

**Evaluation of the GG&C NHS Board pilot hepatitis C  
community outreach clinic**

**Final report**

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## INTRODUCTION

Injecting drug use is the most common risk factor for hepatitis C (HCV) infection, with transmission associated with injecting with infected injecting equipment. In Scotland, of the 23,261 individuals who had been diagnosed with HCV to the end of September 2007, 59% were known to have ever injected drugs<sup>1</sup>. It is estimated that a further 20-30,000 people are infected but are unaware of their condition<sup>2</sup>.

There is currently no vaccine for HCV. Anti viral treatment is available and it's efficacy has improved<sup>3</sup>. Clearance rates of 50%-60% are reported<sup>2</sup>. It is therefore important that those infected have access to treatment. Anti-viral treatment is not always considered appropriate but patients can still benefit from ongoing monitoring, advice about lifestyle changes or living well with HCV, and hepatitis B and hepatitis A vaccination. Only 20% of those estimated to be chronically infected with hepatitis C in Scotland have accessed specialist treatment services and, of these, only 20% had received anti-viral treatment<sup>2</sup>.

More than a two-fifths (n=9503, 41%) of diagnosed cases reside in Glasgow and, of these, 6063 (64%) are known to have injected drugs. Anecdotally, approximately 60% of diagnosed patients referred to Glasgow hospitals for hepatitis C treatment assessment do not attend their first appointment, much higher than the national figure of 12% for non-attendance at outpatient clinics<sup>4</sup>. Many patients do not attend for further appointments.

The reasons why patients do not attend hospital appointments is complex. Hospital non-attendance in general is associated with male sex, youth, and deprivation<sup>4</sup>, factors that describe the injecting drug use HCV population in Glasgow. Length of waiting time has also been linked with non- attendance<sup>4</sup>. The distance that IDUs have to travel to access tertiary treatment centres may also be a factor. A previous study of IDUs in Glasgow has shown a correlation between needle/syringes sharing and distance from needle exchange suggesting that IDUs are unwilling to travel far for harm reduction services<sup>5</sup>. In addition, IDUs can have ongoing drug and social problems which may prevent them attending hospital appointments.

To address the high rate of attrition in Glasgow, Greater Glasgow and Clyde NHS Board set up The Hepatitis C Community Outreach Pilot Service to meet the needs of the clients of Glasgow Addiction Services. Clinical Nurse Specialists were employed to provide integrated services to clients with addiction problems who had been identified as being HCV positive. The service was to provide a link between the hospital treatment centres in Glasgow and the Community Addiction Services.

The aims of the service were to:

- Provide support, information and advice to HCV infected individuals accessing addiction services
- Improve the referral process
- Increase access to treatment
- Reduce the default rate amongst those that are referred for treatment
- Establish and maintain effective links between the Community Addiction Teams (CATs), tertiary treatment centres, voluntary sector, primary care and other addiction services.

Greater Glasgow and Clyde NHS Board also commissioned an independent evaluation of the service. This report is an account of that evaluation.

## **SERVICE SET UP**

Four Community Addiction Teams (CATs) were chosen to take part in the pilot service- the South (Gorbals), South East (Castlemilk), North East (Easterhouse) and the West (Drumchapel).

The CATs provide an integrated model of care for clients, with health and social care staff working together. This multi-skilled team offers a wide range of services for clients with addiction problems.

Three Community Rehabilitation units linked to these CATs were also chosen to take part in the pilot service: South East Alternatives, servicing the South and South East CATs; New Horizon, servicing the North East CAT; and Momentum, servicing the West CAT.

Three Clinical Nurse Specialists (CNS) were employed to provide specialist input and assessment for treatment. The CNS were based in the hospital setting and provided a minimum of two outreach settings at each of the four CATs on a weekly basis. The rest of their time was spent delivering treatment and care in the acute setting.

Two of the CAT nurse staff from each team were identified and were given training to be able to carry out blood borne virus (BBV) testing on clients as required. The CAT nurses were to provide a testing service to those clients who did not know their HCV status. If a client was found to be positive the nurse would then refer the client to the CNS for assessment. The CAT nurses were also to be a point of contact for referrals and booking appointments for the CNS's sessions.

All of the CAT and Community Rehabilitation staff received training on hepatitis C from C-Level. C-level is a non-statutory hepatitis C service providing peer education to those at risk of or infected with HCV and also awareness raising to staff working with such individuals through education and training. The aim of the training was to provide social care/key worker staff with sufficient knowledge so that they could provide their clients with appropriate information and education about the hepatitis C virus. Social care/key

workers were to discuss with their clients the implication of testing being offered and establish if the client was ready to be tested prior to a referral being made.

All clients attending the CAT or Community Rehabilitation services were eligible for referral to the Hepatitis C Outreach pilot. A client could be referred to the outreach service for two reasons:

1. to obtain a test for HCV and other BBVs
2. to be assessed for treatment for hepatitis C

Prior to seeing their first patients the CNS took time to establish links and relationships with CAT and Community Rehabilitation staff. This involved attending team meetings, talking to individual workers when the opportunity arose, sitting in on meetings between workers and clients. This process continued during the term of the pilot and eventually extended to GPs and other workers involved in Shared Care clinics.

In May 2006, the first clients were referred to the outreach service.

Before turning to the evaluation of the pilot, it is important to note that several unforeseen factors had an impact on the implementation and running of the service. These are noted below.

#### **Accommodation issues**

- At the start of the project there was no office accommodation for the CNS. When a place was identified it needed to be rewired, shelved and furnished. There were long delays in obtaining all the equipment ordered.
- There was a delay in starting in the West CAT due to refurbishment of treatment rooms. Clinics did not start until August 2006.
- There were problems finding a room for a second session at the North East CAT. The second session started in February 2007 and was held in Easterhouse Health Centre.

### **Staffing issues**

- Key addiction staff involved in the project changed jobs or went on long-term sickness absence. Additionally there was a re-structure within Glasgow Addiction Services that meant that many of the CAT managers were moved or took on additional responsibilities.
- There were difficulties with appointing administrative support for the CNS. There were two rounds of interviews with no suitable candidates prior to an appointment.

### **Paper work and referral process issues**

- Initially the CNS were advised by medical records to use temporary case notes to record activity with patients and to merge this with a permanent case note in preparation for an appointment with a consultant. It was thought this would make it easier to function across the different hospital sites. Notes were merged when a decision was made as to which hospital the patient would attend. This never worked as case notes were rarely merged and it caused confusion having two versions.
- CNS' access to the Addiction Services' database, PIMS, was restricted in the first part of the pilot. Training for the PIMS database did not take place until March 2007 and there were problems with gaining access for a few weeks after that. This resulted in huge backlogs of data to be entered once access was established.
- Outreach Database. The design of this database occurred after the project had started and there were a number of changes made to it throughout the pilot phase. This meant that CNS had to go back and add more information to entries already in the database.

## **THE EVALUATION**

### **Aim**

The overall aim of the evaluation was to provide information on whether community outreach is an acceptable model of service delivery and to make recommendations on any wider implementation.

### **Objectives**

To determine:

- What components of the outreach clinic were most valued by clients
- How the outreach clinic impacted on the outcome of people living with hepatitis C
- The characteristics of clients who were most likely to make use of the service
- The referral routes
- The influence that the community specialist nurses had on other addiction staff's confidence and competence in dealing with hepatitis C issues
- The range of support offered to clients and the uptake of this support
- If input from the community specialist nurse affected clients' ability to cope with hepatitis C
- If clients are more receptive to onward referrals to other addiction services e.g. alcohol services
- What proportion of patients attending the service were referred for treatment
- If the default rate for those referred from the community outreach clinic was improved
- The impact on tertiary services
- The numbers seen by nurses, numbers of new infections, numbers who were aware of their diagnosis but not currently seeking treatment or care for their condition.

### **Method**

There were three strands to the evaluation: monitoring data, staff perspectives and service user perspectives.

### ***Monitoring data***

The original proposal envisaged that the PIMS database would be accessed to determine how many clients were referred to the service during the pilot and to describe their demographic characteristics, drop-out rates, numbers of HCV tests and diagnoses, numbers of onward referrals and types of services referred to, numbers of HCV positive clients referred to and retained in (joint) tertiary treatment. However the problems encountered by the CNS in accessing this database at the beginning of the pilot led to the development by the research team of an independent database to capture the essential data. The final analysis was based on a merged file of both databases.

### ***Staff Perspective***

A cohort of various members of staff was interviewed about their perceptions of the service and their role within it. The first round of staff interviews took place between May and July 2006 and consisted of three Clinical Nurse Specialists (CNS), eight Community Addiction Team (CAT) social care workers, three Community Addiction Nurses (CAN) and four Community Rehabilitation workers. Apart from one social care worker and one CAN, all were re-interviewed in June 2007; the social care worker was unwilling to take part and the CAN was unavailable for interview.

A third round of interviews was planned for October 2007. By this time it was clear that community rehabilitation projects had not been involved in the pilot service to the extent that this had first been envisaged. For this reason, community rehabilitation staff were not invited for interviews for this third round. While all CAT staff who had participated in the first round of interviews were invited for a third interview, fewer took part than before: two social care workers and one CAN. All three CNS took part. As with the second round of interviews, staff were invited by telephone to participate but many calls were not returned. Several staff commented that non-participation was because of staff shortages and low morale.



All staff were interviewed at their main workplace: CNS at Gartnavel Hospital, others at the addiction team offices or drug project premises. All interviews were conducted in private office space, were tape recorded and lasted between 20 and 45 minutes.

The CAT Managers for each of the 4 pilot sites for the Outreach Service were contacted prior to the start of evaluation to help identify participants. Each CAT manager provided a list of the nursing staff involved in the project and a list of all the social care staff working within the team. They each suggested a number of staff that would be available to be interviewed for the evaluation. The researcher contacted the CAT nursing staff involved in the outreach service to arrange a room to conduct interviews in each area. On the day of the first interviews, social care staff were selected for interview on a random basis depending on what team members were in the office at that time and were willing to take part. One CAT Nurse and two social care staff were interviewed from each of the 4 pilot centres.

All of the managers of the community rehabilitation projects were contacted to arrange interviews. Two of the community rehabilitation managers provided the researcher with a date and time for interviewing their staff. On the arranged interview days the researcher was provided with two staff for interview. These staff were selected on the basis of who was available at the time and willing to take part.

One community rehabilitation project did not provide any workers for interview despite repeated attempts to arrange interviews. At the time they were undergoing a structural change within the organization and had a high turnover of staff.

The researcher contacted the CNS's directly to arrange an interview time with each.

### ***Service user perspective***

A cohort approach was planned to capture clients' views of the service at the outset and then 10-12 months later. Recruitment for the service user interviews started in August 2006. The planned interview format was a semi-structured questionnaire which consisted

of questions including demographic characteristics, their expectations of the service, referral routes, health and social needs, patient satisfaction, previous experience of treatment or support with their diagnosis and how the current service had impacted on their ability to cope with their diagnosis. Ethical approval had been granted from NHS Greater Glasgow Primary Care Ethics Committee on the basis that the researcher would not directly approach clients, but would provide posters and leaflets explaining the study for service users to read and who could then approach the researcher if they were interested in taking part. The researcher would then explain the study to the client and, if the client was willing to take part, obtain consent and contact details for follow up interviews. After almost 3 months of data collection only 7 respondents had been recruited to the study of whom two were hepatitis C antibody negative.

At this point interviewing was stopped and a redesign of the study methods was undertaken. After an ethics resubmission, approval was given for the CNS to explain the study to clients, collect contact details from potential study participants and, with consent, pass these to the researcher. The researcher was not given approval to make a direct approach. This, again, did not yield a high return and only 15 names were collected for follow up.

Once given contact details, potential respondents were telephoned by the researcher to arrange a time and venue for interview. This proved a difficult task. Some clients were not contactable, some did not turn up for interview. By the time this part of the study was cleared by ethics, a large proportion of the time for data collection had elapsed. Only four clients were interviewed for the study. The study design was changed to a case history approach and interviews were tape recorded.

