

# HEPATITIS C PATIENT JOURNEY EVALUATION

FINDINGS FROM  
AN INITIAL  
SCOPING EXERCISE

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## Foreword

Hepatitis C is a significant and growing public health issue in Greater Glasgow and Clyde. NHSGGC is home to around 10,000 people diagnosed with hepatitis C, representing over 40% of the national total. The Hepatitis C Managed Care Network (MCN) was formed in 2006 to develop and co-ordinate services for people living with hepatitis C. Our stated aims are to ensure that services for people living with the virus are both patient-centred and equitable.

Patient-centred hepatitis C services should treat people as individuals, placing them at the centre of their care and recognising their views, needs and experiences. Equitable services should ensure that all people with hepatitis C receive the best standards of care and access to care irrespective of who they are, where they live, where they access services, and what complications they may have.

Over recent years the Health Board and MCN have significantly developed hepatitis C services in the area, aiming to increase the number of people whose infections are diagnosed and provide them with effective care, support and treatment. We recognise the need to understand the views and experiences of people living with hepatitis C in order to continually improve the services we provide.

The MCN commissioned this report from the Scottish Drugs Forum (SDF) to identify the issues faced by people as they engage with a wide range of hepatitis C services. We were pleased to work with the User Involvement Group at SDF given their history of engaging with people at risk of hepatitis C, and their experience of placing those in need of services at the centre of policy discussions.

This report is the first stage in an ongoing process of user involvement and consultation within the MCN. We hope that these findings are of relevance to service providers and commissioners working in the field and, most importantly, that they help improve the experiences of people living with hepatitis C.

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## 1. Introduction

Approximately 10,000 people who have been diagnosed with hepatitis C (HCV) are resident in the area of NHS Greater Glasgow and Clyde. They represent 41% of all diagnoses in Scotland (HPS 2008a). It is estimated that 90% of those infected acquired HCV infection as a result of injecting drug use (HPS 2008b).

About two-thirds of hepatitis C infections remain undiagnosed, and many people who are aware of their status are not engaged with treatment and care services (ibid). Local data also show that about half of those referred to hospital fail to attend for their outpatient appointments (Stevens 2008).

Phase I of the National Action Plan for Hepatitis C (Scottish Executive 2006) made Health Boards responsible for improving their services for testing, treatment, care and support. Key aims were to increase the proportion of infections that were diagnosed, and improve the accessibility of clinical care and treatment services.

As part of the Health Board's response to these aims, the Managed Care Network for Hepatitis C (MCN) sought to involve people living with HCV "*in improving the quality of care, in influencing priorities and in planning services.*" (Scottish Executive 2001).

The MCN commissioned the Scottish Drugs Forum (SDF) to conduct a peer-led evaluation of the experience of people with HCV as they progressed from initial diagnosis to engagement with clinical services.

In the absence of specific national standards for HCV services, the experiences of people with HCV were assessed using existing evidence-based guidance and standards from a range of relevant sources. These included publications from the Scottish Government, Scottish Intercollegiate Guidelines Network, Royal College of General Practitioners, Royal College of Physicians of Edinburgh, and the MCN.

This evaluation was designed as an initial scoping exercise, intended to identify the key issues as perceived by people diagnosed with hepatitis C, in order to inform further work in Glasgow and Clyde.

By publishing this report, we aim to contribute to local understanding of the experiences of people living with HCV and to the development of services designed to meet their needs.

## 2. Methods

Study participants (n=79) were recruited using convenience and snowball sampling at three sites in Glasgow, two peer support services for people living with hepatitis C (C-Level and Anam Cara), and via the local user involvement group of the Scottish Drugs Forum (SDF) a national drugs organisation. Individuals were eligible to participate if they had ever received a positive hepatitis C antibody test.

An interviewer-administered questionnaire was developed following an iterative process involving staff, volunteers and service users from the MCN, SDF, C-Level and Anam Cara, and revised following pretesting with members of the SDF User Involvement group. Questions were revised to ensure that the language used was appropriate to the target population. The clarity was improved and ambiguous terms removed. The final version of the questionnaire is available at Appendix A.

The survey consisted of thirty-three questions in which key aspects of the patient journey were addressed, including testing, referral to non-clinical support services, referral to specialist care, and experience of specialist care and treatment. Information was collected using a combination of open and closed questions.

Interviews were held at C-Level, Anam Cara and three SDF settings, and were conducted by two trained peer researchers from SDF during July and August 2007.

All respondents received a study information sheet and gave written consent to participate in the evaluation. These documents are available at Appendix B.

Participants were offered a £10 supermarket voucher as reimbursement for their time, and a copy of the '*Feeling Better about Hepatitis*

C<sup>1</sup> patient information DVD (Scottish Executive, 2007)<sup>1</sup>.

Interviewers were trained in providing information and in making appropriate referrals for respondents who identified further needs as a result of participating in the study.

Quality assurance was provided by the User Involvement worker from SDF who checked all completed surveys for consistency and accuracy. Regular supervision sessions were held with both peer researchers to review their research diaries and address any personal or professional issues that arose for them during the study.

Quantitative data were subjected to descriptive analysis using the statistical software package SPSS (version 14.0 for Windows). Free-text responses were reviewed to identify key themes, then post-coded and entered into SPSS for quantitative analysis. Direct quotes were extracted to provide qualitative support for identified themes.

## 3. Results

### 3.1. Demographics

Data were obtained from 79 participants who completed interviewer-administered surveys. Three-quarters of these (59/79) were male, and the mean age of the sample was 36 years (SD = 7 years).

