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Hepatitis Australia would also like to acknowledge the members of the Project Reference Group and staff of the following organisations for their assistance:

ACT Hepatitis Resource Centre
Australian Injecting and Illicit Drug Users League (AIVL)
Cairns Base Hospital Liver Clinic, Queensland
Department of Health and Human Services, Tasmania
Hepatitis C Council of New South Wales
Hepatitis C Council of South Australia
Hepatitis Council of Queensland
HepatitisWA
Hepatitis C Victoria
Multicultural Health and Support Service, Victoria
Multicultural HIV and Hepatitis Services, New South Wales
National Centre for HIV Social Research
Northern Territory Aids and Hepatitis Council
Tasmanian Council on AIDS, Hepatitis and Related Diseases
The Connection, Australian Capital Territory

The National Hepatitis C Needs Assessment 2008, was researched and written by Dr Jacqui Richmond, Hepatitis Australia and funded by the Australian Government Department of Health and Ageing, Hepatitis C Education and Prevention Initiative.

The views and recommendations in the National Hepatitis C Needs Assessment 2008, do not necessarily represent the views of the Australian Government Department of Health and Ageing.
Abbreviations

ACT     Australian Capital Territory
AIVL    Australian Injecting and Illicit Drug Users’ League
AOD     Alcohol and other drugs
CALD    Culturally and Linguistically Diverse Communities
ESL     English as a Second Language
GP      General Practitioner
NSP     Needle and Syringe Program
NSW     New South Wales
NT      Northern Territory
PCR     Polymerase Chain Reaction
PRG     Program Reference Group
QLD     Queensland
SA      South Australia
WA      Western Australia

The term ‘Hepatitis Organisation’ has been used throughout the report to refer to the peak national, and state and territory organisations which receive funding specifically to provide services for people living with, or affected by, hepatitis C. Previously, Hepatitis Organisations were referred to as Hepatitis Councils.
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Executive Summary

Purpose
The purpose of the National Hepatitis C Needs Assessment (2008) was to identify the education, information and support needs of Australians living with hepatitis C; to inform the development of improved information, education and support services for people with hepatitis C in Australia. This project builds on, and will provide an update to the Needs Assessment conducted by Hepatitis Australia in 2003.1

Methodology
A triangulation of quantitative (questionnaire) and qualitative (focus groups and semi-structured interviews) were used to characterise the hepatitis C information, education and support needs of people living with hepatitis C in Australia. The questionnaire was informed by the results of an initial three focus groups involving a broad range of people living with hepatitis C. Subsequent focus groups and telephone interviews targeted members of priority populations and explored in greater detail the results of the questionnaire.

Results
In total, 327 people participated in the Needs Assessment. Of these, 261 people responded to the questionnaire, 55 were involved in focus groups and 11 people participated in in-depth interviews.

Questionnaire results
The findings of the questionnaire provide a valuable insight into the information, education and support needs of 261 people living with hepatitis C from diverse backgrounds.

Time of Diagnosis
Diagnosis was a time of concern for questionnaire respondents, primarily because they did not receive adequate information. The majority of respondents were diagnosed by their GP (62%). After diagnosis, only half the respondents (52%) had the impression that hepatitis C was a serious but treatable condition.
Information and education needs
Approximately two thirds of respondents believed they had access to enough information to make informed decisions about their hepatitis C, either all the time, or most of the time. However, the remaining one-third of respondents stated they sometimes, or rarely had enough information to make informed decisions.

The preferred methods of receiving hepatitis C information were face-to-face (67%), printed resources (55%) and internet websites (35%). Hepatitis Organisation print resources and websites were generally considered the best sources of information.

Medical and nursing specialists were highly regarded as sources of information. Other people with hepatitis C and GPs were rated as one of the best and one of the worst sources of information, which reflects the diversity in respondents’ experiences.

Sixty per cent of respondents indicated they had additional, unmet hepatitis C information and education needs on a range of topics.

Support needs
Only 17% of respondents had always felt supported to manage their hepatitis C, and 39% felt supported most of the time. Once again, face-to-face contact was the preferred method of obtaining support (85%).

Liver specialists (37%) and GPs (42%) were the most frequently preferred sources of support. Other useful sources of support included the printed resources produced by Hepatitis Organisations (50%) and the personal perspectives of other people living with hepatitis C (34%).

Approximately a quarter of respondents (23%) either belonged to, or had attended a hepatitis C support group, and a further 28% indicated they would like to belong to a support group, but the majority did not know how to access a support group locally. Forty eight percent of respondents had accessed the services offered by a Hepatitis Organisation.

Disclosure of hepatitis C status was noted as an impediment to accessing support and attending support groups; the majority of respondents (58%) indicated they had chosen to tell only a small number of people they trusted.
Focus group and interview Results
The following data is presented according to themes that emerged in eight focus groups and 11 individual interviews.

Information needs at diagnosis
Consistent with the questionnaire findings, few participants were knowledgeable about hepatitis C prior to diagnosis. The process of being diagnosed with hepatitis C did not result in significant improvements in knowledge for most participants.

Impact of hepatitis C-related stigma
Hepatitis C-related stigma and discrimination were identified as significant barriers to openly and freely accessing hepatitis C information and support.

Information and education needs
Participants’ information needs evolved as they experienced the spectrum of hepatitis C infection.

Similar to the questionnaire respondents, focus group participants preferred to obtain information through face-to-face contact with professionals and other people living with hepatitis C.

Printed resources and the internet were commonly used for information gathering and the latter had the advantage of providing participants with a means of accessing information confidentially. However, participants expressed concern about trusting information on the internet. Younger participants tended to be less discerning about the trustworthiness of information on the internet. Participants also acknowledged that access to the internet remained limited for many people in Australia.

Many participants emphasised that they preferred to use a variety of methods to gather information, as this assisted them to clarify, retain and understand the information presented.

Valued sources of information
When participants were making hepatitis C management or treatment decisions, they valued the opportunity to interact with other people living with hepatitis C. Hearing other people’s stories either face-to-face or through printed resources was highly regarded.
Printed resources produced by Hepatitis Organisations were instrumental to many participants’ understanding of hepatitis C and were considered a cornerstone of information and education activities. However, some printed resources presented only a generalised perspective.

Public education forums offered by Hepatitis Organisations were valued sources of information as they provided an opportunity to gather information directly from a range of experts.

Health professionals, specifically liver specialists and liver clinic nurses, were trusted sources of hepatitis C information. General practitioners were frequently identified as lacking hepatitis C knowledge, which supported the questionnaire findings. Nonetheless, GPs remained a preferred source of information for people living with hepatitis C.