## Results

### Data monitoring

Monitoring of data took place between May 2006, when the outreach service first received client referrals, and 31<sup>st</sup> October 2007.

A total of 328 clients were referred to the service, of whom 218 (66.5%) attended at least once (Table 1).

**Table 1 Number of referrals to outreach clinic**

Number of referrals that attended for an appointment with CNS	218	66.5%
Number of DNA referrals	110	33.5%
<b>Total number of referrals</b>	<b>328</b>	<b>100.0%</b>

The majority of clients who attended were male (n=146/218, 67%). The mean age of all attendees was 36.5 years, ranging from 18-54 years. The main risk factor for hepatitis C infection was injecting drug use (124/218, 56.9%). There was missing information on risk factor for 87 (40%) of attendees.

Almost two thirds of patients attended the outreach clinic one or two times, with a few attending five or more times. The mean number of appointments attended was 2.4 (SD 1.5, range 8) (Table 2). Thirty-nine per cent attended all booked appointments (Table 3).

**Table 2. Number of appointments attended by clients (n=218)**

<b>Number of appointments attended</b>	<b>Number of clients</b>	<b>% of clients</b>
1 Appointment	69	31.6
2 Appointments	71	32.5
3 Appointments	30	13.8
4 Appointments	20	9.2
5 + Appointments	23	10.6
Missing information	5	2.3
<b>Total</b>	<b>218</b>	<b>100.0</b>

**Table 3. Attendance rates (n=218)**

<b>Attendance rates</b>	<b>Number of clients</b>	<b>% of clients</b>
Attended all booked appointments	85	39.0
Initially attended but DNA on subsequent appointments	133	61.0
<b>Total</b>	<b>218</b>	<b>100.0</b>

Table 4 shows that similar proportions of clients were seen at the North East , South and West CAT teams, with a smaller proportion attending at the South East CAT.

**Table 4. CAT source of attendees (N=218)**

<b>CAT site</b>	<b>No of clients attended</b>	<b>% of clients attended</b>
North East	58	26.6
South	64	29.4
South East	24	11.0
West	72	33.0
<b>Total</b>	<b>218</b>	<b>100.0</b>

The majority (n=130, 59.6%) of clients for whom there was information on referral source were referred to the service by CAT teams, with a fifth (n=46, 21.1%) referred by Shared Care. Only one person was referred by a Community Rehabilitation project.

**Table 5. Referral source of attendees (N= 218)**

<b>Referral source</b>	<b>No of clients</b>	<b>% of clients</b>
CAT	130	59.6
Shared Care	46	21.1
Community Rehab	1	0.5
Missing information	41	18.8
<b>Total</b>	<b>218</b>	<b>100.0</b>

A total of 122 HCV test results were available at the end of the data collection period.

The reasons for the discrepancy in the number of test results and the number of those who attended include: clients not returning to be tested, clients not being ready to be tested, test results not being entered on to the database. Of the test results, 56 (46%) were new tests and 66 (54%) were confirmation tests (Table 6).

**Table 6. Number and type of HCV tests (n=122)**

Type of test	Number of tests	%
New test	56	46.0
Confirmatory test	66	54.0
<b>Total</b>	<b>122</b>	<b>100.0</b>

Just over half of those tested (n=63, 51.6%) were currently infected with the hepatitis C virus. Just over a third (n=43, 35.3%) had never been infected (Table 7).

**Table 7. HCV test results (n=122)**

Result	Number of clients	% of clients
HCV AB-ve PCR-ve	43	35.3
HCV AB+ve PCR-ve	16	13.1
HCV AB+ve PCR+ve	63	51.6
<b>Total tests</b>	<b>122</b>	<b>100.0</b>

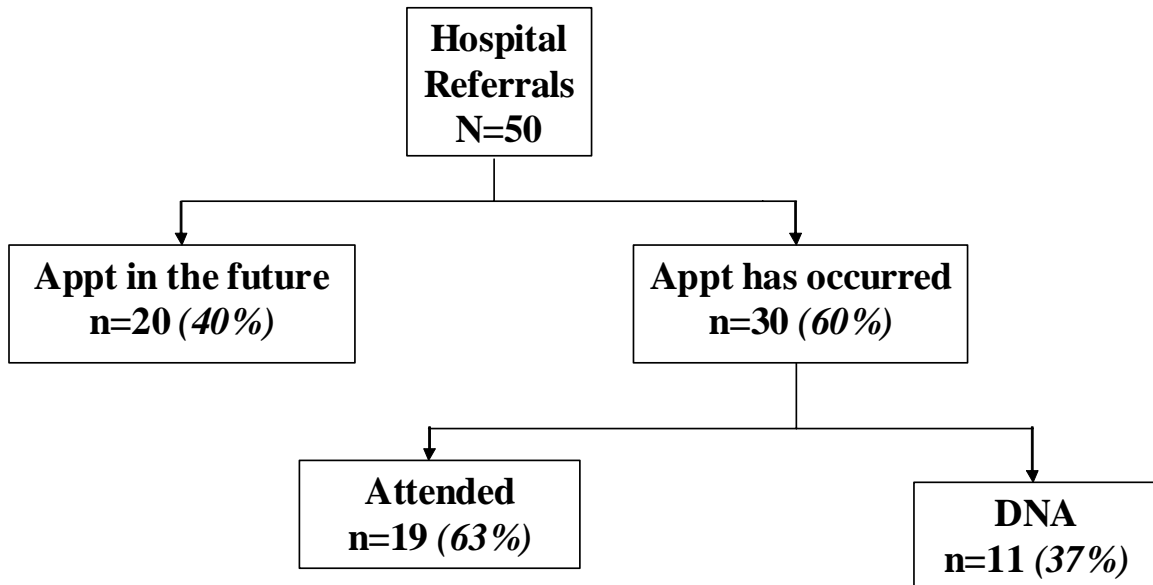
Table 8 shows the breakdown of hepatitis C tests by CAT source. North East CAT was largest source of tests (n=49, 40.2%). However, all clients at the North East CAT were screened for blood borne viruses when being assessed for substitution therapy for drug use. This included drug users who did not inject. This accounts for the larger number of tests and also the high proportion (46.5%, 20/43 of all tests and 41%, 20/49 of North East CAT tested clients who had never been infected with the hepatitis C virus.

**Table 8. HCV test results by source of referral**

CAT site	HCV AB-ve PCR-ve (%)	HCV AB+ve PCR-ve (%)	HCV AB+ve, PCR+ve (%)	Total HCV tests (%)
North East	20 (46.5)	6 (37.5)	23 (36.5)	49 (40.2)
South	7 (16.3)	5 (31.3)	17 (27.0)	29 (23.8)
South East	5 (11.6)	2 (12.5)	12 (19.0)	19 (15.5)
West	11 (25.6)	3 (18.7)	11(17.5)	25 (20.5)
<b>Total</b>	<b>43 (100.0)</b>	<b>16 (100.0)</b>	<b>63 (100.0)</b>	<b>122 (100.0)</b>

Fifty clients had been referred for tertiary assessment and treatment. Figure 1 shows the status of these clients. Just over a third of those who had received a hospital appointment (11/30, 37%) had failed to attend. One client had been commenced on drug therapy treatment. Six clients who were deemed suitable for referral had refused to be referred.

**Figure 1. Hospital referrals (n=50)**



## **Staff Interviews**

### **Aim of interviews**

The main aim of the staff interviews was to elicit staff expectations of the pilot service and to assess how these changed over time. In addition, addiction and social care staff were asked about the impact the service had on their workload and if their confidence in dealing with hepatitis C issues had increased as a result of the pilot. CNSs were also interviewed about their workload outwith seeing clients at clinic appointments.

Below is a breakdown of the types and number of staff interviewed and of when the interviews took place (Table 9).

**Table 9. Types of numbers and staff interviewed**

	1 <sup>st</sup> round (May-Aug 2006)	2 <sup>nd</sup> round (June 2007)	3 <sup>rd</sup> round (Oct 2007)
Community Nurse Specialists	3	3	3
Community Addiction Team Nurses	3	3	1
CAT Social Care Workers	8	7	2
Community RehabWorkers	4	4	0

## **Results**

The results of staff interviews are presented in four sections. The first describes staff perceptions of the usefulness of the outreach service for clients. The second describes their perceptions of the process of developing and establishing the service. The third describes the CNSs workload. Lastly, staff provide some views for improving the service.

### ***1. Usefulness of service to clients***

#### **Referring clients**

At the first interview, there were mixed views about the service. The CNS, in particular, were extremely enthusiastic about the new service.

*“My expectations are that we get as many people as possible with hepatitis C diagnosed and into treatment.” (1<sup>st</sup> round interview).*

CAT and other addiction workers, whilst acknowledging the need for such a service, were more sceptical about what it could and should achieve. Some staff pointed to statistical grounds for service need and some perceived it more generally as another service that they could offer clients. Few discussed ‘service need’ in terms of client demand. CAT staff reported that hepatitis was a priority for few of their clients, few clients talked about it and staff seemed reluctant to raise the topic:

*“They know about Hepatitis C. ‘I’ve got Hep C I will deal with that in 20 years when it is bothering me.’ and again where do you stand, what is your role when somebody says, ‘I am Hep C positive. I don’t want to deal with it’? It is their choice. They are adults. ... Some people are quite happy to live in ignorance. Do we burst their bubble or do we not? So there is that kind of professional mental conflict goes on with myself and I would imagine it would go on with the others.” (1st round interview).*

*“I am not sure whether you should leave it up to them to ask or whether you should kind of impose it on them. To be honest, some of the questionnaires that are going around I don’t know whether they are quite intrusive or not. They are asking quite bluntly ‘are you*



*hep C positive?’ Somebody might not want to share that. So I have not made up my mind on that one.” (1st round interview).*

*“What I expect from [CAT staff] is that they refer people that are appropriate and yes that they are thinking about the project and that they are approaching their clients about that. At the moment I wouldn’t say that that is happening but I think that is because we are very much at the early stages and we are still doing all the PR work and going out and visiting them a lot to try and make sure they know about the service.” (1st round interview).*

By the second interview, some staff described a more systematic approach, perhaps as part of an assessment or as a routine aspect of care management.

*“It has got to the stage now for working practice you have got a new person through the door and you are filling out the paper and you say to them ‘well we have got a hep C clinic running, an alcohol clinic, sexual health.’ That is actually getting put to them as soon as they come in through the door, so they know the services and what’s available.” (2<sup>nd</sup> round interview).*

Other teams engaged clients with the service in an apparently ad-hoc manner or continued to rely on client enquiries to trigger discussion of it.

*“Well it might come up. We do a lot of health groups and it could come up in that or again one to one with the key worker and that. It is client driven. It is the client raising it, the client raising it rather than you going to people and saying just want to speak to you about this particular thing. Yeah, we’ve not actually got it in an application form we have not got it ‘do you have a blood borne virus’ sort of thing or whatever, it is not standard procedure to investigate that.” (2<sup>nd</sup> round interview).*

### Timing of referral

Some care workers, who were on the whole still sceptical about the outreach service by the time of the second interviews, questioned the appropriateness and timing of discussing hepatitis with drug users. They suggested that the service did not fit a wider holistic model of care delivery.