Respondents were asked for the first half of their postcode of residence. With the exception of two respondents, all were resident within the NHS Greater Glasgow and

Clyde Board area. One person was resident in Lanarkshire (ML5) and one in London (NW10).

Almost three-quarters of interviews (58/79) were conducted at SDF settings, 18% (14/79) at Anam Cara, and 9% (7/79) at C-Level.

### 3.2. Testing

Just under half of respondents (39/79 [49%]) had received their last test in a hospital setting, 19% (15/79) in prison, and 11% (7/79) in primary care. Almost 40% (31/79) had been tested in more than one setting.

Respondents were asked what information or support they had wanted at the time they were tested. Thirty percent (24/70) wanted to know what symptoms they might experience and how the virus would affect quality of life. Twenty four percent (19/79) reported a general lack of understanding of hepatitis C at the time, and had wanted any / all information available.

“What symptoms I could expect and what would happen in future.”

Male respondent, aged 31, recruited via SDF

“All that was available – the different strains are confusing.”

Female respondent, aged 32, recruited via SDF

“I needed to find out as much as I could because I knew nothing about hep C.”

M 25 SDF

### Those who understood the testing process and results

When asked to consider their most recent test, the majority of respondents stated that they had understood the testing process and results (60/79). Those who reported a favourable testing experience indicated the importance of adequate pre- and post-test discussion and the information with which they had been provided. Important perceived information needs at this stage included more detail about the hepatitis C virus, how the condition could affect health, and lifestyle changes that could minimise liver damage.

“I got leaflets and someone sat with me and explained about what hep C is and how it would affect me.”

M 30 SDF

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<sup>1</sup> The peer researchers noted a high level of interest in their offer of a copy of the patient information DVD which was accepted by 85% (67/79) of respondents. The DVD “was created as a resource [for] patients who have been diagnosed with hepatitis C” (Scottish Executive 2007) and provides information on diagnosis, routes of transmission, disease progression, myths and misconceptions, disclosure of status and treatment.

A common theme throughout the evaluation was the need for more information on hepatitis C. By providing the DVD, the authors consider that by participating in this evaluation, a number of respondents will have been able to meet at least some of their self-identified information needs.

"I got great support from staff and information from leaflets, videos and staff members."

M 32 SDF

"Info about genotypes and how to live healthily."

M 33 SDF

"They told me all about hepatitis, what it is, and what it would do to me."

M 26 SDF

### Those who did not understand the process and results

One quarter of respondents (20/79) reported that they had not understood the testing process or the meaning of the results. When asked what would have helped them to understand, 35% of this group (7/20) thought that the explanation of the test could have been better and 30% (6/20) would have liked more information about the symptoms of HCV and how the virus might affect quality of life:

"If they had sat me down and explained to me what it was about. I could have understood it more and better."

F 33 C-Level

"If I had been given more information about what hep C would actually do to my body."

M 30 C-Level

Four respondents (4/20 [20%]) reported that they had been tested with neither their knowledge nor consent, two women attending antenatal clinics, one unconscious in hospital following a drug overdose and one whilst in prison.

"Nothing was explained to me. As far as I knew I was just getting a blood test."

F 49 C-Level

"I should have had the tests explained to me before they were done."

F 21 SDF

"I only wanted an HIV test. I didn't know I was getting tested for hep C as well."

M 38 SDF

### 3.3. Referral to non-Hospital Services

The majority of respondents (29/35 [83%]) reported that they had not been referred to any non-hospital information or support services at the time of diagnosis. Of those

that had been referred, 50% (3/6) were referred to C-Level.

### 3.4. Hospital-based hepatitis C Services

#### Those who were not referred to hospital

Around half (40/77 [52%]) had not been referred to a hospital hepatitis C service at the time of diagnosis. These respondents were asked to describe their perceptions of the reasons for this. Of these 40 participants, 25% (10/40) were in prison, and 20% (8/40) indicated that they had ongoing chaotic lifestyles or substance misuse issues at the time.

"I was told that I would be referred once I had stopped drinking but they have not offered me any help to stop."

M 32 SDF

"Probably because I was still using drugs and in a chaotic lifestyle."

M 36 SDF

In a further 25% (10/40) of cases, patients did not know why they had not been referred or thought that this was due to a lack of knowledge or engagement on the part of staff at the testing agency.

"I had to make an appointment myself – they didn't seem interested after I tested positive."

F 31 SDF

"I think they neglected me because they didn't know much about it."

M 38 Anam Cara

#### Those who were referred to hospital

Of those that were referred to a hospital hepatitis C clinic, only 11% (4/37) were given a choice about which hospital they could attend.

Seventy percent of respondents (21/30) did not know what to expect from going to hospital and sixteen of these reported that no information had been given at the time of referral:

"I knew nothing about what was going to happen. Someone could have talked to me and explained what would happen next."

M 45 Anam Cara

"I had tested positive in prison and was unaware that I was even going to be taken to hospital. I was just called for without prior warning".

M 38 SDF

"No-one told me about getting treatment, so I had no clue."

M 32 SDF

Thirty percent (9/30) reported that they knew what to expect from hospital care. Of these, 44% (4/9) expected to receive treatment, and 33% (3/9) felt that they had been fully prepared for this part of their journey.

"I expect to get interferon treatment to clear hep C. I am expecting side effects, fatigue, depression, jaundice."

M 25 SDF

"Expected to get treatment to clear infection."