**Unmet information needs**
Participants identified a variety of topics for which they required additional information. Many of these topics were consistent with the needs identified by questionnaire respondents, including anti-viral treatment, coping with non-response or relapse after treatment, self-management strategies and understanding clinical terminology and concepts.

**Barriers to accessing information**
Key barriers to accessing information included poorly informed health professionals, especially GPs, inappropriately targeted resources and experiences of actual or perceived hepatitis C-related stigma.

**Accessing support**
Participants discussed numerous methods of accessing support, including face-to-face, on the telephone and on the internet. Other people living with hepatitis C were a preferred source of support because they demonstrated the greatest empathy.

**Peer support**
The majority of participants indicated they would appreciate the opportunity to talk to another person living with hepatitis C. Whether the contact was initiated through a support group, telephone service or the internet, depended on the individual’s personal preference, however, the supportive impact was equally as significant.
Consideration of, or commencing on, anti-viral treatment were common triggers for participants to seek peer support.

Distribution of information and support through peers was particularly important for people who inject drugs.

**Practical support**

The need for practical support while on treatment, such as help with meal preparation, shopping and cleaning, was raised regularly by participants.

**Unmet support needs**

The majority of people involved in the Needs Assessment wanted to receive hepatitis C support from health professionals; most frequently their GP and/or liver specialist and liver clinic nurse if they were on anti-viral treatment. In reality, many participants did not have access to support before they were referred to the liver clinic. However, time constraints were a barrier to accessing support both in the liver clinic and general practice settings.

Ideally, participants wanted to be supported by family and friends, but reported that they often lacked understanding of what it was like to live with hepatitis C.
Information and support needs of priority populations

People who inject drugs
Distribution of information and support through peers was very important for people who inject drugs. Resources developed by Drug User Organisations were particularly useful, because the information was specifically targeted towards people who inject drugs.

Homeless people
Homeless people living with hepatitis C have a range of competing demands that need to be addressed. Based on these findings, there is a need to develop the hepatitis C capacity of the staff of organisations working with homeless people.

Culturally and Linguistically Diverse (CALD) populations
Workers advocated for CALD resources to be developed in the community language to provide specific information about treatment, the practicalities of accessing treatment and the importance of monitoring and health maintenance.

General information about the structure and function of the Australian Health Care System was identified by CALD workers as being equally as important as the provision of hepatitis C information.

People living with hepatitis C in custodial settings
Hepatitis C workers in custodial settings described the proliferation of a variety of custodial specific resources including printed, visual and auditory resources, compulsory training and access to supportive health professionals.

The important role of peer education and support in custodial settings was also emphasised. Face-to-face was the preferred method of obtaining information for confidentiality reasons.

Aboriginal and Torres Strait Islander populations
The importance of having a comprehensive approach to providing hepatitis C information and support to Aboriginal and Torres Strait
Islander people was emphasised. A combination of human and printed resources was considered ideal. Participants prioritised the need to build the hepatitis C capacity and infrastructure of Aboriginal and Torres Strait Islander health services concurrently, so information and support could be provided in a familiar and culturally appropriate service.

People living in rural areas
Lack of confidentiality was considered part of the landscape in rural Australia and was a significant barrier to accessing hepatitis C support. Participants explained that while information could be accessed anonymously through the internet or on the telephone, they preferred to access support through direct human contact.

Young people
Generally, young people believed they did not have any particular needs regarding hepatitis C. They considered that because they did not experience symptoms related to hepatitis C, it was not worth worrying about. Most had not sought information or support and the importance attributed to hepatitis C infection was low.

Considerations when using the Needs Assessment
Several issues related to the methodology and findings must be considered when using the Needs Assessment.

Although a broad range of people with hepatitis C were involved in the Needs Assessment, including representatives of the key priority populations, it is acknowledged that the 327 people who were consulted may not be a representative sample of all people living with hepatitis C in Australia. In particular, the needs of people not linked to hepatitis C services may not be accurately reflected in the results, as many participants were accessed through either hepatitis C-related community organisations or hepatitis C clinical services.

Significant barriers were encountered when attempting to consult with people with hepatitis C who come from a range of culturally and linguistically diverse (CALD) backgrounds and people living with hepatitis C in custodial settings. Therefore, their needs were assessed from the perspective of the hepatitis C professionals working in these areas, which may have biased the results,
because they may not have accurately reflected the needs of these priority groups.

People living with hepatitis C were reimbursed for their involvement in the project which may have biased the results.

Limitations associated with the questionnaire design are recognised. Data collection was conducted over a short time frame which may have limited the number of participants and therefore the depth of the findings.

Recommendations
The following recommendations were developed after consultation with Hepatitis Organisations and other professionals working in the sector.

1. Establish a national ‘Hepatitis C Time of Diagnosis Project’ specifically targeting GPs to develop and implement best practice guidelines around the time of hepatitis C diagnosis.
2. Implement a well-designed hepatitis C public education campaign which dispels the myths and misconceptions around hepatitis C and reduces the negative impact of stigma.
3. Develop effective partnerships with anti-discrimination agencies to guide further action to address hepatitis C-related discrimination.
4. Hepatitis organisations and specialist clinical services consider strategies to increase access to quality interactive information services incorporating hepatitis C peers and health professionals.
5. The National Hepatitis C Resource Network (run by Hepatitis Australia), reviews the results of the National Hepatitis C Needs Assessment as part of their planning process for new consumer resources.
6. Hepatitis-related organisations facilitate timely consumer access to information on new developments in hepatitis C and methods of assessing the quality of international websites.
7. Hepatitis and clinical organisations consider strategies to facilitate improved access to support groups across the country.
8. Hepatitis-related community organisations extend the reach of peer based support programs including treatment-specific programs.

9. Hepatitis-related community organisations promote their support services widely to incorporate family and friends of people living with hepatitis C.

10. Hepatitis Australia consults with Hepatitis Organisations, Hepatitis-related community organisations, clinical services and people living with hepatitis C about the Needs Assessment findings and the strategic development of hepatitis C information, education and support services in Australia.
Introduction

Project overview
The purpose of the National Hepatitis C Needs Assessment was to identify the education, information and support needs of Australians living with hepatitis C. It is anticipated that the recommendations arising from the needs assessment will guide evidence-based planning and delivery of hepatitis C information and education programs and support services throughout Australia.

The key goals of the project were to:

- Identify the major education and information needs of people with hepatitis C.
- Identify the major support needs of people with hepatitis C.
- Identify gaps in current education, information and support provision to people with hepatitis C and canvass options for addressing these gaps.