*“There seems to be this drive, ‘let’s get people into this pilot scheme because we need to be looking good, because whatever, because it is a pilot scheme’. You need to tread carefully with people, you are working with people that, their confidence and their self esteem is shattered you know, as I have already said probably 100 times, they are leading chaotic lifestyles. To then bring them in here and bring them in a room just as we are sitting in and go ‘right OK Hep C is this and that, it’s a virus and we can cure it and blah, blah and do you want tested?’... I can understand why the Scottish Executive or whoever wants to do that because they don’t want the stuff to keep on spreading at the rate that it is but at the same time if you provide that sort of service, in my opinion people are not going to engage with it.” (1st round interview).*

*“So if somebody’s not ready or whatever, I’ll support that and I’ll take the time and I will respect their feelings and I will try and give them information and I will try and encourage and persuade them and support them towards looking at hep C but that doesn’t mean they have to get a test.....So...if that takes three, four, five months, then at the end of it they do go for a test then you’ve won. Instead of barging in and saying ‘you’re going to get tested.’” (2<sup>nd</sup> round interview).*

*The only paperwork I know about the hep C pilot is a blue referral form and it feels as if you filled out the referral form and then...you know, everything just speeds past you. It should be a case of ‘let’s discuss the client first’, ‘so what’s happening?’, ‘why are you referring him in?’. Do you know what I mean? So getting a sort of background and ‘OK, well we’ll give him an appointment and you can come in as well and we’ll sit down, the three of us’, not going about it like ‘this is the test and this is what we’re going to do’. Just let’s explore what is happening.” (2<sup>nd</sup> round interview).*

In contrast, CAT nurses and CNS were inclined to see the outreach service as a central part of a holistic or person-centred approach and a particular strength of the service. Several made the point that any contact with a drug user was a valuable opportunity to improve their knowledge of hepatitis C risk and methods to reduce its impact. CNS were confident that the information and support that they gave to clients dispelled myths and allayed their fears.

*“I think the majority of them are quite relieved. I think they think that they have got this Hepatitis C and there are so many rumours going about it, you know that it is the silent killer, it kills you within five years. There are so many things going on and then, you know when you actually sit down with them and explain that it is actually quite a slow progressing thing, that there is treatment for it, you can visibly see them relaxing and you know, feeling not quite so anxious about it.”* (1st round interview).

‘Client readiness’ emerged as a key issue in CAN and CAT staff decisions on whether and when to discuss the outreach service with clients. Staff assessments of the client’s lifestyle, stability, drug use and likely reactions to a potentially positive test result were frequently stated as reasons that the service would be unsuitable at a given time. In this regard, some interview data imply that staff fears about client relapse in the face of a positive hepatitis C test may be as important as any fear expressed by clients. When staff described factors that acted as barriers to clients’ decisions to engage with the service, they emphasised fear of disease impacts and stigma.

*“They have maybe got a fear in the back of their mind that their world would collapse round about them if they get told this news. They are kind of maybe just avoiding it as such because they are maybe on a roll with their recovery and their rehabilitation and they are just staying away from that because they might think it may set them back a bit.”* (1st round interview).

There was no change in these findings across the three phases of staff interviews.

### **Ideal type of client**

Some staff participants expressed the view that since drug use was a high-risk behaviour for hepatitis C, all drug users should be targeted by the outreach service. However, the overwhelming view amongst interviewed staff was that clients who were personally stable and no longer using drugs were the ideal type of client to target for the outreach service.

*“Anybody they think has got hepatitis or been in contact they should go and get tested.”*  
(1st round interview).

*“Clients who are maybe starting to get their lives together, maybe starting to take an interest in their health.”* (2nd round interview).

*“I just don’t see the point in going anywhere near people that are chaotic, you know? I just don’t see the point.”* (2nd round interview).

Despite the emphasis on client stability as a factor in establishing their suitability for referral, there was no apparent agreement on just how ‘stable’ a client had to be to be considered suitable for either testing or treatment.

Interviewer: *“when they are talking about ‘appropriate’, what type of client are they talking about?”*

CAT staff interviewee: *“People who are stable with their drug use, with their injecting. And also people who are going to start detoxing off their methadone.”* (1st round interview).

*“She has been drug free for about 6 months and she is beginning to get her life together again and she has just got a part time job so I think she will need a bit more time to continue with that stability before we start hitting her with treatment. I am pretty confident that she will come to an appointment to see the consultant here and even if she*

*gets repeat bloods and an ultra sound scan done and then it gets into the system and I think you know, that's good and who knows, in a years time it might be that she is ready for it."* (1st round interview).

Staff reported wide variation in client reactions to positive diagnoses. At the extremes some were said to be startled into addressing drug and health issues whilst others were said to become reckless in their despair.

*"If it's somebody who's stable and then maybe making the decision to get tested for the wrong reasons, you could put them back to square one."* (2<sup>nd</sup> round interview).

### **Value of service**

In the first round of interviews, several staff noted that the drug users engaging with the service already knew about their positive hepatitis C status. The general perception amongst staff at all levels was that the service had low value because few new diagnoses were being made and those without prior knowledge of their status were still avoiding the service. Their emphasis on these aspects of measurement regards the findings of the pilot evaluation may help explain their feelings of disappointment in the impact of the service. However, their feelings may be misplaced because the service was not conceived to discover new diagnoses but rather its aims were to provide a service to diagnosed individuals who were not currently seeking treatment, care or support. This being so, there appears to have been a disparity between the aims of the service as envisioned by the implementation/ steering group and those delivering the service.

By the second round, staff gave a strong impression that they conceived the service as something that they could offer to clients and the reasons and process of pre-test and post-test counselling appeared to be well understood. Several participants, however, pointed out that it remained the case that few, if any, clients were being tested for the first time.

Others emphasised the positive impacts that could be achieved by pre- and post-test discussion. For example, some clients had been told years before that they had hepatitis C but had been given no further information. For these people the service had provided a positive impact.

*“It’s kind of enlightened a lot of clients and they’re a lot more upbeat on dealing with things and the fact that it can be dealt with so proactively.” (2<sup>nd</sup> round interview)*

### **Range of support for clients**

No drug user had begun clinical treatment for hepatitis C at the time of the second interviews in June 2007. Reasons given for this were that it was difficult to take blood samples from injecting drug users and so more appointments were required to complete assessments; fewer hepatitis C diagnoses were made than expected; prison or other factors including chaotic lifestyles disrupted the treatment journey; because of the complex paperwork and process required to refer into tertiary care it was taking longer than expected to get clients to the liver assessment stage. CNS were positive about the potential for education to reduce further infections and about dietary and lifestyle changes that could benefit patients, particularly those on waiting lists. They also acknowledged that drug users might think less positively about the potential benefits of waiting lists..

*“I will try and encourage and persuade them and support them towards looking at hep C but that doesn’t mean they have to get a test. You know? Even if they’re aware about what’s happening and not passing it onto anybody else, that sort of thing. That’s a start.” (2nd round interview).*

*“Some of the clients that are coming through aren’t appropriate, but a lot of them are just needing advice so ... it is reassuring them, giving them advice about diet, alcohol you know.” (1st round interview).*

*“I don’t think there’s been anybody who has actually started on treatment yet, but that’s purely because when they get told ‘yes, you’re going onto treatment waiting list’ they’re*

*put onto the waiting list, you know, like any other client, I don't think we should be pushing to get them through any faster..... But I don't think that's a bad thing, actually having to wait for your treatment, because it gives you a bit more time to get your head around what...you know, it gives you time to prepare yourself, make sure that your addiction issues are as stable as they can be, you need that bit of time to really work at that and to work at you know being in the best place, and being as stable as you can be in treatment.” (2nd round interview).*

CNS pointed out that because of the advice they had given, clients were more knowledgeable about hepatitis C and enjoyed more acceptance at home.

*“Although the numbers haven't been very good, it is really the quality and also the effect that that has had not only on the client but on the clients' families as well. Just them having more information even helps them as they interact with their partners and other family.” (3rd round interview).*

### **Confidentiality and data recording**

CAT staff expressed concerns about client confidentiality in the service. This was particularly acute in the first round of interviews but less often mentioned in the second round. Unfavourable comparisons were made with other services where clients could be anonymously tested for hepatitis C and staff said that, for this reason, they advised some clients to use alternative anonymous testing services.

*“I personally would not refer any of my clients to it for testing because it has come back now in terms of confidentiality that the GP would be notified. And I think that is quite scary for some people particularly if they are very, very stable.” (1<sup>st</sup> round interview).*

They also voiced concerns about confidentiality at reception desks and in the handling of referral paperwork. Busy services, insufficient or unsuitable private accommodation and linked clinics presented risks for breached of confidentiality.

Between first and second interview, the issue of recording and sharing information about hepatitis C testing appeared to have become less intense. Differences between addictions care staff and nursing staff in terms of their professional training and experience may have been the basis of some animosity but it appeared that a shift in perspective had been achieved with CAT staff inclining towards the requirements of established medical procedures.

### **Location of service**

There was some discussion about the appropriate location of the outreach service. Some suggested that for former drug users, especially those using rehabilitation services, the CAT was not a suitable venue. To have a blood test, community rehabilitation clients would need to go to CAT premises (it was assumed without the support of their rehabilitation key worker) and there confront a scene dominated by current drug users. Some felt that community health services would be more appropriate as they were both local and open to all.

*“Clients who are in the community rehab they don’t want to go to the CAT to have bloods taken because that is seen as a backward step you know, they are getting their life together to go there and there is a bit of stigma attached to it.”* (1st round interview).

Staff participants widely agreed that CATs were probably not the best location for a hepatitis C outreach service and Shared Care clinics were proposed as sensible alternatives.

*“One of the consultants said to me that he always felt that the GP study that they’re doing now, looking at former injectors, he feels that that will be more successful because they’re the clients, the patients that will come through with addiction issues behind them and they will be ready for treatment, rather than looking for people who still have addiction issues.”* (2nd round interview).



CNS and CAT staff described introducing the outreach service to GPs and Shared Care Clinics and, although CNS initially met resistance from some GPs, they were especially keen to foster these relationships by providing pre-test and post-test discussion.

*“The shared care clinics are being targeted just now. And hopefully we will get more uptake of people coming from these clinics. Because I think the patients that we are seeing just now [via CATs] unless you are getting somebody who has been in treatment for a long time the rest are still pretty chaotic. So I think the shared care clinics are going to be our big intake.” (1st round interview).*

*“The best thing I have ever done is going out with every single member of the shared care, the social care workers, to their clinic either in the building or out at GPs surgeries. Talking to the GPs and just sitting in with them on their territory, their clients, their setting where they are in control. That is their baby and that has paid off in the last weeks because now they are coming to me.” (3rd round interview).*

In common with other drug treatment services, often clients did not keep appointments with the outreach service. By the second round of interviews, to address the problem of non-attendance, some CATs were trying to organise hepatitis C outreach appointments to coincide with clients' methadone clinic attendance.

*“They turn up for their methadone scripts very reliably and if we are there in the background or if I am there in the background at a methadone clinic and the worker ‘would they like to see me?’ often the answer is ‘yes’. So it is a very good opportunity to get that first engagement with somebody and start to break down barriers.” (2nd round interview).*

At other CATs, the scheduling of methadone clinics meant that there was no available physical space or staff time to provide bolt-on services in this way. Furthermore, staff in a range of posts commented that such bolt-on services were manipulative or unethical.

*“I think there are some issues around having a methadone prescription and saying ‘I’ll see you before you get your methadone prescription’ because it is a bit manipulative.”* (2nd round interview).

## **2. Process of service implementation: staff perceptions**

### **The referral routes**

At first interview, none of the CAT social care staff participants said they were confident in the referral process for the outreach service. By the second round of interviews all interviewed staff were aware of the service although some seemed less certain than others about the particulars of referral processes. Staff were aware that only a small number of clients had been referred into the service and reported both client dissatisfaction and their own frustrations with the flow of information about those they had referred. By the third round it was clear that the referral systems in operation were adaptations on the original design with variations between CATs.

### **Set up**

Staff described considerable delays in setting up the service and establishing data recording and communications systems. Pre-implementation planning was frequently criticised by those interviewed and CNS staff explained that this was the reason for slow progress with service delivery. Before the pilot service could be launched, CNS had to produce protocols, negotiate time and space for the outreach service separately with each CAT and design and repeatedly redesign referral and data recording documents.

*“All the protocols and the pathway that we had to use, we did not realise that we would have to be doing [design for] them ourselves. And we didn’t have a lot of guidance... We do things in the wards all the time and we have protocols in place but because this is brand new we thought that all of those things would have been in place and they weren’t.”* (1st round interview).

Staff participants explained that service development had taken longer than planned also because key individuals held sole responsibility for influencing or implementing change.

Unfilled posts, changes of staff, staff holidays, illness and prioritisation of other issues could thus significantly delay service planning or implementation.