M 36 SDF

"The testing process was well explained to me and I was kept informed about what would happen next."

M 36 Anam Cara

When asked to identify what had gone well in relation to the experience of hospital services, 49% (17/35) reported effective communication and treatment with respect by healthcare professionals.

"I got good information and was treated with respect by the nursing staff. I got the information I needed face to face."

M 36 SDF

"Staff used simple language, made to feel welcome, I was encouraged."

M 48 SDF

"Once I was there everything went well. I was treated with respect and everything was explained to me at every stage of my treatment."

M 38 SDF

Respondents were asked to describe what would have improved their experience of hospital HCV care. Thirty-seven percent of cases (16/43) would have liked more information, 12% (5/43) wanted a quicker and

easier way to arrange appointments, and 12% (5/43) would have appreciated more support.

"Getting more information about how the hospital treatment would happen and what I could expect like symptoms and treatment."

F 48 SDF

"If I could have been given the choice of where to attend."

M 32 SDF

"More active support. Shorter waiting times."

M 30 SDF

"Being given better information about the treatment process and who I would be seeing."

F 26 SDF

### 3.5. Treatment for hepatitis C

#### Those who had received treatment

Sixteen respondents (16/79 [20%]) had received treatment for their hepatitis C infection. The median year for commencing treatment was 2005 (range 1985 to 2007).

The majority of people who received therapy (11/16 [69%]) expected a 'cure' and 25% (4/16) anticipated side effects from the treatment.

"I just thought it would cure me."

F 44 Anam Cara

"[I expected] that it would cure me, but that there would be some difficult side-effects."

M 38 SDF

"I knew that there could be side effects from treatment. I also thought the success rate was higher than I now know it is."

F 40 Anam Cara

"I had a negative vision of treatment. I thought it would be a frightening experience"

M 36 SDF

All respondents (16/16) who received treatment reported they had experienced side effects and these were described with varying levels of severity. Sixty-three percent (10/16) reported mental-health related side effects, and half (8/16) had flu-like symptoms.

“Really difficult. My whole personality has changed as a result of going through treatment.”

F 40 Anam Cara

“It was mentally and physically hard.”

M 37 C-Level

“The treatment done its job but it wasn't good with the side effects.”

M 40 C-Level

Of those who had received treatment, 31% (5/16) reported that they had to stop treatment early because of side effects.

Respondents were asked to describe what had gone well with respect to their treatment. Thirty-eight percent (6/16) reported viral response / successful outcome of treatment and 31% (5/16) identified the information and support that they had received from the clinic.

“The end result was best for me.”

M 40 C-Level

“Liver function tests were getting better every time.”

M 38 SDF

“Outcome. Opinion of self.”

M 30 SDF

“I was treated with respect and everything was explained well to me as it came up.”

M 38 SDF

“The hospital were always there for me when I needed support.”

F 40 Anam Cara

When asked what would have improved their experience of therapy, 31% (5/16) reported that they would have appreciated more information and/or support during treatment.

“More informed GP with regard to infection and treatment side effects.”

M 30 SDF

“I could have got a lot more support. I needed respite to get time away from my children.”

F 44 Anam Cara

“The hard part was I nearly relapsed [into drug use] because of the side effects.”

F 40 SDF

### Those who had not received treatment

Half of respondents who had received treatment (8/16) reported that all their needs had been met during treatment.

“The hospital were always there for me when I needed support.”

F 40 Anam Cara

“Nothing could have been any better for me.”

M 36 SDF

“Didn't have any complaints.”

M 48 SDF

Eighty percent of respondents (63/79) had not received treatment. Of these, 21% (13/63) attributed this to continuing use of alcohol and other drugs, and 10% (6/63) to their own fears or concerns about side effects.

“I was still using at the time I was tested. I've not got round to finding out about treatment now that I'm clean.”

M 36 SDF

“I've been told that I won't get treatment until I stop drinking, they won't give me any help to stop drinking though.”

M 32 SDF

“I was told that the side effects of interferon were really bad and this put me off going for treatment.”

M 38 SDF

“I had heard horror stories about how bad the side effects could be.”

M 30 SDF

### 3.6. Perceptions of discrimination

Respondents were asked if they thought they had ever been discriminated against as a result of their hepatitis C status, and were asked to expand on their answers.

#### Those who had not experienced discrimination

The majority of participants, 80% (61/76), reported that they had not had the experience of discrimination. Just eight of these gave further details and indicated that this was because they had not disclosed their status to other people.

"I haven't took the chance as I don't know how my family will react, so I haven't told anyone"

M 47 SDF

"No discrimination as I've not told people."

M 38 SDF

### Those who felt discriminated against

Twenty percent of respondents (15/76) reported that they had experienced discrimination and all expanded upon their answers. Six of these reported negative reactions from family, friends and neighbours.

"Local people who know I have hep C have made comments in public."

M 40 SDF

"Some friends and family have fears around it and act strange sharing cups etc."

M 48 Anam Cara

"People who know I have it have avoided me in social circles."

F 31 SDF

Five respondents perceived that they had suffered discrimination when accessing hospital services.

"When I was at hospital all the staff wore gloves around me and I had a big orange sticker put above my bed saying 'HEP C RISK'."

F 25 SDF

"It was ... the attitude of the nurses on wards in hospital."

M 34 Anam Cara

"At the hospital there was a big sticker on my file which I thought looked as if it just said 'unclean'."

M 32 SDF

Three people reported negative responses when accessing dental care.