To ensure hepatitis C education, information and support services are grounded in the identified needs of people with hepatitis C, wide consultation with people living with hepatitis C was undertaken to reflect the diverse array of life circumstances and experiences of the community. However, it is important to highlight that people involved in the Needs Assessment represent a convenience, self-selected sample, which may not be representative of the population living with hepatitis C in Australia.

The project included people living with hepatitis C of all ages from:

- metropolitan and regional areas
- rural and remote Australia
- culturally and linguistically diverse (CALD) communities
- priority populations for hepatitis C health promotion:
  - people living with hepatitis C who inject drugs
  - people living with hepatitis C in custodial settings
  - Aboriginal and Torres Strait Islander people living with hepatitis C.

Although recognised as important, the needs of people at risk of contracting hepatitis C were not considered in the scope of this assessment.
Methodology
A Project Reference Group (PRG) comprising of ten members (including two Hepatitis Australia staff), was convened to guide the progress of the Needs Assessment. Membership of the PRG represented key stakeholders in the fields of hepatitis C education and research, and included representation from the Australian Injecting and Illicit Drug Users League (AIVL), state-based Hepatitis Organisations, the National Centre for HIV Social Research, the Multicultural HIV/AIDS and Hepatitis C Service (New South Wales (NSW)) and three people from the Hepatitis Australia Community Reference Group.

A triangulation of quantitative (questionnaire) and qualitative (focus groups and semi-structured interviews) methodologies were used to characterise the hepatitis C information, education and support needs of people living with hepatitis C in Australia. The Needs Assessment was advertised widely through Hepatitis Organisation activities in the states and territories, their respective quarterly magazines and via websites during the 2008 Hepatitis Awareness Week. Data was collected between March and July 2008.

Questionnaire
A questionnaire exploring the information, education and support needs of people living with hepatitis C was developed in consultation with the PRG and considered the data collected during focus groups held in Victoria, Western Australia (WA) and South Australia (SA) (refer to Appendix 1). The questionnaire was available through the internet using Survey Monkey, and in hard copy. Both versions were identical, and were distributed during May 2008 to coincide with World Hepatitis Awareness Day.

An online link to the questionnaire was posted on the Hepatitis Australia and state and territory Hepatitis Organisation websites. In addition, the questionnaire was distributed through internet chat forums including the online hepatitis C forum (www.hepcaustralasia.com), Needle and Syringe Program (NSP) forum and Diversitylink (Multicultural HIV/AIDS and Hepatitis C Service).

Hard copies of the questionnaire were distributed upon request to individuals and/or workers through the state and territory
Hepatitis Organisations, the Australasian Hepatology Association (AHA) membership (hepatology nurses), Tasmanian Department of Health and Human Services and, Youth Organisations in the states and territories. Completed hard copies were returned to Hepatitis Australia.

Focus groups and interviews
Three focus groups were conducted with a range of people living with hepatitis C in metropolitan and rural Victoria, WA and SA, to inform the development of the questionnaire. Subsequent focus groups were conducted with specific priority populations. Focus group participants were recruited through Hepatitis Organisations, Drug User Organisations, Alcohol and Other Drug (AOD) Services and Multicultural Health Services in Victoria, NSW, Queensland (QLD), Australian Capital Territory (ACT), SA and WA. Focus group participants were offered a nominal sum for their time in participating in the focus group and reimbursement of reasonable travel costs.

Significant barriers prevented the organisation of focus groups with people living with hepatitis C in custodial settings and people from a range of CALD backgrounds. Access to people living with hepatitis C in custodial settings was not permitted because the project had not been approved by a Human Research Ethics Committee. The barrier for CALD communities was created by the logistics of conducting a focus group with people from a diverse range of CALD communities, such as language difficulties, confidentiality and need for cultural sensitivity. Therefore, the needs of people living with hepatitis C from these two priority populations were explored from the perspective of the hepatitis C professionals working in custodial settings and those working with people from CALD communities through teleconference-style focus groups.

Semi-structured telephone interviews were conducted after the focus group and questionnaire data has been analysed to allow further in-depth exploration of key themes. Interviews were targeted towards people living with hepatitis C in geographic areas not included in the focus groups; specifically people living in Tasmania and the Northern Territory, and people living in rural and remote areas of Australia. Interviewees were offered a nominal sum for their participation.

Refer to Appendix 2 and 3 for an outline of the questions used to guide the focus group discussions and telephone interviews.
Results of the Needs Assessment
In total, 327 people living with hepatitis C participated in the National Hepatitis C Needs Assessment 2008, including 261 who responded to the questionnaire, 55 who were involved in focus groups and 11 people who were interviewed. In addition, seven professionals working with people in custodial settings and eight professionals working with CALD communities were also involved.

Results of the questionnaire

Demographic characteristics
In total, 261 people living with hepatitis C responded to the Needs Assessment questionnaire:
• 168 completed the questionnaire on the internet
• 93 completed a hard copy of the questionnaire.
The demographic characteristics of questionnaire respondents are outlined in Table 1.

Table 1: Demographic characteristics of questionnaire respondents (n=261)

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<tr>
<td>Other – Urdu/Panjabi, French, Serbian, Indonesian, Auslan</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Unknown</td>
<td>14</td>
<td>--</td>
</tr>
<tr>
<td><strong>Year of hepatitis C diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1990 and before*</td>
<td>32</td>
<td>14</td>
</tr>
<tr>
<td>1991 – 1995</td>
<td>65</td>
<td>27</td>
</tr>
<tr>
<td>1996 – 2000</td>
<td>55</td>
<td>23</td>
</tr>
<tr>
<td>2001 - 2005</td>
<td>31</td>
<td>13</td>
</tr>
<tr>
<td>2006 - 2008</td>
<td>56</td>
<td>23</td>
</tr>
<tr>
<td>Unknown</td>
<td>22</td>
<td>--</td>
</tr>
<tr>
<td><strong>Number of years living with hepatitis C before diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than one year</td>
<td>47</td>
<td>19</td>
</tr>
<tr>
<td>1 – 5 years</td>
<td>63</td>
<td>26</td>
</tr>
<tr>
<td>6 – 10 years</td>
<td>35</td>
<td>14</td>
</tr>
<tr>
<td>11 – 20 years</td>
<td>45</td>
<td>18</td>
</tr>
<tr>
<td>More than 20 years</td>
<td>55</td>
<td>23</td>
</tr>
<tr>
<td>Unknown</td>
<td>16</td>
<td>--</td>
</tr>
</tbody>
</table>

* Diagnosis prior to 1990 as ‘non - A, non - B hepatitis’
Diagnosis of hepatitis C

Respondents were asked about their experience of being diagnosed with hepatitis C. The professionals involved in diagnosing respondents’ hepatitis C are detailed in Graph 1.