### **Training**

At first interview, when the outreach service had just begun, staff pointed out that it had been in the region of six months since their training. Many said they had forgotten much of what they learned either because they had found the content too intense, the pace too fast, material inadequate or because they had no opportunities to put it into practice since the training.

*“The hep C training we did, 6 months ago, maybe longer, I think they also added a bit in about this new service.”* (1st round interview).

*“I have been trained on it. We got somebody, I think it was one of the C-Level came and told us about the new system being set up and I went along but that is quite vague in my head. I have got a flowchart on it so I could go and check it and then inform the client. I would not know off the top of my head.”* (2nd round interview).

*“Some of the lecturers that came in, there was one doctor in particular and it was just all statistics, you know? I didn’t take anything in in that full session, not a thing. And there were a lot of times there was no back up as in paper. There was nothing written down for us to take away... and I found that very unhelpful.”* (1st round interview).

Several staff participants said they were able to draw on their former experience or professional training and sympathised with colleagues who only had training on hepatitis C specifically in preparation for the new service. In interviews, many CAT staff said that they would like training refreshers or updates. There were also indications that CAT social care and community rehabilitation workers were losing confidence in their abilities so that by the time the service started they were already beginning to relinquish responsibilities to CANs and CNS.

*“I take quite an interest in hepatitis C and HIV. I have done training before and I will look it up now and again to try and keep my mind active with the subject. But I think for someone just coming into the field maybe, a new member of staff, or somebody that has maybe not done previous hep C training, it might not have been enough. Because we got the effects of hepatitis C, how it is transmitted, different genotypes, interferon, it was all a bit too much to take in if you were a new member of staff.” (1st round interview).*

### **Records – data recording, sharing, confidentiality**

CNS perceived that at the beginning of the project there were no clear plans for record keeping or data recording of quantitative data for the pilot study. They felt that as a result, the study’s quantitative analyses would not adequately reflect their work and the outcomes of the outreach service. Practical difficulties and service delays had also occurred because of administrative inconsistencies, use of temporary case notes and failure of coordination between patients’ appointments and records.

*“Sometimes it is a struggle to keep on top of it..... We have our blue referral form that when people are being referred in they fill in top and we write on the back. They have a wee sheet that we use that they clip to the front of that and it lets us know where we saw them, who saw them, all their details, their CHI number, PIM number, Care First, the dates we saw them and we use that to make sure that the letters are done. Outreach entry is done in the database and the PIM entry is done and we put the numbers beside it but unfortunately every time the database is updated the numbers all change and what I really hate is that the database has been changed so many times where there were things that we asked for a way back in the beginning and if it could have been done last year we wouldn’t keep having to take a week off and go back and do all this data entry.” (3rd round interview).*

### **Early uncertainty on responsibility**

At first round interview, most CAT and other addiction staff seemed uncertain as to their specific roles in the outreach service. Many expressed feelings of frustration. There was linkage between staff comments that it was taking a long time to establish the service,

that they lacked ownership or involvement in its design or that plans kept changing or that no one seemed to know what was happening. CAT nursing staff appeared to have some more information but not enough to be confident in carrying out their specified roles. Community rehabilitation and CAT care workers often felt that the service had little to do with them or gave vague answers when asked to describe their duties.

*“It should be ours, it’s not the medical teams.”*

*“I think maybe it’s a bit too much the expectation that the link staff here and other staff in community rehab that are involved would be knowledgeable enough because we were told that the staff here would be quite involved in the pre counselling before the testing kind of thing but a one day training course isn’t really enough and I think that’s what staff including myself feel a bit unsure on.”*

*“I do feel a lot of that could been avoided if there had been more organisation before we’d actually started our jobs and it had taken a lot of time to get the whole organisation of it up and running.”*

*“All we can really do here is make the referral with the form and there was a bit of an issue of how did the blue form get to the CAT team? Should we post it, do they come up for it?”*

*“It has been quite medically orientated so I don’t really feel much a part of it.”* (1st round interview).

### **Early tensions**

Relations between CNS and CATs were, according to CNS, strained or even quite hostile at the beginning of the pilot project. Asked whether the CNS with responsibility for working at one CAT was part of the team there, one participant said, *“Not at all. Not at all”* (1st round interview).

These strained relations may have their origins in other aspects of service provision or inter-disciplinary conflict. Whatever their origins, the following quote which refers to the staff training events, suggests that these were already being played out before the service started.

*“One man wouldn’t even sit and have lunch with us or a cup of tea. He said ‘No if you don’t mind I would prefer not to sit with you.’ (1st round interview).*

Remnants of such strained relations were still apparent as service resistance during the second phase of staff interviews. CAT staff particularly objected that, in their opinion, the service was driven towards processing clients through a programme of testing and treatment without regard for the client-centred approaches already in place.

*“To tell you the truth I wouldn’t refer a client into it. I think its too quick, and its brutal, its clinical, its...there you are. That’s what it is basically and I feel when I try to speak about it its like ‘no, no this is what we’re doing, it’s a fantastic thing, it’s a pilot and we’ve got loads of resources’ and its like ‘stop’ you know, ‘just stop talking the paperwork and just speak to me. You know? And let’s negotiate something here, let’s find out what we can do for the client. You know what I mean? Its not about you and numbers and hep C Pilot’. If that’s the case then I’ll keep my clients well away from it. Because what happens is, ‘come in, sit down, get your blood taken. Right, here’s your treatment options blah, blah, blah’, you know? It’s just like a conveyor belt.” (2nd round interview).*

Development of the outreach service also took place in the context of staff tensions and poor employment relations, said to have been caused by wider structural changes in Glasgow drug treatment provision.

*“It is a time of change within the addictions service and they are still coming to terms with having to work together under the one umbrella of social care and nurses. There is still a lot of friction there.”* (3rd round interview).

*“They were having to apply for their own jobs, and there was a lot of stresses and strains, and they’re asking them to do things and stretch them that they’ve never done before.”* (2nd round interview).

### **Thaw in team relations over time**

CNS appeared as the main players in instigating change and making arrangements for the outreach service. More than other categories of staff, they linked their own professional development to the development of the service and described their struggles to build trust in their relationships with CAT and rehabilitation projects.

*“We have now got a much better idea of how things work and much closer relationships with our colleagues in addictions. We have had more than six months experience in seeing clients through the project since the last interview so I would say we are much more grounded in what we are doing now and we certainly adapted.”* (2nd round interview).

All staff participants were able to identify at least one colleague of whom they could ask clinical questions about hepatitis C or about the operation of the outreach service. The three CNS described their staff team as mutually supportive, meeting often to discuss strategy and progress. CAT staff most often identified a CNS as the colleague that they would approach with questions about hepatitis C or about the organisation of the service. Several participants suggested that these communications had eased relationships.

*“[I can ask] the nurses or the nurse team leaders out there or the CAM (Community Addiction Manager) so I feel that there’s plenty of folk to ask if I’m stuck.”* (2nd round interview).

The quality of individual professional relationships seemed to be key to successful collaboration between CNS, CATs and other drug projects. For example, a given worker might consider referring a client only to a specific individual on an ad-hoc basis rather than liaising with the wider service team. Individual positive experience was thus essential to overcome blockages to service provision in a wider climate of inter-staff-team suspicions. While referrals were made and services provided on the basis of these staff bonds, gaps in provision occurred with any break in routine such as holidays or periods of illness.

*“I haven’t referred anyone for a few months, and just now I’m sitting on two referrals ...The addiction worker wasn’t there on Thursday, so I was a wee bit disappointed on that and it’s something I’m going to be doing this morning. I’m hoping to speak to one of the other addictions team nurses who I’ve had quite good contact with over the last year and who I have made a few referrals to and he’s been happy to come up and get them, but he was off on holiday last week so it was one of the other nurses I spoke to.”* (2nd round interview).

Despite the reservations that many staff had at the start up of the service, by the second interviews, the CNS felt that the service was more known about and accepted by addiction staff.

*“I think the general feel is that this is a good service. I mean at one point I think we felt we had to keep reminding them that the service was there because there was only one person that was referring folk to us and at that point we had to bring it up at the team meeting and say ‘right, this service is here.’ But there has definitely been more of a variety of folk referring in, which is good....it is quite good that other folk are starting to look at their clients and think ‘right, would they be suitable for it?’”* (2<sup>nd</sup> round interview).

### **Service evolves as CNS led**

Although the outreach service was conceived as a joint venture between CNS and CATs, responsibility for setting it up soon fell to the CNS because, as one put it in her first



interview, “*we are employed to do it*”. She said she would have welcomed more input from CAT teams and CAMs in particular but, at the time of first interview, this was not forthcoming. Initially, CNS experienced problems in communicating with CATs and reported having to persuade them of the value of the new hepatitis C service. By third round interviews, many CAT staff said that they had been impressed by CNS dedication to implementing and improving the service.

*“There is always that tension, you know, how much of a lead should be coming from the community addiction, how much should be coming from us and I guess yeah it would be nice, I think it would be nice if it was a higher profile from the community addiction side of things, you know all the CAMs were really up on it. You know really enthusiastic and bring it up at all their team meetings and that is not the case.”* (1st round interview).

*“The only change I see is coming from [CNS]. She is trying her best. She is really putting her heart and soul in to it. Trying to increase numbers, trying to be flexible with the service. Trying to look at, if it is not working, what else can we do? How can we reach these people what do we need to do?”* (3rd round interview).

Several factors appear to have influenced this shift towards CNS taking a dominant role in service delivery.

Particularly in the early stages of service delivery, CAT social care workers reported lacking confidence in their ability to discuss hepatitis C with their clients and mainly preferred to leave this task to CANs or CNS.

*“I take it, it would only happen for me if one of the clients I am key working raises issues about hepatitis C. And I would feel the need, because I have maybe not quite got the expertise or training or we don’t provide that so specific support for people with hepatitis C, I would need to link with another agency....I know at the North East CAT team they have got the hep C nurse in the clinic, so I could refer up there.”* (2<sup>nd</sup> round interview)

Similarly, CANs reported lacking confidence or experience in taking blood samples and CNS were able to cope with the smaller than expected number of clients presenting for counselling or testing.

At least some community rehabilitation and CAT staff resisted the implementation of the service, most often because they had not been consulted about the processes.

*“It seems to be something that the medical team’s doing....They took us down and gave us a couple of days training about hepatitis C and about treatment options, about transmission routes and stuff, different types. That was really good, and that was to sort of get us more informed before your pilot kicked off. And then from there it was just, it was more hearsay than, it was mentioned a couple of times in team meetings but there was no formal like ‘look this is what we’re doing, this is what we plan to do, this is the resources, this has come from the Scottish Exec’ or whatever, you know, ‘this is our aim, this is how we’re going to do it, here’s the information packs’ you know, ‘if you’ve got any problems here’s the designated person you can go to’ you know? There just seems to be no...it seems to be in the nursing team and they’re doing it. And if you can get involved in it, it is a bonus.” (2nd round interview).*

Whilst CNS described very busy schedules, neither CAT care workers nor CANs reported that provision of the outreach service had had any significant impact on their workload. Some thought that their workload on hepatitis C issues might rise if the number of clients using the service rose but few said that they expected this to happen.

#### **Ongoing resentment about service ‘ownership’**

Most staff said that a hepatitis C service was needed but some may have resisted the introduction of the outreach service because they perceived it as essentially external and imposed on them rather than something that was developed and shaped by them.

*“It should be ours. It’s not the medical team’s, do you know what I mean? Its about working together and for that to work its going to take somebody that’s got a bit of authority to take a hold of it and challenge people, you know?” (2nd round interview).*

### **How process could have been improved**

At third interview, CAT staff were asked whether the outreach service could have been better if anything had been done differently. Their responses indicate frustrations about not being consulted at the planning stages and even some resentment at their, by this stage, diminished roles in implementing the service.