"My dentist will only offer me appointments at specific times since he found out I am hep C positive."

M 20 SDF

"My dentist made me return to the surgery for the last appointment of the day after I informed him I was hep C positive. My appointment had been made for earlier in the day and I had to go back at the end."

M 30 SDF

Two respondents reported problems with potential employers.

"I was offered employment however the company procrastinated when informed of recent medical history."

M 36 SDF

### 3.7. Impact on those affected by hepatitis C

In order to understand the impact on those affected by the virus, participants were asked if their status had affected people around them (e.g. partner, children, family, and friends).

#### Those who reported no impact on friends and family

Just over half of respondents (41/77) reported that their status had not affected people close to them and thirty provided further information to support their answer. Twenty of these indicated that they had chosen not to disclose that they were living with hepatitis C.

"I've not told anyone that I have hep C because I'm scared of their reaction."

M 36 SDF

"I've tried to keep my status a secret."

M 30 SDF

Six reported that their partners were also living with hepatitis C.

"I've not told anyone except my partner who is also positive."

M 30 SDF

"My partner isn't bothered ... but that's probably because he's hep C as well."

M 47 SDF

Four indicated that their family members were well informed about the virus.

"My family are clued up about hep C so [they] don't worry."

M 33 SDF

"My family are aware of the issues surrounding hep C. I didn't tell anyone outside my immediate family."

M 36 SDF

## Those who felt that their hepatitis C had affected people around them

Forty-seven percent (36/77) reported that their status had affected their friends and family, and all gave further details of this impact. The majority reported fears and concerns regarding onward transmission of the virus. Many of these concerns were based on a lack of understanding on the part of others regarding routes of transmission.

"My family are more careful around me, they give me my own cup, cutlery etc."

M 42 SDF

"I haven't been made welcome in my own family's houses because they don't understand much about how it can be caught."

F 44 Anam Cara

"My family treat me different because I have hep C, they don't understand how you can catch it."

M 45 Anam Cara

"My mum and wee brother both had to get tested when I got my positive results. My family didn't know much about it at the time I got tested positive."

M 26 SDF

Other concerns about onward transmission were based on recognised risk factors.

"I was caring for my grandmother and had to take care not to mix up our toothbrushes etc."

F 21 SDF

"I have to take care that my children don't get our toothbrushes mixed up."

M 20 SDF

"I have to watch if I'm bleeding my partner or mother get very wary."

M 46 Anam Cara

## 4. Discussion

### Testing

Participants in this study had accessed HCV testing in a range of settings, and many had been tested on multiple occasions and in more than one setting. It is widely recognised that pre- and post-test discussions are an important element of the testing process (RCPE 2004, SIGN 2006, RCGP 2007). These discussions provide an opportunity for healthcare professionals to address the information and support needs of people considering testing, and to ensure that they understand the process and meaning of the testing process and results.

This study indicates that, for many people accessing testing, opportunities to provide information and support at the time of testing were missed. Other work has suggested that one-third to one-half of people are tested without adequate information or explanation being provided (Hopwood & Treloar 2004, Smith & Lyons 2006), and this experience is reflected in our findings. Many participants reported that they did not understand the testing process or the meaning of results, and a small proportion reported that they had been tested without their knowledge or consent.

Respondents identified their information needs at the time of testing. Many lacked even a basic understanding of hepatitis C and expressed a need for general information about the condition. More specifically, they had concerns about the impact of HCV on quality of life, symptoms that could be expected and general prognosis. Phase I of the National Action Plan for Hepatitis C recognises that "*individuals who have been diagnosed with the virus will inevitably have a number of immediate questions and concerns [and that] services have a duty to provide this information in a way that is clear and accessible to the individual*" (Scottish Executive 2006). This study suggests that there is a need to increase efforts to address any "*fear, worry and confusion*" that could be experienced at the time of diagnosis (ibid).

### Hospital hepatitis C care

National clinical guidance recommends that "*referral to specialist care should be considered for all patients with active HCV infection*" (SIGN 2006). Over half of the participants in this study reported that they were not offered such a referral at the time of diagnosis. Common perceived reasons for this on the part of respondents were that they had been in prison at the time, that they enjoyed a chaotic lifestyle or that the person

who tested them lacked knowledge or ability to engage.

The majority of people who were referred to hospital did not know what to expect, and most stated that little or no information had been provided at the time of diagnosis or referral. Less than one third of those who were referred to hospital knew what to expect. However, some respondents indicated that they had benefitted from clear and informative pre- and post-test discussions.

This study explored patients' perceptions of what had gone well at hospital as well as areas in which improvements could be made. Research elsewhere suggests that the prospect of engaging with healthcare professionals is often a source of anxiety to people with hepatitis C (Zickmund et al 2004, McLaughlin et al 2000). These anxieties often include fear of judgemental staff attitudes relating to injecting drug use, complicated clinical terminology and a lack of clarity in the clinical process. Almost half of the respondents to this study who had attended hospital highlighted the value they placed on the effective communication skills shown by clinical staff. They especially valued being treated with respect and having each step of the patient journey explained to them in simple language.

When asked how their experience of clinical care could have been improved, the need for more information and support was re-emphasised. Respondents were keen to understand what would happen to them in hospital and had continuing concerns relating to the impact of HCV on their health and wellbeing.

The National Action Plan for Hepatitis C notes that "*only half of those referred [to hospital] attend clinics*" (Scottish Executive 2006). The paucity of information provided at the time of diagnosis and referral may contribute to this high attrition rate. There are opportunities to increase engagement with clinical services by providing potential patients with information that is both accessible and appropriate to their needs. This study suggests that once people have engaged with a clinical HCV service, they are likely to value the approach and interpersonal skills of the staff they meet there.