Graph 1: Category of health professional involved in diagnosing hepatitis C for respondents (n=254).

<table>
<thead>
<tr>
<th>Category of diagnosing health professional</th>
<th>Percentage of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practitioner</td>
<td>62% (n=158)</td>
</tr>
<tr>
<td>Specialist doctor</td>
<td>14% (n=36)</td>
</tr>
<tr>
<td>Drug and Alcohol worker</td>
<td>8% (n=22)</td>
</tr>
<tr>
<td>Sexual health clinic worker</td>
<td>5% (n=13)</td>
</tr>
<tr>
<td>Nurse</td>
<td>4% (n=11)</td>
</tr>
<tr>
<td>Blood Bank</td>
<td>3% (n=6)</td>
</tr>
<tr>
<td>Prison worker</td>
<td>2% (n=4)</td>
</tr>
<tr>
<td>Antenatal screening</td>
<td>2% (n=4)</td>
</tr>
</tbody>
</table>

Forty-eight percent (n=120 out of 249) did not know anything about hepatitis C before they were diagnosed and 13% (n=33) were uncertain. Thirty-eight percent (n=96) indicated they knew something about hepatitis C before they were diagnosed and, most frequently they had heard about hepatitis C through their peers (n=30).

At diagnosis, only 13% (n=32 out of 249) had been provided with a pre-test discussion, 81% (n=203) had not and six percent (n=14) were uncertain. The topics covered during the pre-test discussion are shown in Graph 2. There was no difference between respondents diagnosed before and after the year 2000 in terms of receiving pre-test counselling prior to diagnosis (79% versus 83%).
Graph 2: Topics discussed during pre-test discussion (n=32)*.

* more than one response was permitted.

Following on from respondents’ experiences of being diagnosed with hepatitis C, respondents identified their impression of the seriousness of hepatitis C based on the information they were provided at the time of diagnosis. The results are presented in Graph 3.

Graph 3: Respondents’ impressions about the seriousness of hepatitis C at the time of diagnosis (n=209).
In addition, a further 9% (n=20 out of 209) responded to the ‘other’ response category and noted that they were told hepatitis C was a serious disease that could not be treated. Nine respondents had been given no information about hepatitis C at diagnosis. Respondents diagnosed since the year 2000, were more likely to be told that hepatitis C could be treated (71%, n=67 out of 94) and less likely to be given the impression that hepatitis C was a fatal disease (17%, n=16), and that it was a relatively unimportant disease (12%, n=11).

**Referral to specialist services**

In total, 55% (n=144 out of 261) of respondents had been referred to a specialist medical service since being diagnosed with hepatitis C. Of those who had been referred to a specialist medical service, the majority of participants (41%, n=59 out of 144) had been referred to a specialist medical service at diagnosis, 36% (n=52) were referred within 12 months of diagnosis, 6% (n=8) were referred after one to two years, 7% (n=11) were referred after three to five years and 10% (n=14) were referred over five years after diagnosis.

Overall, 49% (n=123 out of 250) had received, or were currently receiving interferon-based treatment for their hepatitis C. The majority (79%, n=97 out of 123) had taken pegylated interferon and ribavirin.

It is worth noting that 51% (n=73 out of 144) of respondents who had been referred to a specialist clinic had received interferon-based treatment. This result suggests that some respondents may have misunderstood the concept of being referred to a specialist service, because an additional 50 respondents indicated they had been treated, but not referred to a specialist.
**KEY POINTS: Results of the questionnaire**

**Diagnosis of hepatitis C**

- Most respondents were diagnosed by a GP.
- Few respondents had been involved in a pre-test discussion at diagnosis, which demonstrates the need for improved implementation of the education requirements for the National Hepatitis C Testing Policy.
- Just over half the respondents had been referred to a specialist medical service (i.e. liver clinic).
- Half the respondents had received interferon-based treatment.
Hepatitis C information and education needs

Overall, two-thirds of respondents believed they had access to enough information to make informed decisions about hepatitis C all the time, or most of the time. However, one-third stated they had enough information to make informed decisions only sometimes or rarely (refer to Graph 4).

Graph 4: Proportion of respondents who have had access to enough information to make informed decisions about hepatitis C (n=239).

Preferred methods of obtaining information

The preferred methods of receiving hepatitis C information were face-to-face (67%, n=159 out of 237), printed resources (55%, n=131), internet websites (35%, n=83), over the telephone (14%, n=34) and from internet chat rooms or forums (13%, n=31).

Sources of hepatitis C information

Respondents identified their best and worst sources of hepatitis C information including both human sources and physical resources; the results are identified in Tables 2 and 3.
Table 2: The best sources of hepatitis C information identified by respondents in order of preference (% (n)).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Respondents % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who was the best source of hepatitis C information? (n=225)*</td>
<td></td>
</tr>
<tr>
<td>Liver specialist</td>
<td>40 (91)</td>
</tr>
<tr>
<td>Liver clinic nurse</td>
<td>40 (89)</td>
</tr>
<tr>
<td>Another person living with hepatitis C</td>
<td>36 (80)</td>
</tr>
<tr>
<td>General practitioner</td>
<td>34 (76)</td>
</tr>
<tr>
<td>Community worker from Hepatitis Organisation</td>
<td>30 (66)</td>
</tr>
<tr>
<td>Community worker from Drug User Organisation</td>
<td>16 (36)</td>
</tr>
<tr>
<td>Drug and alcohol worker</td>
<td>14 (32)</td>
</tr>
<tr>
<td>Family members and friends</td>
<td>7 (16)</td>
</tr>
<tr>
<td>Community worker from Haemophilia Centre'**</td>
<td>3 (6)</td>
</tr>
<tr>
<td>What was the best source of hepatitis C information? (n=209)*</td>
<td></td>
</tr>
<tr>
<td>Hepatitis Organisation printed resources</td>
<td>59 (123)</td>
</tr>
<tr>
<td>Printed resources (non-Hepatitis Organisation)</td>
<td>39 (81)</td>
</tr>
<tr>
<td>Hepatitis Organisation website</td>
<td>37 (77)</td>
</tr>
<tr>
<td>International internet websites</td>
<td>25 (53)</td>
</tr>
<tr>
<td>Hepatitis Organisation telephone service</td>
<td>14 (29)</td>
</tr>
<tr>
<td>Internet chat room or forum</td>
<td>13 (28)</td>
</tr>
<tr>
<td>Support group</td>
<td>11 (23)</td>
</tr>
</tbody>
</table>

* more than one response was permitted.