*“I think a bit of staff consultation. I think just a bit of, just giving the staff their place, getting us together. We were sent on 2 days’ training, told that the pilot was starting up and to refer people in.....I think ‘aye, put us on training and get staff up to speed with information about hepatitis C but then maybe have a look at how we’re going to go about this...’what do you think? What would be a good way?’ instead of ‘nurses are doing this, this is what you have got to do.’ People are going like that ‘Naw,...I’m not putting my client through that.” (1<sup>st</sup> round interview).*

*“The only thing I would change possibly is perhaps have a named social care member of staff. I don’t know if social care feel that they have been squeezed out of this, but they don’t have ownership of the project because it is all done through the nursing staff. However I hear that there are concerns within the addictions teams about blurring of roles and people’s skills feeling undervalued. And perhaps this should be recognised as a nursing role, a medical role that is in the domain of nurses but we depend very, very much on the social care workers because these are the people who have the most stable clients and I just wonder if they had a voice or a responsibility for the project if it would help, if it would help with our communication to them as well” (3rd round interview).*

### **3. CNS workload**

All three CNS were asked about their workload in addition to clinic appointments with clients.

One of the most time consuming aspect of their post was the amount of paperwork involved.

*“But the amount of paperwork involved...letter to the CAT nurse, letter to the social care worker every time they come, letters to the GP. You know even if they attend or do not attend you have still got to keep them informed. If you do any blood tests you have to send the GP a copy of the letter and their results. If you refer them into the hospital then that is another letter to the consultant you are referring them to. It is a lot.”*

This could be compounded by the lack of accommodation at various clinics.

*“When we go out to a GPs surgery we are much more of a guest and the service is certainly not geared up for us so we can find ourselves without accommodation, We are on the hop, moving about moving all these bits of paper about. We don’t have that referral form that is precious to us to actually physically move through the system. So that is difficult. As I say the room is not obviously ours there can be a lot of interruptions and there can be a lot of moving about and it may be that you are putting the worker out of the room while you do your bit and then you are worried about holding clinics up and that kind of thing. So you then come back to try and process what you have done with limited information. We are now booking all clients onto the hospital system so we need enough information to be able to check if they have attended before, do they have a hospital number. If they move constantly, the chances of the addresses matching are slim. So there can be a delay before we can actually confirm and process information.”*

Additionally, information had to be entered onto a database, which often changed throughout the pilot as new pieces of information were added. This was an unexpected part of their job and did take a good deal of time.

*“We keep having other meetings with the records, medical records people here and they keep changing what we are meant to be doing so that has been frustrating because you*

*keep thinking right we have got it sorted now and then there is another meeting and they say “aw actually we need to do even more work on this and we need even more.” And I can see with the databases you know each time that we have a meeting there is more work you know and we have got to go back through all the clients that we have seen and add things in.”*

One of the aims of the service was to provide support for service attendees. This became a vast task as clients came to see the CNS as supporting them not only with their HCV infection but with other aspects of their lives as well.

*“We have followed this girl up to about a year and a half now and she has stopped smoking heroin, stopped injecting for[ the last few] months. She was referred into the hospital but didn’t make the appointment because while we had been seeing her she felt that her GP was taking more of an interest in her and was taking her health problems seriously and as a result the GP [had discovered another medical problem and was treating this]. She then came back to see me “and this has got nothing to do with ma hep C and I am still no using but I have got [ another health issue] I explained to her that’s not my job but she still insisted. So we phoned the GPs surgery while she was there and got her an urgent appointment for the next day. She was then referred in by the GP and had had all these [tests], During all these appointments her liver appointment came up and she missed it and she had been very upset by this. So I still see her every 2 to 4 weeks depending on what she needs. She is not ready to be seen by the gastro side yet because I don’t think she can cope with much more.”*

*“Again it involved a lot of admin and negotiating with different people and actually taking her to the hospital appointments, going over the results with her and she still phones. In fact quite a few of them they still phone even though we don’t have any direct contact with them and they email. “I have been for my scan, I’ll let you know the result. They keep in touch with us because we are still that kind of wee lifeline. We are not their addiction worker, we are not the hospital we are the ones that kind of mediates things.”*

As will be seen in the section on client interviews, this support was greatly appreciated by clients. However, it also provided job satisfaction for the nurses themselves. One of the CNS described her pleasure in the outcome of one her clients.

*But things that can't be measured in this project that I have got a wee extra bonus, one she has never gone back to injecting. The other good thing about it is her partner always injected, he has now stopped injecting and is smoking and he is now referred himself to the service. So he referred himself. I have then had to go to the CAT worker and say "can you fill in a referral form with all his details, I have seen him." So I am now following him up. But it is things like they are not very good at cooking. So she will come up and she will say "I went and bought this and I don't know what to do with it." And I am like "Make a pot of soup." "But I don't know how." These are things that you can't measure. So all the paperwork, including recipes, count.*

#### **4. Proposals for improvement**

Staff participants had some ideas about how the service could be improved. Some suggested a system with elements - such as involvement of CAT social care workers - that had been part of the original service design.

*"There is absolutely no point in promoting it from a health perspective within a CAT without involving social care because the majority of clients are sitting in Shared Care clinics and that is where we need to target. That is the majority." (3rd round interview).*

Others suggested that the focus on the number of clients that could be reached by the service had been a mistake. By second interview, the low through-put of clients for hospital referral and treatment was discussed frequently and most interpreted this as a sign that the service had failed in some way.

*"I think the main aim at the start was to get numbers, numbers, numbers. Eh I think through the process of time and change I think it has finally come to the realisation that, that hasn't worked." (2<sup>nd</sup> round interview).*

*We haven't got a lot of people tested. We haven't got a lot of people into treatment."*  
(3rd round interview).

Record keeping, data processing and targeting shared care clinics were also mentioned. However, client confidentiality continued to cause particular concern. Staff participants called for solutions so that clients might avoid future negative financial, employment or insurance decisions on the basis of medical records of testing for blood borne viruses.

They also pointed to problems with the evaluation itself.

*"Perhaps the evaluation was too short, too ambitious to measure something truly worthwhile in this period of time."* (2nd round interview).

### **If the service was to continue**

Staff participants noted that, if continued, the outreach service might be extended to cover more CAT teams, work more closely with community rehabilitation teams and include an improved training programme. CNS requested help with records and data recording.

*"It should be rolled back to the CAT teams that are not involved yet, but we couldn't manage that on our own clearly. This is a handful as it is. So that would mean more staff."* (3rd round interview).

*"One of the things that we have neglected: I don't think the rehab centres have had a fair crack at the whip. Then again they know where we are, they know how to phone in and access us but we haven't really given them a lot of attention."* (3rd round interview).

*"Things that we do need to sort out: we need a better training package."* (3rd round interview).

*“What ideally I would love is a data coordinator that can put all the stuff in PIMs, that can do all the stuff from the outreach database and keep that up to date because we struggle.”* (3rd round interview).



## **Client interviews**

### **Aim of interviews**

The interviews aimed to elicit client's views of the service. Interviews were semi-structured and tape recorded. Three case histories are presented below.

### **Case 1**

#### ***Demographic characteristics***

Maureen is aged 45, lives alone and is currently on a methadone prescription. She began injecting 21 years ago, when she was aged 24 years, but had not injected for the past 21 months.

#### ***Previous diagnosis and treatment***

Maureen had been diagnosed with hepatitis C in the early 1990s following a donation of blood.

*I was off drugs for a period of 5 years. I went to give a pint of blood one day. My friend gave a pint of blood every few months. So I thought that's a good idea, I'll do that because I had been tested for HIV, Hep B and been given injections against A and B. So I didn't have hep A or B. I didn't know about hep C at the time, didn't have HIV or AIDS so thought maybe I can give a wee pint of blood. So I went up with my friend to the blood centre on Sauchiehall Street in Glasgow and because I hadn't given blood before they said they would have to screen it. Six weeks went by and a letter came through the door and I still have the letter to this day. It stated that I had been proven to have a blood borne disease.*

Although drug free at that time, the diagnosis had upset her so much that she started using again.

*Well when I found out I had hep C I wasn't on drugs at the time but it didn't take me too long to get back into drugs. I thought 'I am going to die', that's how it was kind of put to me you know? That was it, 'I am going to die'. I'd be as well going without pain you*

*know?....I took a breakdown. I just basically couldn't handle the fact I was away from everything and away from the life that I led to end up with something so serious, you know? I still find it difficult. ..I found it difficult to cope with. I still don't accept that I have got it. Although I do accept it you know, I am still finding it difficult to know that I have it. ....*

*Well I actually went on to binge drinking. I am known as a binge drinker, past tense now. I was known as a binge drinker and that was basically to black out, you know? Went back to drugs a couple of times throughout the years. Just hiding from the whole situation basically. I would move from alcohol, binge on it for a few days then come off it and be ill. And when I took heroin I would go right down hill, I wouldn't look after myself, you know? It was just I was wrapped up in this horrible merry-go-round. I would come off one thing and jump onto another because I could not face everything.*

The blood transfusion service had referred her to hospital.

*They referred me to Gartnavel and they spoke about bringing me in for a liver biopsy just to see how far on I was. The biopsy was normal.*

She had been offered treatment but had declined.

*They wanted me to go on Interferon. Well I had full health at that point and what they were telling me... it was only found out in 1989 as you know and I was diagnosed in 1992..... The nurse I saw was telling me what she knew about it, which I realise now wasn't a lot, you know? I was offered Interferon but now there is Interferon and Ribavarin. At that particular time the Interferon was going to be used 3 times a week and she was telling me basically I could lose my hair, lose weight. I'd be nauseated up to 4, 5 days a week, it wasn't a cure it was just going to prolong my illness and at that particular time I had all my hair and I thought 'no'. It wasn't an immediate no. I went home and it took a few days, maybe even a couple of weeks to decide no I wasn't doing it. And when I went back and told the nurse she was not very happy.,*

### ***Referral to outreach service***

Maureen had been introduced to the CNS by her counsellor, who she saw when she picked up her methadone prescription.

*I was not told about the outreach, I was just basically introduced to [CNS] when I was down for my prescription. I was told she dealt with the liver and I went 'really?' so I kind of latched on to her before she latched on to me because I thought 'I need to get this dealt with. We had a good talk and I told her I had had a biopsy. She asked what they were doing to help me, appointments and stuff, and that time I was getting absolutely no response from doctors, hospitals, nothing. I couldn't find out anything.*

### ***Attendance at outreach***

At the time of interview, she had been attending the outreach clinic for about three months and was fulsome in her praise of what she had received.

*I only met [CNS] about 3 months ago. And I have seen her approximately 6 times. She will phone me, ask me how I am. Right out the blue, you know? Just basically how are you? How are you keeping pet, made any appointments for the hospital. Failing that, if I've not she is the first one to get on top of it. You know to push appointments for me, which is great. As I say I have never had as much demanding for appointments until I met this lady. She has just turned everything round for me, really.*

Currently she was waiting for a biopsy and was prepared to consider treatment.

*The outreach nurse asked me would I consider it now. I says "yes" now I have found out more about it and it is not as bad as it first seemed and it is not as... long a process. I believe now that it's down to one day a week.*

*I have a lot of issues now, one that I am getting older, two that I see side effects, you know, and as I says she asked if I would consider it now and the answer is yes. I would consider it now... as I say I now know what hep C involves and the treatments are not as primitive as I found out years ago. Back in 1992...I think you could maybe understand*

*why I wouldn't accept the treatment then because I was a young woman. I had my strength and I wasn't prepared to lose my hair, not prepared to lose weight.*

*That is why I did find it so easy this time when they asked me to contemplate treatment I said for definite, yeah. Now that I know what is happening and it is not a long drawn out process. If it actually works. If, if, if.....*

### ***Other issues dealt with by service***

Whilst Maureen was waiting for her biopsy, the outreach nurse had also arranged for her to have other health problems dealt with.

*Yeah, she actually called before she went on holiday for 2 weeks ago and just to ask how I was doing and she says have you received the results yet for the MRI scan. So from one thing she has actually got [my other problems] treated and that has all started from this woman...the liver nurse that has done this for me.*

She was full of praise for what the outreach service had and was currently doing for her.