## Clinical Treatment

One-fifth of respondents had experience of anti-viral treatment and, of these, half had commenced therapy within the last three years. The clinical efficacy of HCV treatment ranges from around 41-51% of patients (genotype 1/4) to 73-82% (genotype 2/3). Overall, 55% of people who receive therapy can expect to clear the virus (SIGN 2006).

The usual treatment for HCV involves weekly self-administered injections with pegylated interferon which is associated with a number of side effects. Previous work has shown that:

"over 30% of people receiving treatment experience depression, anorexia, weight loss, irritability, hair loss, joint pain, nausea and insomnia, and more than 50% experience fatigue, headache, and muscle aches" (Fried 2002)

In this study, levels of unrealistic optimism regarding the expected outcome and experience of treatment were identified, findings that have been made in other studies (Hopwood, Treolar & Redsull, 2006). Over two-thirds of participants who commenced therapy had expected to be 'cured' and just one quarter anticipated side effects.

All respondents who commenced therapy reported that they had suffered from side effects, with varying degrees of severity. Mental health side effects were most commonly experienced, and vividly described by a number of participants. One in three respondents reported that treatment was stopped prematurely due to side effects.

Patient-centred information and support were again identified as key facilitators to treatment. One half of patients were so satisfied with their experience of treatment they could not identify any areas for improvement. Other patients reiterated the need for information about the clinical process that prepared them for the experience of treatment. Support needs included practical measures to help cope with family demands whilst on therapy and to avoid relapse into problematic alcohol or drug use.

The majority of participants in this study had not received treatment and were asked to identify the reasons for this. A number

recognised that treatment was not appropriate for them as they were still addressing addiction issues, including both alcohol and illicit drug use. Ten percent had chosen not to access therapy as they had serious concerns regarding side effects.

### Stigma and Discrimination

The majority of respondents reported that they had not experienced hepatitis C-related discrimination. From the limited additional information provided, it would appear that this may be associated with respondents having chosen not to disclose their status to others for fear of a negative reaction. This may reduce the risk of stigma and discrimination but may also result in loss of opportunities for the person living with hepatitis C to access emotional and practical support from those closest to them.

One-fifth of respondents indicated that they had suffered from discrimination on the basis of their HCV status, and this finding is congruent with the findings of Australian research (Day, Ross & Dolan, 2003). In line with previous work (ibid), discrimination was most often reported in relation to social, healthcare and employment settings.

	Study Sample	Day, Ross & Dolan (2003)
Social	40% (6/15)	33% (22/67)
Healthcare	33% (5/15)	37% (25/67)
Employment	13% (2/15)	16% (11/67)
Dental	20% (3/15)	9% (6/67)

Experience of discrimination in all these settings is reminiscent of early responses to HIV. This was a function of low levels of public awareness, inaccurate perceptions regarding vectors of onward transmission, and stigma associated with recognised routes of transmission. It has been noted elsewhere (Astone-Twerell, Straus & Munoz-Plaza, 2006) that people infected with hepatitis C through injecting drug use are often subject to 'double stigma' based on both their HCV status and their (current or previous) drug use. From the additional information provided by respondents, it is possible to identify two key aspects to these reported experiences.

Firstly, some reported experiences are based on clearly discriminatory and inappropriate behaviour, e.g. a hospital inpatient reported that he/ she had had a label above the bed stating his/her hepatitis C status and a dental patient was asked to attend at the end of the day.

Secondly, other responses suggest that people with hepatitis C may inaccurately perceive themselves as being discriminated against. For example, one respondent noted that the medical notes contained a sticker with information about hepatitis C status. This information could be relevant to clinical care and its inclusion in their notes may be appropriate. However, this respondent went on to say that she had perceived the sticker as being 'big' and "*thought [it] looked as if it just said 'unclean'*". Previous work indicates that people with hepatitis C and those with a history of injecting drug use are likely to approach clinical encounters with a '*fear of mistreatment*' (Merrill et al, 2002) and an expectation that clinical staff are likely to be '*uncaring*' (M<sup>c</sup>Laughklyn, M<sup>c</sup>Kenna & Leslie, 2000).

### Those affected by hepatitis C

Of those who reported that their status had not affected people close to them, many had either not disclosed or reported that their partners were also hepatitis C positive. This suggests that many individuals and couples living with hepatitis C feel unable to disclose their status to those closest to them for fear of a negative reaction. As stated before, it is appropriate that people can choose who they disclose their status to, but it is concerning that they may be denied opportunities to access support from friends and family members.

Just under half reported that their status had affected people around them. This was often associated with inaccurate and exaggerated perceptions held by family members regarding routes of transmission.

This situation is likely to increase feelings of stigma amongst people living with the virus and further reduce opportunities for them to receive support from family members and close friends.

## Limitations

A number of limitations were identified in relation to this scoping exercise.

Firstly, the evaluation adopted convenience and snowballing sampling methods. Whilst this method was practical for this scoping exercise and proved effective in engaging with persons traditionally considered 'hard to reach' it was not possible to generalise these findings to all Glasgow and Clyde residents living with hepatitis C, including those infected through routes other than injecting drug use<sup>2</sup>.

The following table highlights some key differences between the study population and all persons diagnosed with HCV in the area. It can be seen that people who participated in this evaluation are more likely to be male and to have been tested in a custodial setting.

