

## Characteristics of an ideal Hepatitis C service - summary paper

### Introduction

This paper outlines the process undertaken in engaging with key stakeholder groups to determine the characteristics of an ideal Hepatitis C service. Siobhan Fahey (SF), the Greater Manchester Programme lead for Hepatitis C and Julie Cunningham (JC), commissioning manager within the Commissioning Business Service (CBS) and project lead for the service redesign group led this piece of work.

The outputs from the stakeholder meetings are described within this paper and will be used as a key part of a business case being proposed to the Process for Investment and Reform (PIR) group in February 2010. The characteristics of the service will be used to support the preferred model of delivery.

### Background

The Greater Manchester Hepatitis C strategy was published in August 2006. The strategy focused on four main areas:

- Improving prevention
- Improving services around testing
- Improving treatment services
- Improving surveillance

A health needs assessment was undertaken by a sub group of the Greater Manchester Hepatitis C Strategy Group. One of the main findings of the needs assessment was that estimates of prevalence of hepatitis C in Greater Manchester was in the region of 20,000 cases. One of the key factors accounting for this high prevalence is the high numbers of injecting drug users. The report also concluded that the numbers of patients who were receiving treatment or who had received treatment was relatively low, concluding that only a small proportion of those infected were coming into contact with treatment services.

In response to this, the CBS were commissioned to project manage the Service Redesign group, in February 2009, specifically focusing on improving the testing and treatment elements of the pathway.

### How we progressed

All sessions followed the same format. The aim was to get an unbiased and open view from the various stakeholder groups. At each meeting we asked the same four questions:

- What are the overarching characteristics of an ideal hepatitis C service?
- What are the characteristics of an ideal testing service?
- What are the characteristics of an ideal treatment service?
- What are the characteristics of an ideal post treatment service?

We had a mixture of dedicated meetings that we specifically organised for this purpose and meetings that were already established to which we requested to be on the agenda. Where possible we provided refreshments and hospitality. We ensured that there was always someone sponsoring or chairing the meeting so that we could focus on facilitating the group work. We asked the groups to do their own writing, electing a scribe and spokes person to feed back to the main group. We deliberately kept our input to a minimum only interjecting if clarification was needed. We acted as timekeepers to ensure that equal time was given to each section and that the meeting finished on time. Where appropriate we asked additional questions for some groups depending on their specialty (this is described in the table below). The comments were captured on flip charts and typed up and circulated back to the group for them to confirm that we had correctly captured what was discussed.

Comments from the stakeholder groups were reviewed by JC and SF. During this process we aggregated the comments and removed any duplication. We also noted any comments that we felt to be outside of the scope of the project. These are listed below:

- Stigma attached to diagnosis
- National screening programme
- More training for alcohol and drug services
- Research on post treatment
- Official acknowledgement re time off work due to the effects of treatment
- Expert Patient Programme for Hepatitis C
- Raising awareness in colleges and universities
- Harm reduction (safer injecting)
- Getting help with travel insurance
- Support when applying for a visa for family members
- People with Hepatitis C from other areas in the UK

## Challenges

One of the major challenges in conducting the events was time. It took a great deal of effort to arrange the events and to support the facilitation and organisation both before and following each event. Another key challenge was managing the expectations of those attending. We made it clear to the groups that their input to describing the elements of an ideal hepatitis C services was part of a bigger process and that the project steering group would be undertaking a vigorous evaluation process to determine the most appropriate model of care that would both provide best outcomes for patients and best value for money.

## Next steps

The service redesign group will use the comments from the stakeholder groups to support the development of the preferred model of delivery. The group will propose a series of different models which will then be evaluated. The preferred model will form the basis of the business case. By engaging with the various stakeholder groups, the service redesign group have captured a wide range of views and will represent them in the preferred model.

## Conclusion

This paper is a record of the process of engagement we went through with the various stakeholder groups, giving them opportunity to comment on what they thought were they key characteristics of an ideal Hepatitis C service in relation to the various parts of the pathway. It outlines the key stages and discussion that have taken place regarding the development of the characteristics of a Hepatitis C service. There has been a considerable amount of time and effort put into discussing Hepatitis C services and in ensuring widespread stakeholder engagement across the local health economy.