The majority of participants indicated they were satisfied with the sources of information, this was reflected by a high level of non-response to the questions about poor sources of hepatitis C information.

‘Liver specialists’ and ‘liver clinic nurses’ were most frequently identified as the best source of hepatitis C information, and ‘GPs’ and ‘family members and friends’ were identified as the worst sources of information.

‘Hepatitis Organisation printed resources’ were the most respected source of information and ‘non-Hepatitis Organisation printed resources and ‘international websites’ were reported as the most inaccurate information source.

* Please note people living with hepatitis C and a bleeding disorder were not specifically targeted during participant recruitment, which may explain the low response to this question.
Table 3: The worst sources of hepatitis C information identified by respondents in order of preference (% (n)).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Respondents % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Who was the worst source of hepatitis C information? (n=173)</strong></td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>50 (87)</td>
</tr>
<tr>
<td>Family members and friends</td>
<td>46 (79)</td>
</tr>
<tr>
<td>Another person living with hepatitis C</td>
<td>36 (62)</td>
</tr>
<tr>
<td>Liver specialist</td>
<td>14 (24)</td>
</tr>
<tr>
<td>Liver clinic nurse</td>
<td>7 (12)</td>
</tr>
<tr>
<td>Drug and alcohol worker</td>
<td>7 (12)</td>
</tr>
<tr>
<td>Community worker from Hepatitis Organisation</td>
<td>7 (12)</td>
</tr>
<tr>
<td>Community worker from Drug User Organisation</td>
<td>6 (10)</td>
</tr>
<tr>
<td>Community worker from Haemophilia Centre</td>
<td>2 (4)</td>
</tr>
<tr>
<td><strong>What was the worst source of hepatitis C information? (n=90)</strong></td>
<td></td>
</tr>
<tr>
<td>Printed resources (non-Hepatitis Organisation)</td>
<td>48 (43)</td>
</tr>
<tr>
<td>International internet websites</td>
<td>43 (39)</td>
</tr>
<tr>
<td>Hepatitis Organisation telephone service</td>
<td>14 (13)</td>
</tr>
<tr>
<td>Hepatitis Organisation website</td>
<td>12 (11)</td>
</tr>
<tr>
<td>Support group</td>
<td>11 (10)</td>
</tr>
<tr>
<td>Hepatitis Organisation printed resources</td>
<td>10 (9)</td>
</tr>
<tr>
<td>Internet chat room or forum</td>
<td>6 (5)</td>
</tr>
</tbody>
</table>

* More than one response was permitted.

General practitioners were identified as both one of the best and the worst source of hepatitis C information. This reflects the diversity in participants’ experiences and potentially inadequate knowledge of, or access to, ‘hepatitis C-friendly’ GPs.

**Unmet information needs**

Overall, 60% (n=156 out of 261) of respondents indicated they had additional, unmet hepatitis C information and education needs. Forty six percent (n=72 out of 156) needed more information on hepatitis C treatment including future treatment options, treatment options for non-responders to pegylated interferon and ribavirin, clinical trial information, the process of accessing treatment and managing treatment side effects. Further information on self-management options such as complementary and alternative medicine (CAM), diet, symptom management and managing alcohol and drug use was requested by 22% (n=34 out of 156). Fourteen percent (n=22 out of 156) wanted more information on interpreting clinical information such as genotypes, extrahepatic manifestations of hepatitis C, living with
cirrhosis, liver transplantation and interpreting blood tests such as liver function tests. Nine percent (n=14 out of 156) indicated they needed further information on the social aspects of living with hepatitis C such as sexual transmission, disclosure and dating, disclosure and employment, follow up after experiences of discrimination, issues for family members and friends and, accessing both financial and individual support.

KEY POINTS: Results of the questionnaire

Hepatitis C information and education needs

- Access to hepatitis C information was generally sufficient to assist two-thirds of the respondents to make informed decisions about their health.
- Sources of hepatitis C information were evenly spread between health professionals and the services and staff of Hepatitis Organisations and printed resources.
- Face-to-face contact and printed resources were the preferred sources of hepatitis C information.
- The best sources of hepatitis C information were Hepatitis Organisation printed resources, liver specialists and liver clinic nurses.
- General practitioners, non-Hepatitis Organisation printed resources, family members and friends were most frequently cited as the worst sources of hepatitis C information.
- Unmet information needs included: hepatitis C treatment options and developments; self-management options such as CAM, diet and symptom management; interpreting clinical information and social aspects of living with hepatitis C.
Hepatitis C support needs
Access to hepatitis C support services was explored. Seventeen percent (n=40 out of 233) indicated they had always felt supported to manage their hepatitis C, 39% (n=91) felt supported most of the time, 24% (n=56) sometimes felt supported and 20% (n=46) rarely felt supported to manage their hepatitis C.

Preferred methods and sources of hepatitis C support
Overwhelmingly, respondents preferred to access support through individual face-to-face contact (refer to graph 5).

Graph 5: Respondents’ preferred methods of obtaining hepatitis C support (n=227)*.

* more than one response was permitted.

In addition to respondents’ preferred method of obtaining support, they also identified their preferred sources of support (refer to Graph 6).
Graph 6: Respondents’ preferred sources of hepatitis C support (n=219)*.

* more than one response was permitted.

Respondents indicated their three most important sources of hepatitis C support (refer to Table 4). The results reflect that Hepatitis Organisation printed resources (50%, n=86 out of 172), another person living with hepatitis C (35%, n=75 out of 216) and a GP (35%, n=75 out of 216) were the most useful sources of hepatitis C support.

Table 4: The best sources of hepatitis C support identified by respondents in order of preference (% (n)).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Respondents % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who were the best sources of hepatitis C support? (n=219)*</td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>34 (75)</td>
</tr>
<tr>
<td>Another person living with hepatitis C</td>
<td>34 (75)</td>
</tr>
<tr>
<td>Liver clinic nurse</td>
<td>32 (70)</td>
</tr>
<tr>
<td>Family members and friends</td>
<td>30 (66)</td>
</tr>
<tr>
<td>Partner</td>
<td>28 (61)</td>
</tr>
<tr>
<td>Liver specialist</td>
<td>27 (60)</td>
</tr>
<tr>
<td>Community worker from Hepatitis Organisation</td>
<td>22 (49)</td>
</tr>
<tr>
<td>Drug and alcohol worker</td>
<td>13 (28)</td>
</tr>
<tr>
<td>Community worker from Drug User Organisation</td>
<td>12 (27)</td>
</tr>
<tr>
<td>Community worker from Haemophilia Centre</td>
<td>2 (5)</td>
</tr>
</tbody>
</table>
What were the best sources of hepatitis C support? (n=174)*

<table>
<thead>
<tr>
<th>Source</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis Organisation printed resources</td>
<td>49 (86)</td>
</tr>
<tr>
<td>Hepatitis Organisation telephone service</td>
<td>25 (43)</td>
</tr>
<tr>
<td>Hepatitis Organisation website</td>
<td>39 (68)</td>
</tr>
<tr>
<td>Printed resources (non-Hepatitis Organisation)</td>
<td>32 (56)</td>
</tr>
<tr>
<td>International internet websites</td>
<td>17 (30)</td>
</tr>
<tr>
<td>Internet chat room or forum</td>
<td>14 (25)</td>
</tr>
<tr>
<td>Support group</td>
<td>13 (23)</td>
</tr>
</tbody>
</table>

* more than one response was permitted.