	Study sample	NHSGGC †
Male	75% (59/79)	67% (6,272/9,361)
Tested in Prison	19% (15/79)	7% ( 648/9,361)
Tested at GP	11% (7/79)	24% (2,215/9,361)
Tested in Hospital	49% (39/79)	42% (3,976/9,361)

† Source: HPS 2007

Secondly, HCV-positive antibody status was self-reported and not confirmed before participation in the evaluation. Confirmatory testing was beyond the scope of this exercise because of concerns regarding confidentiality and cost, and would have required use of peer researchers. However, previous work has suggested that false-negative reporting is more common than false-positive reporting (Best et al 1999).

Questionnaires were administered face-to-face, which may have introduced interviewer bias and resulted in socially desirable answers being provided (Tourangeau and Yan 2007). To mitigate these factors, the survey was designed to encourage reporting of both positive and negative experiences. For example, respondents were asked to consider their experience of testing and to identify both "*what went well*" and "*what would*

*have made it better for you*". In addition, the SDF peer researchers had received training in research methodology and ethics and were aware of the need to minimise undesirable influences on their work.

Finally, respondents were not asked when they had engaged with testing and treatment services or whether they had accessed services outwith Greater Glasgow and Clyde. As a result, the findings may not reflect current local practice.

As noted in the methods section, the use of convenience and snowball sampling means that it would not be appropriate to generalise these findings to the whole population of people with hepatitis C. However, the findings presented here are not at variance with other published studies, and we consider that this evaluation provides a useful indication of the needs of local people living with hepatitis C.

## 5. Recommendations

### 1. Information for people living with & affected by hepatitis C

The main recommendation from this evaluation concerns the information provided to people living with and those directly affected by hepatitis C. Information should be available through a range of resources and face-to-face interventions. It should be clear, consistent and address the expressed concerns of target populations. When developing information, consideration should be given to the following key areas:

- a. Clarify the facts regarding onward transmission, to address inaccurate concerns surrounding normal social contact, and to reduce genuine transmission risks associated with the sharing of toothbrushes, razors etc.
- b. Address the knowledge and attitudes of family members, partners and friends of people living with the virus, enabling them to provide practical and emotional support when needed. Such information should highlight some of the difficulties that people can experience following diagnosis, how to manage the symptoms of HCV infection, and particular issues concerning treatment.

<sup>2</sup> Representing 10% of those with a known risk factor (HPS 2008a)

- c. Provide practical advice to enable people living with the virus to maximise their own health, including suggestions regarding diet, exercise, stress management etc.

It is recommended that further research is conducted to identify these information needs. All information resources should be developed and pre-tested with members of the target populations.

## 2. Hepatitis C testing

It is appropriate that HCV testing should be available in a number of settings, including prisons, primary care and drug and alcohol services. Wherever a person accesses testing, this service should be delivered to an agreed standard, including adequate pre- and post-test discussion. In line with recommendations of the Managed Care Network:

“All patients should be offered a pre-test discussion with a suitably trained healthcare professional. This discussion allows the patient to understand risk factors, the testing process, the meaning of test results, and confidentiality of this information.

It is important that the patient understands these in order to give informed consent to be tested. Any fears and anxieties should be discussed, as well as the implications of a positive or negative result.

Results should be given in person and supported by a post-test discussion, whatever the outcome.”

(HCV MCN 2007)

## 3. Referral to Clinical Care

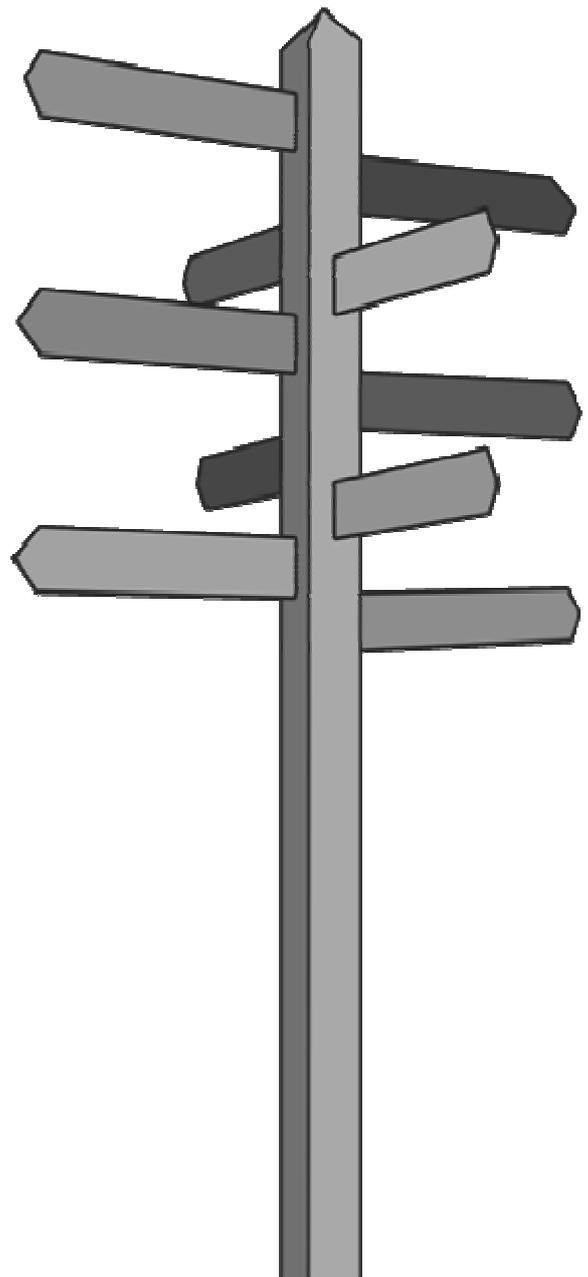
Whilst referral to hospital HCV care should be considered for all people diagnosed with hepatitis C, it is important to recognise that many people have more pressing issues that need to be addressed before they are ready to engage with clinical HCV services. These may include alcohol or drug use, imprisonment, and difficulties coming to terms with their diagnosis.