## List of Stakeholder events

Event /date/ venue	Details
<p>World Hepatitis C day <b>19<sup>th</sup> May 2009</b> Town Hall (5 hours)</p>	<p>Attendance: <b>70</b> registered for this event.</p> <p>Facilitated by the Hepatitis C Strategy group.</p> <p>Mainly health care professionals for the inside event. There was a manned a stall with details of the service redesign group. There were a variety of people from Community Drug Teams, drugs and alcohol services and patients and their carers.</p> <p>Questionnaires were distributed on the day, giving people the opportunity to comment on service redesign at a later date if they wished.</p> <p>There was also a public event outside in Albert Square where there was a marquee, band, Real radio, freebies. Ex- patients, patients in treatment, carers, support workers and general members of the public attended</p>

<p>Support group <b>28<sup>th</sup> May 2009</b> Friends meeting House, Manchester (2 hours)</p>	<p>Attendance: approx <b>30</b></p> <p>Chaired by Carl Curphey Supported by Steve Miles</p> <p>Julie Cunningham presented the work of the service redesign group, requested input into the characteristics of service. The main concerns were around support during treatment and access to benefits and information. Martin Peacock from C- Level (Scotland) was also at the meeting. He presented details of his organization and the services they provide.</p>
<p>Stakeholder day <b>12<sup>th</sup> June-</b> Innovation Forum (4.5 hours)</p>	<p>Attendance <b>16</b></p> <p>This group was mainly service providers from statutory and non statutory organisations. There was one commissioner and two ex- patients. During the afternoon there was group work and discussions around the 4 key questions</p> <p>Facilitated by Julie and Siobhan</p>
<p>Patient user groups <b>27<sup>th</sup> July-</b> Friends meeting house (4 hours)</p>	<p>Attendance <b>29</b></p> <p>The meeting was very well attended with group members willing to share their views on what they would want to see from a Hep C service.</p> <p>Sponsored by Steve Miles Facilitated by Julie and Siobhan</p>
<p>BME patient stakeholder group <b>19<sup>th</sup> August-</b> Sangam Restaurant Rusholme (3 hours)</p>	<p>Attendance <b>12</b></p> <p>The meeting was specifically commissioned to target patients and family members from the Asian community. Shabana Begum kindly provided a translation service for us.</p> <p>Facilitated by Julie and Siobhan</p>
<p>Nurses Group <b>21<sup>st</sup> August,</b> Dermatology</p>	<p>Attendance <b>5</b></p>

<p>meeting room, Central Manchester NHS FT (3 hours)</p>	<p>Although this group was small in number it represented the core of expertise from the Hep C nursing community in Greater Manchester. In addition to the key questions we asked the nurses group to outline the characteristics of managing a Hep C clinic.</p> <p>Chaired by Esther Pears Facilitated by Julie and Siobhan</p>
<p>Prisons group <b>2<sup>nd</sup> September</b>- Sentinel House, Eccles (2 hours)</p>	<p>Attendance <b>10</b></p> <p>This group is an established sub group of the Hep C strategy focusing on developing a Prisons strategy. We requested a dedicated meeting to focus on the characteristics of an ideal Hep C service in a prison environment.</p> <p>Chaired by Dr Erika Duffell Facilitated by Julie and Siobhan</p>
<p>Consultants meeting <b>7<sup>th</sup> September</b> – Surgical Seminar room, Central Manchester NHS FT (2 hours)</p>	<p>Attendance <b>5</b></p> <p>This group was specifically arranged in order to get treating clinicians together to discuss the ideal characteristics. In particular we asked the clinicians to consider the core elements of an assessment service and where it should sit on the patient's pathway. We also discussed the possibility of this group becoming the core of a managed clinical network to oversee future developments within Hep C treatment beyond the scope of the strategy. In the short term they agreed to be the expert clinical reference group to oversee guidance and support during the development of the business case.</p> <p>Chaired by Dr Martin Prince Facilitated by Julie and Siobhan</p>
<p>Microbiology Network Advisory Group <b>18<sup>th</sup> September</b>- One Central Park, Newton Heath</p>	<p>Attendance <b>30</b></p> <p>This group is an established group comprising all laboratory leads from trusts across GM. We requested a slot on the</p>

	<p>agenda to discuss the proposed new testing algorithms. We also gave an update re the HCV strategy and acknowledged the labs input into the baseline review.</p> <p>Testing algorithms still in development – awaiting final version to be completed by Dr Klapper. Will be instrumental in ensuring that commissioners are able to quality assure the service.</p> <p>NAG meeting chaired by Dr Burman Discussion facilitated by Julie and Siobhan</p>
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This next section summarises the comments from the stakeholder events