Support group membership

Fifty-two respondents out of 227 (23%) either belonged to, or had attended a hepatitis C support group. Nineteen respondents out of 48 (40%) reported that their support needs were met ‘most of the time’ by attending the support group and a further 19 respondents (40%) believed their support needs were met sometimes. Five respondents (10%) rarely had their support needs met and 5 respondents (10%) always had their support needs met by attending the support group.

Fifty two respondents out of 183 (28%) indicated they would like to belong to a support group, 65 (36%) did not want to belong and 66 (36%) were uncertain about whether they wanted to belong to a support group. Of the respondents who did not belong to a support group but wanted to attend, 39 out of 52 did not know how to find out about support groups in their area, 30 did not want to disclose their hepatitis C status and 29 indicated they did not know of one available in their area. Several respondents provided more than one answer.

Disclosure of hepatitis C status

Respondents were asked about disclosure of their hepatitis C status. The majority (58%, n=127 out of 219) indicated they had chosen to tell only a small number of people they trusted. Thirty one percent (n=67) had chosen to be open and tell everyone about their hepatitis C status. Seven percent (n=16) had told people they had a liver disease or blood disorder instead of naming hepatitis C, and 4% (n=9) had decided not to tell anyone they had hepatitis C.
KEY POINTS: Results of the questionnaire

**Hepatitis C support needs**
- Hepatitis C support was not readily available.
- Face-to-face was the preferred method of obtaining hepatitis C support.
- Health professionals (specifically GPs and liver clinic nurses) and other people with hepatitis C were the preferred sources of hepatitis C support.
- Hepatitis Organisation printed resources, GPs and other people with hepatitis C were the best sources of support.
- Support group membership was not common.
- Not knowing how to find out about support groups was the main barrier to attending support group meetings.
- Disclosure of hepatitis C status generally involved telling a small group of trusted people.

**Contact with Hepatitis Organisations**
Forty-seven percent (n=108 out of 228) of respondents had accessed the services offered by a Hepatitis Organisation. Forty-four percent (n=101) had not accessed the services of a Hepatitis Organisation and 8% (n=19) were uncertain. There is the potential for these results to be biased, because one of the main recruitment methods used for the Needs Assessment was Hepatitis Organisation networks. However, other recruitment sources not associated with Hepatitis Organisations were deliberately utilised to reduce the potential bias.

Respondents indicated that Hepatitis Organisations should broadly advertise their services by targeting GP clinic waiting rooms (76%, n=168 out of 220), public hospitals (67%, n=147), mainstream television (62%, n=137), state, local and regional newspapers (62%, n=137), mainstream radio (55%, n=121), community radio (40%, n=88) and community television (39%, n=86).
KEY POINTS: Results of the questionnaire

Contact with Hepatitis Organisations
• Contact with, and utilisation of the services of Hepatitis Organisations was limited to half the respondents.
• Hepatitis Organisations need to broadly advertise their services through health settings and mainstream and community media outlets.

Summary
The findings of the questionnaire provide a unique insight into the information, education and support needs of a diverse cohort of people living with hepatitis C in Australia. Diagnosis was a time of concern for questionnaire respondents, primarily because they did not receive adequate information. The majority of respondents were diagnosed by their GP, and only a small proportion had been involved in a pre-test discussion, therefore, the majority did not have an understanding of hepatitis C prior to their diagnosis. Approximately half the respondents had been referred to a specialist medical service since they were diagnosed, which means the other half had not received specialist advice, counselling or information regarding their hepatitis C. Improving the delivery of pre-test information for people being tested for hepatitis C and subsequent referral to specialist services, including support services, is an ongoing challenge.

Approximately two thirds of respondents believed they had access to enough information to make informed decisions about their hepatitis C. Primarily, respondents relied on health professionals and other people living with hepatitis C to provide them with information. Face-to-face contact was the preferred method of obtaining information; however printed resources, particularly resources produced by Hepatitis Organisations, were the most useful. Conversely, non-Hepatitis Organisation resources were identified as the worst source of hepatitis C information along with GPs. Based on the findings of the questionnaire, hepatitis C information and education resources need to be broadly distributed in the community, and available in a variety of formats including both printed and human resources.
Respondents identified several topics for which they required additional information which reflected a sophisticated understanding of hepatitis C and the need for specialist information. Improving referral to specialist services is one method of improving respondents’ access to the information they require.

Fewer respondents felt supported to live with hepatitis C compared to the proportion that believed they had access to enough hepatitis C information. Once again, face-to-face contact was the preferred method of obtaining support, and respondents identified health professionals and other people living with hepatitis C as the best sources of support. Printed resources produced by Hepatitis Organisations, particularly quarterly magazines which contained personal stories, were an important source of support.

Most state and territory Hepatitis Organisations have established peer support groups; though membership was not common among respondents. The principle reason was that respondents did not know how to find out about support groups, which was not unexpected considering less than half had accessed the services offered by a Hepatitis Organisation. Disclosure of hepatitis C status was an impediment to accessing support and attending support groups. Improving awareness of, and access to, hepatitis C information and support services, such as Hepatitis Organisations, should be a focus of future strategic planning activities.
Results of the focus groups and telephone interviews

The following section of the report includes a thematic analysis of the data collected during the focus groups (n=55) and telephone interviews (n=11). The interview and focus group data was analysed by identifying the main themes (i.e., the same topics or concepts that were mentioned several times by different groups). However, these themes were not universally mentioned in every focus group or interview. The interview and focus group data highlight a diverse range of perspectives, some of which support the questionnaire findings and others which highlight specific concerns for individuals. Specific themes identified during the focus groups and interviews with participants from priority populations are presented separately.