It is recommended that people are given a choice regarding the timing of their referral to hospital. If they need to address other priorities in their lives first, these should be

tended to and the issue of HCV care revisited when they are ready. This will require effective partnership working between testing agencies, clinical services and providers working in associated areas, including drug and alcohol services, criminal justice, mental health, social care etc.

## 4. Further research and evaluation

As noted in the introduction, this report represents the findings from an initial scoping exercise into the experiences of people with hepatitis C. This was intended to identify key themes to inform further evaluation and research activity in this area. We recommend that further work is conducted to build on the findings of this scoping exercise and develop the contribution of people living with hepatitis C to the planning, design and delivery of services designed to meet their needs.



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## 7. Appendix A: Survey Tool

The first part of the survey is just about you and your experiences of hepatitis C. We will ask about your friends, family etc. later on.

I am going to start by asking some general questions about you:

1.	What is your date of birth?	___/___/___	
2.	What is the first part of your postcode?	-----	
3.	Gender	M <input type="checkbox"/> F <input type="checkbox"/>	

### QUESTIONS ABOUT YOUR EXPERIENCE OF TESTING

4.	a: Tell us the places where you have ever been tested for hepatitis C.  b: Where was your most recent test?		a: Ever Tested Tick all that apply	b: Most Recent Test Tick one
		GP	<input type="checkbox"/>	<input type="checkbox"/>
		Brownlee	<input type="checkbox"/>	<input type="checkbox"/>
		Other Hospital	<input type="checkbox"/>	<input type="checkbox"/>
		C~Level	<input type="checkbox"/>	<input type="checkbox"/>
		Prison	<input type="checkbox"/>	<input type="checkbox"/>
		Community Addiction Team	<input type="checkbox"/>	<input type="checkbox"/>
		Shared Care Clinic	<input type="checkbox"/>	<input type="checkbox"/>
		Other drug service	<input type="checkbox"/>	<input type="checkbox"/>
		Homeless Health Service	<input type="checkbox"/>	<input type="checkbox"/>
		Other (please specify below)	<input type="checkbox"/>	<input type="checkbox"/>

### THINKING ABOUT YOUR MOST RECENT TEST:

5.	What information / support did you want around the time you were tested?	<hr/> <hr/> <hr/> <hr/> <hr/>	
----	--------------------------------------------------------------------------	-------------------------------	--

6.	What information / support did you receive?	<hr/> <hr/> <hr/> <hr/> <hr/>																																		
7.	Who provided this information / support?	<hr/> <hr/> <hr/> <hr/> <hr/>																																		
8.	Did you understand the testing process and what the results meant?	Y / N		If Y go to Q10																																
9.	If no, what would have helped you understand the test or the results?	<hr/> <hr/> <hr/> <hr/> <hr/>																																		
10.	When you received your positive result, were you referred to any other service(s) for help with your hepatitis C?	Y / N		If N go to Q12																																
11.	Which services were you referred to?	<table border="1"> <tr><td>GP</td><td><input type="checkbox"/></td></tr> <tr><td>C~Level</td><td><input type="checkbox"/></td></tr> <tr><td>Anam Cara</td><td><input type="checkbox"/></td></tr> <tr><td>Community Addiction Team</td><td><input type="checkbox"/></td></tr> <tr><td>Shared Care Clinic</td><td><input type="checkbox"/></td></tr> <tr><td>Other drug service</td><td><input type="checkbox"/></td></tr> <tr><td>Other (please specify below)</td><td><input type="checkbox"/></td></tr> <tr><td> </td><td> </td></tr> </table>	GP	<input type="checkbox"/>	C~Level	<input type="checkbox"/>	Anam Cara	<input type="checkbox"/>	Community Addiction Team	<input type="checkbox"/>	Shared Care Clinic	<input type="checkbox"/>	Other drug service	<input type="checkbox"/>	Other (please specify below)	<input type="checkbox"/>			<table border="1"> <tr><td>GP</td><td><input type="checkbox"/></td></tr> <tr><td>C~Level</td><td><input type="checkbox"/></td></tr> <tr><td>Anam Cara</td><td><input type="checkbox"/></td></tr> <tr><td>Community Addiction Team</td><td><input type="checkbox"/></td></tr> <tr><td>Shared Care Clinic</td><td><input type="checkbox"/></td></tr> <tr><td>Other drug service</td><td><input type="checkbox"/></td></tr> <tr><td>Other (please specify below)</td><td><input type="checkbox"/></td></tr> <tr><td> </td><td> </td></tr> </table>	GP	<input type="checkbox"/>	C~Level	<input type="checkbox"/>	Anam Cara	<input type="checkbox"/>	Community Addiction Team	<input type="checkbox"/>	Shared Care Clinic	<input type="checkbox"/>	Other drug service	<input type="checkbox"/>	Other (please specify below)	<input type="checkbox"/>			Tick all that apply
GP	<input type="checkbox"/>																																			
C~Level	<input type="checkbox"/>																																			
Anam Cara	<input type="checkbox"/>																																			
Community Addiction Team	<input type="checkbox"/>																																			
Shared Care Clinic	<input type="checkbox"/>																																			
Other drug service	<input type="checkbox"/>																																			
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Shared Care Clinic	<input type="checkbox"/>																																			
Other drug service	<input type="checkbox"/>																																			
Other (please specify below)	<input type="checkbox"/>																																			
12.	Were you referred to a Hospital hepatitis C clinic  (e.g. Brownlee or a Gastro/Liver clinic)	Y / N		If Y go to Q14																																