*Everything that she has offered has been positive as in respect of hospital appointments she has pushed for them knowing that I wasn't getting any help from my GP. She is there for me constantly. If I need to speak to somebody about anything she is there. I suffered from depression through this. She is there for me, I have actually just to pick up the phone. I have actually got her mobile number if I have to speak to her. She just makes me feel that there is somebody there for me, you know? Cos I have went through years of nobody, absolutely nobody. And the possibility that, as I say, there is somebody there for me for definite, it's not a maybe it's a definite, and she pushed for one thing and ended up getting a lot of things done for me that possibly I would never have known about.*

### ***Coping with hepatitis C***

Maureen was asked if the outreach service had helped her cope with her hepatitis C diagnosis.

*I am dealing with this today - I believe this is because I am getting a lot more outreach, brilliant word for it because I feel somebody has outreached and brought me in and says "no you aren't a number." You deserve to get treated like everybody else. [It has had] a dynamic effect on me.... She has made me feel like I am a human being.*

*Now I won't ever go near drugs. I can put my hand on my heart and say that because I have somebody to help me. Alcohol maybe and I know I should never, it should be total abstinence but I will be honest, it won't be total abstinence where that's concerned. I will maybe have one weekend when I will go over to my sister's and have a bottle of wine, but it doesn't go over. I don't go mental, bananas.*

*I think now that I am more happy with myself considering every aspect of the word. Considering I have got this horrible illness and the way that I am getting treated by the nursing staff, and the fact that someone has put their hands out for me. To help me and the fact that I am getting help in every aspect of the word, help with my liver, [and my other health problems]. I just feel a lot happier in myself, a lot more contented that someone's there, you know? Yeah my attitude has changed towards a lot of things as in no more drugs for me, drink in a kind of normal level. What she has done for me is incredible, no two ways about it.*

### ***Hopes for future service***

Maureen was asked what she hoped for in the future from the service.

*Well [CNS] will make sure I keep appointments and I know I will have appointments now and I know my names is on the computer, my name is there. It makes a difference when you have someone that's friendly and you know she is not going to jump at you for not keeping time or you know? Although I don't play around with her because she has done so much in the few months that I have met her. She has just turned me back round again, you know? And having a friendly face and a friendly voice is so important especially when you are dealing with something so horrible and I think you would have to be in this situation to understand it. Just to know [that there is somebody] trying to understand my needs and what I am going through and that.....As I say getting back into the hospital*

*again, getting things done, you know? Appointments coming in through that door. It may sound crazy to you but to me getting an appointment through the door, it's like brilliant. I am on the phone to my Ma and my whole family's attitude has changed towards me. You know because they see me a much quieter person.*

With regards to her hepatitis C needs, she was quite clear about what she would like.

*I need for definite to get an up to date liver biopsy to see what stage I am at. That's important to me. I really need to know what stage I am at. Then I could possibly move up the ladder a couple of steps more and be more content with myself, you know? Um my needs are.. I need [CNS] to talk to you know? I've got her I don't abuse that situation whatsoever and I just need to be heard. I need to know where I stand. I don't want to be a number and pushed to the back of the queue because I didn't keep one appointment. I need to be heard and I need to know where I stand, where my health lies. I don't want them hiding behind a bush. I want them to tell me straight.*

### ***Were expectations realised?***

All participants were asked what their expectations had been of the service at the beginning and had they been realised. Maureen said that she had not really had a chance to think of what the service could do before she became involved. Nevertheless, it was apparent that she had received a service that was totally unexpected.

*Since I have met that lady she has got me on leaps and bounds. Different parts of my body getting dealt with and she's pushed for results and she has pushed for appointments to be brought forward.*

### ***Most important aspect of service***

*Providing a service which is really needed for folk like myself, getting the appointment for the hospital, pushing for appointments, not letting go, getting appointments brought forward for folk that has been denied through their GP and just being there for folk,*

*which I've never had before. I have never heard anybody saying anything bad about [CNS] She's great. Everywhere I go she seems to be I go up to see ma sister who gets taken into hospital quite a lot. She is up at that end, in the Royal, and I see her at Gartnavel. We are always bumping into each other. She will call me to see how I am "I have no seen you for a couple of weeks," and things like that. But we need more.*

***Interviewer - this is my last question, suggestions for improvement...***

*We need more. We need more of folk like [CNS].*

## **Case 2**

### ***Demographic characteristics***

Paul is aged 26 years, lives with his parents and is currently receiving a methadone prescription. He began injecting when aged 17 years and had not injected for the past three years.

### ***Previous diagnosis and treatment***

Paul was first diagnosed with hepatitis C in 2003.

*It was the Brownlee Centre, they diagnosed it and then they sent me to the Royal Infirmary to go for treatment.*

*I got an ultrasound and they felt at the time that I needed the medication for it, the Ribavarin, Interferon and I went onto that for 24 weeks but I ended up getting back into the drugs again. I had a lot of problems in my life at the time. They decided to take me off the treatment because there was a lot of side effects with it like vomiting and paranoia, just a big long list of side effects....It was their decision they wanted to take me off the treatment, which was the right decision looking back on it now.*

*But the treatment, the nurses and that, couldn't have been any better. Once I got into treatment and that it was like, it was a good service. They would sit and they would tell me everything about hepatitis C, the scarring and how the scarring would work on my*

*liver, if the scarring got worse what would happen. They explained everything to me and gave me a good background on it but obviously I fell by the wayside.*

*I definitely thought [though] that it was worth it to give it a go. At first it wasn't as bad but then as the treatment got stronger and stronger that was when it got worse and worse and my parents started to notice things [Paul hadn't told his parents about his hepatitis] and then I started getting back into the drugs and everything and I just wasted away.*

*They [treatment providers] knew that I was using again...They told me they didn't want me on the treatment anymore it was wasting my body away too much and maybe come back and see them at a later date and maybe see about the treatment again but at the moment it was no, there was no use keeping me on it. It was just going to bring me down even more.*

### ***Referral to outreach service***

Paul had been referred to the outreach service by his addiction worker.

*Well I was on a methadone programme and I told them in here that I had hepatitis C and my worker said that there was a hepatitis C nurse came up and so I said I would like to see about how my liver is and where I am at the now. And they referred me to [CNS] and within maybe about 3 weeks to 4 weeks time she called me up and I saw her...She reassured me about it and everything and got me an appointment with the doctor and that was all done within maybe about 2 months, tops. But when I went to see the doctor he said that everything seemed OK with my liver so they didn't want to put me onto the treatment for it.*

*They have given me another appointment for 6 months time from that last appointment to go and see again and see how my liver is then but they didn't feel that I needed the treatment the now and they said that there are other advances coming through the now, possibly maybe in a year's time they could get like much better drugs for it or whatever. But when I first found out that I had hep C I thought 'aw no, I am going to die within a year or something' but since then I have been more reassured that it is something that it is up to me really how long I live with it. If I am going to go out and drink and take loads*



*of drugs and everything I am going to die a lot quicker than if I take care of myself. I know it will still linger but there is a chance that it can be taken away.*

### ***Attendance at outreach***

At the time of interview, Paul had been attending the outreach service for about 4 months and had attended about three times.

*....3 I think. But she was there on the day that I saw the doctor as well. She came in and sat with me. She was quite supportive about it as well.... because I didn't know the doctor and like drugs was something I really go into in the first place because of my shyness and everything and I was always kind of shy and that kind of brought myself out. Because I had met [CNS] a few times and knew her and she would maybe speak for me if I was getting tongue tied or whatever, it helped for her to be there when I saw the doctor but the doctor couldnae have been any nicer anyway.*

Like other interviewed clients, Paul was extremely pleased with the service he had received.

*That is a good service..... if it wasn't for here I would never have seen [CNS].*

Despite his previous unpleasant experience of treatment, Paul now had less worries about undergoing treatment in the future, particularly given the support he felt he would receive from the outreach service.

*Probably not [have any worries about treatment].....as I said, I ended up a with a lot of problems, I won't go into it but there were a lot of problems. But I was making my way into the Royal by myself and I was keeping my injections in the chemist as I didn't know how long they kept cold in the fridge and I didn't want my parents to know. Going up and then down and injecting myself with it and then taking it back up and they were disposing of it for me. But I suppose with a bit more support it would have been a lot easier. I am saying easy, what I mean is it wouldn't have been as hard if I had a wee bit of extra help.*

*....If I was given the chance again I would probably take the treatment again straight away and feel it was worth the risk. I was told [before] that it was 60:40, 60% like it would not get rid of the disease and 40 it would but I have now been told that it is 40:60 so I am willing to try it again at any time.*

### ***Other benefits of service***

In addition to having been referred and assessed for treatment, Paul also spoke of other benefits he had derived from the service.

*...Definitely it has helped. I have learned how my liver would degenerate if I am using other things and things like that. It has helped me learn more about hepatitis C. The letters that she gave me, the notes that she gave me and she sat and she gave me a good discussion about it for maybe about half an hour telling me all about the damage that could have been done to my liver and that if I am putting goodness into my liver how it regenerates itself, so long as I am not abusing it too much. So I definitely did find out a bit more.*

### ***Current priorities***

Paul was still using drugs and his main priority at the time of interview was to become drug free.

*Getting myself drug free and trying to get a life. Where I live the only thing I can do when I go out is bump into old friends who maybe still use or whatever and it is not much of a life where I live anyway. What I need to do is I need to get myself drug free, I need to get a job and get out of the scheme that I live in. That is the only thing that would be able to help me. Get myself, my life back to some sort of order cos I can't live with my parents for the rest of my life and stay under their roof 24/7, that is just something that I can't do. It kinda drives me round the bend sometimes as well they are maybe wanting me to stay in because they know if I am going out I am going out for one thing. And I did college courses recently and things like that but it is still, and I can understand why they haven't got the trust in me because I have done it that many times but after being so long*

*clean of drugs [injecting] you would think that they, well I am saying you would think they would be happy with it but... I think they are just wanting the best for me, I know that. They just want the best for me so I am willing to just take their advice the now and maybe try and get into groups and see maybe ex-addicts, things like that, just try and get a better lifestyle altogether.*

***Were expectations of service realised?***

Paul's expectation, based probably on his previous experience, was that he would have been referred for and given treatment.

*Really the expectation of getting back onto the treatment and hope that if I get back onto this treatment it would maybe rid me of this disease that could kill me in I don't know maybe 20 years time or 10 years time. See I don't know what tomorrow is going to bring if I am going to start drinking, if I am going to go back to drugs or whatever and my expectations I suppose were to just to try and get onto the treatment and rid myself of it and I will go back to that appointment in 6 months time and see how they think my liver is then. That was really my main expectation was to go onto treatment but I suppose in a way it has been good that they have said that my liver is in that good a condition that it doesn't need the treatment the now and there is not much scarring or, well I think it was not much scarring or no scarring, so that was just really my main expectation was to get onto the treatment.*

Despite his main expectation not having been realised, Paul nevertheless saw the service as worthwhile.

*I would recommend it to anybody. It was a lot quicker than the Royal.... Very helpful people, they will help you out and like various ways they will talk you through anything you need to know about and just let you know everything that you need to know.*

### ***Most important aspect of service***

*Probably it all happening, going so fast because I never expected it to be that fast an experience. Well not experience, but like to get me from A to B so quickly from one place to the next but I think it was about 4 months or something from the CAT team right through to Gartnavel...so that was really, really quick compared to what I had to wait for before.*

### ***Suggestions for service improvement***

Paul was asked if he had any suggestions as to how the service could be improved.

*No, not really. I thought the service was [good], done a world of good for me anyway like getting in and seeing about it straight away and really quick and the quickness couldn't be any better.*

*I suppose maybe more of the workers.... I mean I don't know if they are mentioning it to the people with hep C in here about [CNS] and if it has been mentioned in other CAT teams round Glasgow to like people with hep C or testing for hep C, cos I've heard there is something like 80% of people that have injected have got hep C but they don't know it so maybe getting more people with hep C tested. Maybe the workers in the CAT teams pushing them towards that kind of thing and then obviously following it up.*

## **Case 3**

### ***Demographic characteristics***

Mary is aged 32, lives with her young child and partner and is currently receiving a methadone prescription. She said she had injected only once, eight years previously, although she had used heroin and other drugs extensively in the past. At the time of interview she had been undergoing treatment for hepatitis C for four weeks. Mary had had many social problems in her life, many of which she felt were now resolved.