It is important to note that not all the findings of the focus groups and interview data will resonate with the experiences of workers in the field or people living with hepatitis C, however this is to be expected. At times in the report, the qualitative data is included to provide contradictory evidence to that presented by the questionnaire results, which brings attention to different perspectives and issues. Nonetheless, in other parts of the report, the qualitative data will serve to support and explain findings from the questionnaire. However, at all times, remember that participants involved in the National Hepatitis C Needs Assessment 2008 may not be representative of the population living with hepatitis C in Australia. Therefore, the questionnaire, focus group and interview data need to be interpreted with care and consideration as not all needs can be, or are, represented.

Characteristics of focus group participants

Fifty five people living with hepatitis C were involved in eight focus groups conducted between March and June 2008. Details of the target group location and participant characteristics for each focus group are outlined in Table 4. Specific details such as age, time since diagnosis and experience of hepatitis C treatment were not collected from focus group participants or interviewees.
Table 4: Details of focus groups conducted for the National Hepatitis C Needs Assessment 2008 (n=55).

<table>
<thead>
<tr>
<th>Target group</th>
<th>Location</th>
<th>Number of participants</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>People living with hepatitis C in a metropolitan area</td>
<td>Melbourne, Victoria</td>
<td>6 participants</td>
<td>4 male, 2 female</td>
</tr>
<tr>
<td>People living with hepatitis C in a metropolitan area</td>
<td>Perth, Western Australia</td>
<td>10 participants</td>
<td>4 male, 6 female</td>
</tr>
<tr>
<td>People living with hepatitis C in a metropolitan area</td>
<td>Adelaide, South Australia</td>
<td>10 participants</td>
<td>5 male, 5 female</td>
</tr>
<tr>
<td>People living with hepatitis C in a rural area</td>
<td>South Australia (teleconference)</td>
<td>2 participants</td>
<td>2 male</td>
</tr>
<tr>
<td>People living with hepatitis C in a rural area</td>
<td>Orange, NSW</td>
<td>9 participants</td>
<td>7 males, 2 females</td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander people living with hepatitis C</td>
<td>Canberra, ACT</td>
<td>9 participants</td>
<td>7 male, 2 female</td>
</tr>
<tr>
<td>Vietnamese injecting drug users living with hepatitis C</td>
<td>Footscray, Melbourne</td>
<td>5 participants</td>
<td>3 male, 2 female</td>
</tr>
<tr>
<td>Homeless people living with hepatitis C</td>
<td>Brisbane, QLD</td>
<td>4 participants</td>
<td>3 male, 1 female</td>
</tr>
<tr>
<td>Professionals working with people living with hepatitis C in custodial settings</td>
<td>NSW, QLD, SA, Tasmania, Victoria and WA (teleconference)</td>
<td>7 participants</td>
<td>1 male, 6 females</td>
</tr>
<tr>
<td>Professionals working with people living with hepatitis C from CALD communities</td>
<td>NSW, QLD, SA and Victoria (teleconference)</td>
<td>8 participants</td>
<td>1 male, 7 females</td>
</tr>
</tbody>
</table>

In total, 64% (n=35 out of 55) of focus group participants living with hepatitis C were male and 36% (n=20) were female.

**Characteristics of interviewees**

Semi-structured telephone interviews were conducted with five males and six females living with hepatitis C (n=11). Interviews were between 30 minutes and 90 minutes duration. Participants were purposefully recruited from Tasmania (n=3) and the Northern Territory (n=3) through the respective Hepatitis Organisation, because focus groups were not conducted in either region. In addition, people living in rural and remote regions of far north Queensland (n=4) were specifically recruited for interview through a liver clinic. Finally, one participant living in rural NSW volunteered to be interviewed.
Hepatitis C information and education needs

Overall, focus group participants and interviewees indicated that access to hepatitis C information had improved over time. Information was critical to participants’ ability to make decisions about hepatitis C and to their quality of life. It is worth noting that approximately half the participants involved in the focus groups and interviews had not been in contact with a Hepatitis Organisation.

Information needs at diagnosis

Consistent with the questionnaire findings, few participants were aware of hepatitis C prior to diagnosis. In reality, the process of being diagnosed with hepatitis C did not result in significant improvements in knowledge for most participants. Many participants described being diagnosed with hepatitis C as stressful, which was compounded by the provision of inadequate, inaccurate or no information. One participant described the experience of being diagnosed and the impact of inadequate information on subsequent health behaviour:

When I was first diagnosed … the doctor said “looks like you’ve got hep C”, and that was it. And I left it like that … like I had a sore toe. I left it like that for a couple of years. And then I started hearing things about living with hep C and liver damage, and I thought I better go back to my doctor and see what this is all about.

In the absence of adequate information being provided at the time of diagnosis, participants discussed their experience of seeking information.

I was diagnosed in 1996 … and when I went looking for information, it was very difficult to find any. Nobody seemed to know anything at all, and it was totally terrifying. I was given some pamphlets … but I actually felt really alone.

I was diagnosed with hepatitis C about three years ago … I was left pretty much in the dark. The doctor told me I had hep C, and I went “urghhh?” He sent me to a community care centre, where they gave me a copy of the big, green manual and told me to go away and read it. I went into a panic because I didn’t understand the information in the manual …
Fear and denial were common reactions resulting from self-directed information seeking, because participants did not have the ability to understand the information without assistance. Several participants reflected on strategies that would have been useful at diagnosis in terms of information provision and referral to other services.

It would have been so useful to have been given a brochure or a phone number to call [when I was diagnosed] … because I think at that stage I didn’t really take it seriously …

Others articulated the importance of referral to a specialist service such as a liver clinic or Hepatitis Organisation to help alleviate fear and suffering.

It would have been useful to be directed to a specialist who could have allayed my fears, because I think for two years I just thought I was going to die … I really went through a lot of unnecessary grief.

It’s vital the doctors refer patients to a support service at diagnosis … Ideally, GPs would … [say] – ok you’ve got hep C … there’s this organisation called the Hepatitis C Council that can help, you need to get in contact with them, here’s their number.

The provision of information at diagnosis was described as critical to participants’ future health seeking behaviour. For one participant, inadequate information at diagnosis resulted in a low priority being attached to hepatitis C, which had a deleterious effect on their overall health status.

After diagnosis I left my hep C for 15 years, I just pretended it didn’t happen. No one ever told me I should be worried about it, so I didn’t. I wasn’t presenting with symptoms at the time … I didn’t get any information about abstaining from alcohol, that may have prevented damage to my liver. Now I have just found out that I’ve been declined a liver transplant because I’m too sick.
Participants highlighted the importance of providing lifestyle information at diagnosis, as well as information on preventing transmission, when to disclose, and treatment options. Health maintenance and self-management information including dietary advice, reducing alcohol consumption and exercise was considered by participants to be critical information that needed to be provided at diagnosis and reinforced throughout.