**The overarching characteristics of an ideal Hepatitis C service**

- Accessible
- Multi Agency
- Multi Disciplinary
- Clear pathway with multiple entry points
- Chronic Disease Model
- Achieve 18 week target
- Evidence Based
- Sustainable
- Managed Clinical Network
- Workforce development
- Conforms to Patient Charter  
Race Equity Act  
PPI Law
- Support services.
- Safe
- Effective
- Cost-effective
- Innovative

- Patient Centered
- Culturally sensitive
- Good retention of workforce

### **Characteristics of an ideal prison hepatitis C service**

- Increased prevention, testing and treatment within prisons.
- Fits in with prison regime
- Equal to non-prison services
- Hepatitis C virus expert group in each prison
- Whole prison approach
- Evidence based
- Improved interface across prisons and from community to prison and prison to community.

### **Characteristics of an ideal Hepatitis C testing service**

- Trained testers
- Clear pathway
- Accurate
- Timely
- Reduction in duplication
- Screen at risk population
- Rapid referral on for positive results
- Discussion to accompany test
- Agreed process for testing, including:
  - pre and post test discussion
  - referral onward
  - info for patients in appropriate language
- Results available to treating centre
- Offer test to family members
- Use negative result as opportunity for Harm Reduction Advice

### **Characteristics of an ideal Hepatitis C testing service for prisons**

- Every prisoner should be tested unless they “opt out”
- Offer during initial screening
- Prisons should have specific performance indicators
- Use health trainers
- Ensure dried blood spot testing is available

### **Characteristics of an ideal Hepatitis C assessment service**

- Does not increase number of patient steps from diagnosis to treatment
- Assessment by supervised trained Clinical Nurse Specialist
- First referral to a treatment centre
- All patients to receive agreed assessment
- Referral onwards if specialist treatment plan needed
- Specialist treatment centre to accept original tests
- Agreed procedure for DNAs
- Patient tracking function
- Clear pathway
- Referral criteria
- Agreed procedure for “Watchful waiting” if treatment not yet appropriate

### **Characteristics of an ideal Hepatitis C treatment service**

- Experienced senior clinician
- Full time nurse
- Adequate administrative support
- Standardised clinician-nurse-patient ratios according to National and local guidelines
- Hepatitis C to be coded separately
- Access to non-invasive fibrosis assessment
- Rapid availability of blood results for treatment monitoring
- Workforce education and training at all levels
- Accessible treatment
- Treatment available from GPs
- Good access to translation services
- No waiting list
- Career pathway for nurses
- After hours nurse-led telephone support for patients on treatment
- Dedicated treatment team

### **Characteristics of an ideal Hepatitis C treatment service for prisons**

- Full time treatment nurse
- Sufficient administrative support
- Consultant clinic in each prison every 6 – 8 weeks
- Value for money

## **Characteristics of an ideal Hepatitis C post treatment service**

### Chronic Hepatitis C team

- Tracks patients including those leaving prison
- Uses database
- Multi Disciplinary Team approach
- Specific remit
- Clear pathway

### Advanced Liver Disease Patients

- Refer back to local provider
- Local referrer able to manage/refer complications

### Unsuccessful treatment

- Followed up by treatment centre
- Access to new treatments when available

### Patient at risk of re-infection

- Refer to appropriate agency for support

## **Characteristics of an ideal Hepatitis C post treatment service for prisons**

- Adequate referral onwards - post prison
- Signposting including drug and alcohol, peer support services.

### **Characteristics of an ideal Hepatitis C support service**

- Support
- Information
- Signposting
- Help for carers
- Expert Patient Programme
- Resource Centre
- Online Support
- Advertise Hepatitis C Trust Helpline
- Complementary therapies
- Advocacy
- Counselling
- Not based in a drugs agency
- Advice on benefits, housing, nutrition, work, college
- Psychological support
- Family support
- Buddying
- Home visits
- One – to – one support
- Peer support group
- Organised activities – e.g. exercise, speakers
- Expert-led / peer-led group
- Positive approach
- Offers testing
- Practical help that supports the patient throughout treatment.
- Patient champions
- Prison based
- Separate group for Asian people
- Access to interpreters

- halal food
- Travel expenses
- Namaz (prayer place)
- Childcare
- Asian worker friendly
- Local, e.g. Longsight or Ashton Town
- Men and women separate 6 – 8 pm