### ***Previous diagnosis and treatment***

Mary had found out she was hepatitis C positive about 4 years previously.

*One day I woke up and I was yellow, my eyes were all yellow and I thought what is wrong with me. My skin was all yellow and I got such a fright so I went straight to my doctor and the doctor saw me right away and he says 'I think we need some blood tests here'. He says something is not right and he told me that HIV, hepatitis was what he was taking the blood tests for. Then I was like 'this is all coming back to haunt me'. So when I came back he said to me I had hepatitis C, I did not have anything else apart from hepatitis C but it is incurable. It was hard to take. I just got on with life. The jaundice went away...but I was glad that I was able to find out because I would not have known when I was pregnant and could given it to the baby. Because that was something that was always in the back of my mind when I was pregnant because I had to watch the childbirth and I had to remember[to tell the nurses] I have got hepatitis C please don't [do anything that would jeopardise the baby], I don't want my baby having this, I don't want to take any chances.*

*When I found out about 4 or 5 years ago, I was never stable to go and get the treatment and I didn't feel as if it was right, the timing was right, to go and get it and it was just something that I put to the back of my mind and I knew that I would get the treatment when I was stable.*

*I think the doctor knew that I wasn't too settled yet and he was like get your head down a bit first. He didn't offer any [treatment] so I was left with it.*

### ***Referral to outreach service***

Mary had been referred to the service by her CAT team worker.

*When I told the CAT worker I had hepatitis C she explained to me about [CNS] that works in here that will see you and talk to you about hep C and I was like 'brilliant, fantastic' because I knew in there that this is the time for me. I just felt that everything was going right for me at this time in my life and I would start treatment and have the support that I needed around me. I wasn't using anymore, I don't want drugs in my life anymore, I am not going anywhere, I have got a wee [child] now, who is brilliant. So [CNS] spoke to me and she told me everything that it involved and I told her about myself*

*and she agreed with me as well that this was probably the best time in my life because I didn't have all these roller coasters in my life, all the ups and downs. Everything in my life was just stable so it would probably be the best time to go for it and she did tell me all the side effects but I felt well I have got the kids, more than anybody else I have got to do it for me and the kids you know so that's why I felt when they told me about [CNS] I felt 'brilliant somebody I can talk to' because it was just something I felt I kept at the back of my head. I didn't talk about it, I knew I had it but it wasn't something I wanted to tell anybody about because I felt dirty....*

### ***Attendance at outreach***

At the time of interview, Mary was no longer attending the outreach service. She had been referred on for treatment and was attending the hospital. However, she had attended for a year before getting to this stage.

*If I didn't have [CNS] I would still not have the treatment that I have been getting, if I didn't have [CNS] up here I wouldn't have got the ball rolling with the hep C. And I know it took a long time to get, even with [CNS]. It took a year to get to the stage where I am but that year was to build up and get myself mentally ready as well so it was worth that year because I knew I would be stopping everything. I would be stopping drugs and I was trying to eat my fruit and eat properly and things like that and diet and so it was totally changed for me.*

*I don't have friends or associates or anything like that I don't have that in my life. I don't want it any other way because I think if you have got too many people in your life, people that use drugs, it is so easy you can go back, it is onto that slippery slope. But she [CNS] was always on the end of a phone. That was a good thing, she was always at the end of a phone and things like that and if you were worried about anything I could just phone her up and she would help me out. She was there for me. I couldn't have done it without her I don't think, she explained everything about it and I went to the hospital and they were telling me this and that. I saw [CNS] and she would explain it because it is all medical terms and I was like 'I don't understand it all' at first but now I am getting to*

*grips with it and starting to understand it now. I have got a nice person like [CNS] as well up in the Royal Infirmary. She sees me weekly, to take my bloods.*

### ***Other benefits of service***

Mary pointed out other social benefits from having attended the service and receiving treatment.

*...and my family know about it which is good so I have got the support from them and they know if I am doing this I am settled and am not going about taking drugs. Because they don't really think that the hospital would entertain you either and you have been given the chance of this treatment so I think that, that has giving my family positive [feelings] about me 'she is trying to build her life back again' and I am, I am trying to build my life back again because I have got my child.... So I will get there.*

She also discussed how easy it had been to be referred and also the advantages of being treated in one place.

*...It was very easy because it was all here, so it was. [The service being here] has worked for me 100% because it was...if I didn't have it I would need to see the doctor and then it would be on the waiting list again you know and it is just been great to separate that from the doctor, the doctor is not dealing with that.*

### ***Coping with treatment***

Mary described how she was coping with her treatment thus far.

*I was waiting and waiting and waiting for the treatment to start but when it started, God it started.*

*This is my fourth week of taking it and I am ever so proud of myself going through the jagging because I don't like needles, in my stomach... but you have got to have mind over matter so you have to get through it.*

*I have had side effects. I have had terrible depression, I have had nightmares, a few nightmares, wee kind of upsets and it is extremes, you know. What else - I just want to sleep all the time, I just want to go home and rest all the time.*

*Having [my child] at nursery is fantastic, getting the space, that has fitted in perfectly. What I do is I drop [child] off at nursery and catch the bus and it takes me right over [to the hospital], it is not a problem. I work round it completely and then I come back and I am probably a wee bit late but the ladies at the nursery know about my situation and I tell them I have got the hospital today and they are like that, that's fine if you are going to be 5, 10 minutes late don't worry about it. They are fine about it, everybody is fine about it which makes it a lot easier, you know there is not any stress. There is no stress at all, everybody just works round me and it is very nice of them...because I have had that much stress in my life and it is not stressful it is fantastic. I don't need to worry about it.*

*...[When] I just started treatment that was hard, that just floored me completely. ....As the weeks have started to go on things have started to get easier and I am starting to adapt to the treatment and I think like my first month or my first week, the second week it was like a shock to my body, my body is starting to get used to the toxic things, or chemicals that they are putting into me. And I think that is it is not as hard, it is not as heavy you know because at first, the first week I felt ill, really bad, I felt really ill. Second week felt not too bad.*

*.... I did feel I was prepared for it but I don't think you can ever prepare yourself, you know? You can prepare yourself to a certain extent but you can never prepare yourself for the actual thing because basically they say you will be unwell but then I am actually like 'wow I am really not well here', you know people having to help me. I wasn't used to that cos I was used to doing everything for my [child] and for my partner and doing the house and all the housework you know, with my partner out working and then, bang, I couldn't do that, even though I really wanted to I mentally and physically couldn't do it. I was drained, my body was drained, So I just went to my bed and that is where I went for the first week and I just stayed in it. And I think that is why a lot of the depression kicked in as well because, in reality, I thought I had physically, mentally got myself prepared but*



*I hadn't. You know, when I started, I didn't think about how people would have to be helping me.*

*...I might look like \*\*\*\*, I might feel like \*\*\*\* but so what, who cares. I just know why I am like this and I know it is not going to be forever and I know that will hopefully be the end of it. Something good will come out of it. That is what I am waiting on, the light at the end.*

### ***Coping with hepatitis C***

Referring back to when she had been attending the outreach service, Mary was asked if it had helped to cope any better with her hepatitis C diagnosis and her decision regarding treatment.

*Yeah it has and I know that [CNS], as I said, gave me her number and I know I could phone her tomorrow you know and she would be on the other end of the line if I needed her. That is the good thing about it to know that she is on the other end of the telephone if I really need her. You know if things get bad and I get really low or whatever I can phone [CNS] or if I think I am not coping any more I know I can phone her and say ' [CNS] I am not coping with this' and she would be there for me and I think that is a good thing knowing that you have got that support there at the other end of the phone if you really need it. And she has never ever been any thing but polite.....And that is the nice thing about it she is never made you feel inferior she has always made me feel like a person. She has never made me feel like, I don't know, like a bad person for going and getting hep C and taking drugs or whatever. She looked into the book she did not just look at the cover. You know?*

### ***Current priorities***

*My priority at the moment is the hep c. That is my priority more than anything else, everything else can wait. I am not having any holidays this year, nothing is happening this year. Yes we will have Christmas and the kids will get their presents and [my partner] can have a drink but I am not drinking anything. That is what we knew, that we would be working around hep C, working around the treatment and that is what I*

*have prepared myself for so the year has been taken out for this. I am not wanting to go on holiday and take all the medication with me and all that, I am staying here where I feel I have got people at the end of the line that I can phone if anything was to go wrong.*

### ***Were expectations of service realised?***

Mary expectations had been more than realised.

*I actually didn't expect much, I didn't expect as much as I got. I thought it would take a lot, lot longer to get me to the hospital and to get in touch with the hospital.... I thought it would be a lot harder... but it wasn't, it was made so easy for me.*

*I would definitely give them [CNS] top marks..... If anybody asked me about it and said they wanted treatment or whatever I would tell them where they could go and how they could go about it. Because I wouldn't have known if I wasn't in here, I wouldn't have known how to go about it basically because there is a not, there isn't a lot of information about it, there isn't. And that is the sad thing about it, it is the silent killer, it is the silent killer and so many people have got it and don't know they have got it and that is the daft thing, through people's embarrassment you know, through people's ignorance, or maybe they don't want to know but it is treatable and you know if people would open their eyes and just get tested. If you feel you have put yourself at risk don't do nothing, go out and get tested..... Silent killers, because you don't know you have no tell tale signs.*

### ***Improvements to service***

Mary suggestions for improvements were not directed at the service itself but were more concerned with increasing awareness of hepatitis C in other places.

*I think more leaflets and a lot more like leaflets like in here. [Put them] in doctors' surgeries where people go to, where people go to take kids to. That way you can catch people and make them aware there is a chance that you could catch this, I think there should be a lot more awareness, you know. I look around my doctor's surgery there is nothing, nothing in it. There are no fact sheets about hepatitis C and, you know, I find that sad because there should be. You shouldn't be embarrassed, you know what I mean, because it is treatable. You can manage, you can live with it, you can keep going, as long*

*as you have got that support you can keep going. I think just having a lot more information out there for people could do a lot of good for a lot more people and then it might encourage them to go and get tested. I think a lot of people might be frightened of what the answer might be...[But] I was glad I was. I wouldn't like to be 50 and find out.*

## **DISCUSSION**

The Hepatitis C Community Outreach pilot service was established to meet the needs of clients attending Glasgow Addiction services. Its aims included increasing access to treatment, providing access to appropriate support and advice, to reduce the default rate amongst those that are referred for tertiary treatment and establishing effective links between services involved in the care and treatment of drug using clients affected by HCV.

Three Clinical Nurse Specialists were employed to provide specialist input and assessment for treatment within four Community Addiction Teams (the South, South East, North East and West). All clients accessing these CATs or the community rehabilitation centres that were linked to the CATs were eligible for referral to the outreach service.

This evaluation was undertaken to see if the service had met these aims. The evaluation had three different components: monitoring of data, service providers' perspective, and client's views of the service.

### **Data monitoring**

The data presented were taken from two different sources: the addiction service PIMs database and the outreach evaluation database and contains data from the first client referrals in May 2006 until the end of October 2007. A total of 328 clients were referred to the service over this time, of whom 218 attended for a least one appointment. This is an attendance rate of 66.5%, which is higher than the tertiary centres in Glasgow, which have historically reported a default rate of around 60% among those attending for HCV assessment or treatment.

There was an even distribution of referrals from the North East, South and West CATs. The lower number of referrals from the South East CAT is not surprising as the South East CAT has lower number of clients registered in comparison with the other CATs.

Most of the referrals came from the Community Addiction Teams, however this percentage is likely to drop now that the service is concentrating on shared care clinics. There was only one referral from the community rehabilitation centres. It was originally thought that a larger number of referrals would be generated from community rehabilitation projects as the clients attending these services are further along in their road to recovery and more stable.