13.	If no:  Why do you think you were not referred?	<hr/> <hr/> <hr/> <hr/>	
<p>The following section is for people who answered <b>Yes</b> to <b>Q14</b>, and have been referred to a hospital Hep C / Liver clinic. If they have not been referred to or attended hospital for their Hep C, go to <b>Q30</b></p>			
14.	Were you given a choice about which Hospital you could attend?	Y / N	
15.	At the time, did you know what to expect from going to Hospital?	Y / N	
16.	Could you expand on your answer:	<hr/> <hr/> <hr/> <hr/>	
<b>THINKING ABOUT YOUR EXPERIENCE OF HOSPITAL HEPATITIS C SERVICES:</b>			
17.	What went well?	<hr/> <hr/> <hr/> <hr/>	
18.	What would have made it better for you?	<hr/> <hr/> <hr/> <hr/>	
<b>TREATMENT FOR HEPATITIS C</b>			
19.	Have you ever received treatment for hepatitis C?	Y / N	<b>If Y go to Q22</b>

20.	If no, why not?	<p>I didn't think the treatment was likely to work <input type="checkbox"/></p> <p>I was concerned about side effects <input type="checkbox"/></p> <p>I was still using drugs <input type="checkbox"/></p> <p>I was still drinking alcohol <input type="checkbox"/></p> <p>I was in prison <input type="checkbox"/></p> <p>Other (please specify below) <input type="checkbox"/></p> <p>_____</p>	<b>Tick all that apply</b>
21.	Could you expand on your answer	<p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<b>Go to Q30</b>
22.	What year did you start treatment	_____	
23.	What were your expectations of treatment?	<p>_____</p> <p>_____</p> <p>_____</p>	
24.	Overall, what was your experience of treatment?	<p>_____</p> <p>_____</p> <p>_____</p>	
25.	What went well?	<p>_____</p> <p>_____</p> <p>_____</p>	
26.	What could have been better?	<p>_____</p> <p>_____</p> <p>_____</p>	
27.	Did you have any side effects from the treatment?	Y / N	<b>If N go to Q30</b>
28.	If yes, please describe them in your own words.	<p>_____</p> <p>_____</p> <p>_____</p>	
29.	Did you stop treatment early because of the side effects?	Y / N	

SOCIAL FACTORS			
30.	In your opinion, have you ever been discriminated against because of your hepatitis C?	Y / N	If N go to Q32
31.	If yes, what happened to make you feel discriminated against.	_____ _____ _____ _____	
32.	Has your hepatitis C status affected people around you (e.g. partner, children, family, friends)	Y / N	
33.	How?	_____ _____ _____ _____	
THIS SECTION IS FOR RESEARCHER USE ONLY			
DVD given out?    Y <input type="checkbox"/> N <input type="checkbox"/>  Interview Location    SDF Setting <input type="checkbox"/> C-Level <input type="checkbox"/> Anam Cara <input type="checkbox"/> Other <input type="checkbox"/> (please specify below) _____  Checked by JC?    Y <input type="checkbox"/> N <input type="checkbox"/>			

## 8. Appendix B: Information Sheet & Consent Form

### **Scottish**drugs**Forum**

5 Waterloo Street, Glasgow

#### **STUDY INFORMATION SHEET**

#### **Evaluation of Services for People with Hepatitis C**

Greater Glasgow & Clyde Health Board have commissioned the Scottish Drugs Forum to conduct a survey of people with diagnosed hepatitis C. A major part of this review is to find out people's experiences of living with hepatitis C, and the services they use.

There are no direct benefits to you in taking part in this research; however your views will be used to try to improve the service for drug users.

#### **What will the interview involve?**

We will be asking questions regarding your experience of testing, diagnosis, NHS services, and the impact of hepatitis C on people around you.

The interviewers have been trained by the Scottish Drugs Forum. All are themselves stabilised or former drug users, and all have previous survey experience. The interview will last about 30 minutes.

The information you give in your interview will be treated confidentially. It will not be passed on to anyone at the service you currently attend or any you may have attended in the past. All information gathered will be anonymous and will be used for research purposes only.

You can back out of the interview at any time, or refuse to answer any of the questions, without giving a reason. This won't affect any future treatment you may get at any agency.

#### **Any Questions?**

The interviewers are happy to answer any questions you have about this study.

## CONSENT FORM

### Evaluation of Services for People with Hepatitis C

- I have read, understood and have a copy of the study information sheet on the above study.
- I have been able to discuss the study and ask questions about it.
- I understand that I can withdraw from the study at any time, without having to give a reason and that this will not affect my right to attend this service.
- I understand that any information about me will be kept confidential.

Please tick your response and print your initials and the date below

I give my consent to be interviewed: Yes / No

Print Initials: \_\_\_\_\_

Date: \_\_\_\_\_

**Thank you for your assistance**