you leaving today’s appointment knowing what will happen next in your care?
• Patients see talking to someone who has also been affected by HCV as beneficial

![Figure 11: Have you ever had the opportunity to speak to someone else living with Hepatitis C?](chart1)

• Patients were initially tested in a wide range of services

![Figure 12: Where were you tested?](chart2)
Just under 40% requested a test for HCV, rather than being offered. This may indicate raised awareness on the illness risks amongst those affected.