More than half of HCV tests undertaken were confirmatory tests, suggesting that the service was successful in accessing its target group. Just over half of the clients for whom test results were available tested hepatitis C PCR positive. It is encouraging to see that around a third of clients tested HCV negative and that 13% have cleared the virus.

The difference in the number of clients attending the service (n=218) and those for whom a test result had been recorded (n=122) can be explained partly by clients not being ready to be tested, clients not turning up for a second appointment (the first opportunity to take blood for testing) and a small number of clients that were already in the tertiary system. Most of the clients (50/63) that tested HVC PCR positive were referred to hospital. Of the remaining 13, six some did not wish to be referred. The main reasons that clients did not want to be referred were that they did not feel ready for treatment or they were not yet ready to deal with their HCV status at that point in time. One client was still using drugs, their life was chaotic and they felt that their HCV was not a priority.

### **Staff interviews**

Interviews with addiction and nursing staff were conducted at three time points during the evaluation and were designed to collect staff perceptions of the service and their role within it. The report has outlined some differences in how staff viewed the service, which are possibly a reflection of different values between addiction and nursing staff.

There was a feeling among a number of social care staff that service was driven towards processing clients through a programme of testing and treatment without regard for the client centred approaches already in place. In contrast, the CAT nurses and the CNS

tended to see the outreach service as a central part of a holistic approach and this was a particular strength of the service. It was noted that any contact with the clients of the CAT was a valuable opportunity to improve their knowledge of hepatitis C risk and methods to reduce its impact.

Addiction staff also highlighted the issue of the timing of referrals to the service. Some CAT staff questioned the appropriateness of referring clients they felt were not ready to deal with issues that hepatitis C might bring up. However, interviews with clients suggested that it may not necessarily be the diagnosis itself that is a problem but how it is handled and reported. This, perhaps, underlines the training and education needs of social care staff.

Confidentiality also raised concerns from social care staff. Some thought that the service was inappropriate for their clients as it did not offer anonymous testing and that they, therefore, would not refer clients into the service.

The location of the service was also highlighted in the interviews. There was discussion around whether or not the CAT was the best place for the service to be based. Social care staff stated that clients who were former drug users might have issues around attending the CAT where they could be confronted with a scene dominated by current drug users. The move to shared care clinics was seen as a positive move. Clients that attend shared care clinics were felt to be more stable and possibly at a stage in their life where they were ready to deal with their hepatitis C status.

Training was a major issue during the interviews. CAT staff expressed concerns about the training that was given prior to the service starting. They felt that there was too long a gap between receiving training and the service starting. This led to a number CAT staff lacking confidence in their ability to discuss hepatitis C issues with clients.

This lack of adequate or timely training, coupled with an early uncertainty about responsibility and roles, eventually led to CAT staff relinquishing the responsibility of the service to the CNS.

As the service evolved, it became more accepted by addiction staff. They noted the value of the service and the positive impact it had on their clients. In large part this was due to the efforts of the CNS who spent a great deal of time and effort into promoting the service among addiction staff.

### **Client interviews**

The central themes that emerged from the client interviews were the positive benefits of service and the speed and ease of accessing the service. Only a few clients were interviewed but there was an overwhelming support for the service. All those interviewed felt that the outreach team helped them to cope with their hepatitis C infection. In particular they were all appreciative of the CNS' support outwith clinic appointment times. All interviewed clients felt at ease with the CNS and were able to approach them when they were unsure of anything.

The speed and ease of being referred to the tertiary treatment centres was also an important aspect of the service. Service users felt that the service was quick and their needs were attended to in a timely and supported manner.

It was also clear from the case histories, and from interviews with CNSs, that the latter do more than simply see clients at appointed times. They provided support through phone calls, accompanied clients to other medical appointments and were the first point of contact for other medical conditions. It was also clear that these clients, who are vulnerable and who, perhaps, have had less than pleasant experiences with medical staff in the past, valued these extra activities. Most importantly, this more holistic approach may be, at least, one of the reasons that attendance rates at the clinic and subsequently at tertiary centres are higher than anecdotal historical attendance rates. This holistic approach was in contrast to many of the social care staff's perception of the service as

providing only clinical care. This suggests that social care staff need more information about the role and function of the CNS, which may, in turn, encourage them to refer more of their clients to the outreach service.

### **Study limitations**

It should be noted that this evaluation had a number of limitations.

Firstly, there were very few service user interviews undertaken. As discussed in the Methods section, there were a number of issues around the recruitment of respondents to the study including slow recruitment and lack of ethical approval to approach clients at the beginning of the evaluation period. This led to a change in the study design and a resubmission for ethical approval, which was a lengthy process. Ethical approval was granted for CNS to ask clients if they would be interested in taking part in the evaluation. If a client agreed, the CNS collected contact details, which were then passed on to the research interviewer to follow up. The interviewers made numerous attempts to contact the service users to arrange an interview time. There were many failed attempts at interviews with service users cancelling at the last moment or failing to turn up for the arranged interview. The interview team also failed to make contact with the majority of service users for whom they had contact details for due to individuals moving address, changing phone numbers and receiving no responses from letters sent or phone messages left. Because of these issues, only five interviews were completed. Of these, two were not included in the evaluation due to their taped interview being indecipherable. The case histories presented here, therefore, may not be representative of the clients that use the outreach service.

The evaluation is unable to present reasons why clients referred to the service failed to ever attend an appointment or why some clients attended an appointment and subsequently dropped out. In some cases, it was documented that clients did not turn up for appointments due to incarceration. However this was a small number and further work could be done to follow up and attempt to interview clients who drop out or never



attend the service. By exploring these reasons, steps could be taken to address these issues in providing a more flexible service to meet the needs of the client group.

Another major limitation to the evaluation was the timeline. This report covers from the first referral of clients in May 2006 until the end of October 2007. This may be too short a period to make any conclusions about the success of the project in terms of its aims and objectives of increasing access to treatment. The outreach project has evolved over the study period when it started as a service within the CAT buildings with two set sessions a week. As time went on and the CNS developed their roles and the service they provided, they found the benefits of attending shared care clinics. It was at these clinics they had more success in identifying clients that could benefit from the service. Clients attending shared care clinics are a more stable group in terms of their drug use compared to those still seen at the community addiction teams. The move to shared care clinics has been an on going process of meeting GPs and their clients and this is still taking place. The results of this move away from fixed sessions at the CAT will not be seen until later in the project.

Referring clients into hospital treatment involves a wait for the client as most hospital centres have waiting lists to either be assessed for treatment by the clinician or to start treatment itself. As a result, the figures of clients accessing treatment may not change for sometime yet. It is envisaged that once services are more established over time an increase in individuals accessing treatment will be seen.

Although small, the numbers of clients already referred to hospital and who have had an appointment are encouraging. Sixty three percent of this group attended for their hospital appointment. This figure is better than the current default rate of 60% among those referred from other referral sources.

## **Recommendations**

- The major recommendation is that the service should continue and should be rolled out to the other CATs across Glasgow. Although there has been a move

away from working in the CAT into the shared care clinics, it is important that the link with the CAT remain. Without the relationships that have been established over the last few years this project could not have worked. The CNS's acknowledge the important role that the community addiction nurses and social care staff have played in establishing the service. There are still CAT clients that can benefit from the outreach service even if it is simply gaining more knowledge about hepatitis C. Some clients that have been referred to the service and dropped out may have not been ready to address their hepatitis C status at that point in time. By knowing that the service exists, they can access the CNS when the time is right for them. Every intervention, regardless of how brief is an opportunity to reinforce accurate information and dispel myths about HCV.

- It is also recommended that the links with the shared care clinics are maintained and developed to work in conjunction with the service users' key workers and GPs to provide a holistic model of care for each individual. There is a need for the clinical assessment to be an integral part of drug treatment for clients. It is also important that services be located close to the local community to maximise service accessibility.
- One local service that was under-utilized in this project was community rehabilitation. The project was set up to receive referrals from three community rehabilitation centres associated with the CATs. Clients that attend rehabilitation centres are more likely to have a stable lifestyle and this is often an ideal time for them to address any issues that have around their hepatitis C status. The CNS did establish links with these teams, however these did not develop into clients being referred into the service. There were a number of reasons for this including community rehabilitation workers being reluctant to refer clients to a service that was not anonymous and the fear of clients going back to the community addiction teams to be seen for an appointment which could be seen as a step back for the client. Some of these issues could be resolved through developing stronger links with the community rehabilitation teams by providing more training and support

to staff, involving staff more in the process of setting up the service and holding outreach clinics at the community rehabilitation centres. It is important that managers of the rehabilitation centres are fully involved and are seen to be supportive of the service.

- One of the original aims of the service was to have all staff trained to deal with issues around hepatitis C and conduct pre test counselling as required. There were a number of problems identified with training, including having training too far in advance of the service starting, and that the material presented was too intense and fast paced. As the service evolved it became more a CNS led service with addiction workers referring any issues around hepatitis C to the CNS. As the project developed this way of working became the accepted norm and this seems to have worked well with many clients preferring to discuss hepatitis C with someone separate from their addiction worker. With this in mind, the training for staff should be reviewed, so that it reflects what they feel they require to support clients on a day-to-day basis. This should be developed in consultation with addiction staff and training sessions should be ongoing so that staff can update regularly. The involvement of the CNS in the training is also important as this allows social care staff to put a face to the service and gain an understanding of what the service is and how it can be of benefit to their clients.
- Data monitoring is essential for monitoring the success of a service and more thought needs to be put into how workload of the service is measured. It is suggested that those closely involved in the project work together developing a list of the important information they wish to capture about the service. Once this is completed then a decision need to be taken on whether the current systems can be utilised or adapted. If not then a new database should be developed so that all important information can be recorded easily and provide quick access to enable data monitoring. It is also suggested that an individual is appointed to be responsible for entering the data and producing routine monitoring reports when required. This frees the CNS to be able to deal with patient issues.

- The next step for the project could be developing the service to provide hepatitis C treatment through the community outreach service. This approach could improve accessibility of treatment and the client experience. Before this step could be taken, extensive planning would be required to develop protocols around providing treatment in the community. The service would still be linked to the hospital centres, for backup and support of the outreach teams.

## **Conclusion**

It is clear that for various reasons it took longer than expected to establish the outreach service and improvements depended on innovative and determined efforts particularly by CNS. Fewer clients than staff expected were tested for hepatitis and few were referred for treatment. However the aim of the project was not to increase testing but to identify those who had previously been diagnosed but were not receiving any treatment. Staff disappointment in these outcomes may be, therefore, less important for the overall evaluation than staff concerns suggest. What is important, however, is that lessons are learned about the ways in which team job satisfaction can be damaged when their understanding of service aims is at variance with that of the planners.

Despite these early problems, the service is meeting most of its aims. It is increasing access to treatment for this hard to reach group and it is providing access to appropriate support for clients. The service has improved the understanding and knowledge about hepatitis C among addiction staff to some extent but more work needs to be done with staff training. The service is valued by both addiction staff and clients and can claim many positive outcomes.

It maybe too early to judge if the service has achieved the aim of reducing the default rate amongst those referred to tertiary treatment. However, the early figures presented in this report are promising.

## References

1. Health Protection Scotland. HPS Weekly Report. Vol 42, No 2008/08, 28 February 2008.
2. Health Protection Scotland. Scotland's Action Plan for Hepatitis C: First Year Progress Report.
3. Manns MP, McHutchison JG, Gordon SC et al (2001). Peginterferon alfa-2b plus ribavirin compared with interferon alfa-2b plus ribavirin for initial treatment of chronic hepatitis C: a randomised trial. *Lancet*. Sep 22; 358 (9286): 958-65.
4. Sharp DJ, Hamilton W. Non-attendance at general practice and outpatient clinics. *BMJ* 2001; 323: 1081-1082.
5. Taylor A, Goldberg D, Hutchinson S, Cameron S, Gore SM, McMenamin J, Green S, Pithie A, Fox R. Prevalence of hepatitis C virus infection among injecting drug users in Glasgow 1990-1996: are current harm reduction strategies working? *Journal of Infection* 2000; 40; 1-8