When I did get information, it focused on treatment … so it bypassed the last 12 years that I had just been living since I was diagnosed, where I have been perfectly fine and nothing significant had happened. There has never been any focus on living with hep C and self management, it has always been about being sick and having treatment.

Diagnosis is a crucial time for the provision of accurate information about living with hepatitis C. In addition, people living with hepatitis C need to be told that hepatitis C information is constantly evolving and that information provided today may be superseded. This insight prepares people for a lifelong journey of collecting information and the need to establish trusted information pathways.

When I was diagnosed, the doctor gave me pamphlets and stuff, and told me to read them but not get too stuck on them because there’s new information coming out all the time. Actually he told me … every time you see a pamphlet pick it up because there will be new information in it. This was good advice.

**KEY POINTS: Results of the focus groups and interviews**

**Hepatitis C information needs at diagnosis**

- Diagnosis is a critical time for people living with hepatitis C in terms of accessing accurate information and referral to support services.
- Access to a pre-test discussion about hepatitis C was limited. Referral to community support organisations such as a Hepatitis Organisation was rare.
- Being diagnosed with hepatitis C was stressful, and was compounded by the provision of inadequate, inaccurate or no information.
• The provision of information at diagnosis was critical to participants’ future health seeking behaviour.
• Fear and denial were common reactions to self-directed information seeking, because participants did not have the ability to understand or comprehend the information they were finding without assistance.

**Triggers to seeking information**

Seeking hepatitis C information was described as a lifelong process. Diagnosis was highlighted as being a time when participants felt particularly bereft of information, but as time went on they became more connected to information sources and developed more confidence in their ability to find information. The evolution of the internet helped some participants to find the information they required.

*I started getting information about hep C when I was hooked up to the internet. It’s been good. I google “hep C” and then get lost in the web …*

However, access to the internet was still limited for many people living with hepatitis C. Participants identified that the main triggers for seeking information were to clarify information and/or validate their experiences.

*Sometimes I hear something in the clinic and … I need to just check up on it and make sure I understand what it means.*

*Before, and while I was on treatment, my symptoms would come in waves and there would be times when I felt really, really ill … and I guess this was the time when I looked for information. Because I was scared about what was happening to me.*

Understanding the impact of hepatitis C on the body, and the symptoms, was a significant motivator for participants to seek information. In the absence of a clear understanding of the extent of hepatitis C-related symptoms, many participants sought information so they could feel in control of their health and be involved in the management of their disease.
I’m really aware I don’t want to blame every niggle or health problem on having hep C, but also the symptoms are so varied, I really don’t know what is and isn’t related. That’s why I need as much information as I can, so I know when my doctor can blame something on my hep C and when he should investigate it.

Seeking information was empowering for people living with hepatitis C, because it decreased their reliance on health professionals.

You go to the doctor and you’re always trusting the information they give you. But that can back fire if they don’t know much or they’re not telling you the whole story. I prefer to get my own information ... and be able to discuss this with my doctor ... so I’m on an even playing field.

The triggers for seeking information were motivated by the need for evidence to clarify participants’ health experiences and to participate in their health management. Considering these triggers, information resources need to be developed in a format that is easily understood, be comprehensive, and contain accurate information to enable people living with hepatitis C to meet their education needs.

KEY POINTS: Results of the focus groups and interviews

Triggers to seeking information
- Seeking hepatitis C information is a lifelong process.
- Evolution of the internet was synonymous with improved access to hepatitis C information.
- Development of symptoms and consideration of treatment are significant triggers for people living with hepatitis C to seek information.
Preferred methods of obtaining information

Similar to the data collected from questionnaire respondents, participants indicated that they preferred to obtain information through:

- face-to-face contact with professionals and other people living with hepatitis C
- the internet
- printed resources.

Participants emphasised that ideally, they preferred to use a variety of these methods simultaneously, because it ensured the information was clarified, retained and understood.

A combination between written and verbal information is the best, as long as the written and the verbal are consistent. You can read something and check it up. You can hear something and you can check it up.

I think if you can sit down and talk to a fellow human being about hep C, then … that’s great! And at the end of that process, to be given something to take home in your hand … at the end of the day there’s nothing better than something that’s printed … that’s in your hand; that can guide you.

Face-to-face contact

Face-to-face was the most popular method of obtaining information because participants could engage in a conversation that allowed instant clarification of the information, which lessened their anxiety.

When I’m looking at information by myself I get anxious – my brain goes to the worse case scenario, so it’s good to have someone to talk to about the information and lessen my anxiety.

Participants highlighted the importance of feeling comfortable with, and trusting the individual providing the information.

I prefer human interaction to receive information; face-to-face; someone who you feel comfortable talking to.
Face-to-face contact with an informed and supportive health professional was highly valued as a preferred method of obtaining information.

I used to get really anxious when I was looking for information so I stopped seeking information, cause I got uptight about what I was finding out. So now I wait to when I see my doctor and she gives me the low down on the latest information and put my fears to bed ... especially about treatment, the stories I heard about treatment that people get really sick, they were enough to put me off having treatment. But my doctor was able to reassure me that not everyone gets sick on treatment.

Information provision that resulted from face-to-face contact with peers was an important method of keeping up-to-date. This was particularly common among participants who injected drugs and participants considering treatment. There was the implicit belief that receiving information from peers meant it would be appropriately targeted to their level of comprehension.

I’m pretty open about the fact that I have hep C ... I’m living in a residential detox unit at the moment so there are lots of other addicts here who have it. I have quite a bit of information, so people often ask me questions ... I can explain the information because I’m an addict, I know what they’re thinking and why they’re asking the questions.

You can have all the clinical information in the world, but what is most useful is to talk to other people with hepatitis C ... because it shows you that you’re not alone.

The provision of information through face-to-face contact will require significant financial investment to enhance the infrastructure of Hepatitis Organisations. The provision of information through face-to-face contact will require more human resources and a greater capacity to accommodate the privacy and confidentiality needs of people living with hepatitis C. Additional funding will be required in order to realise this preferred method of obtaining hepatitis C information.
The internet
The internet was preferred because participants could search for information confidentially. The internet facilitated participants’ access to the most current factual information, in addition to contact with other people living with hepatitis C, which was a source of support.

I needed to hear other people’s stories … although I would have loved to have heard people’s stories face-to-face it was too scary … I would have had to disclose … and so it was easy for me to do it on the internet.

The advantages and disadvantages of using the internet will be discussed further in the report.

Printed resources
Printed resources and publications were considered to be a vital method of receiving hepatitis C information by participants, because they reinforced facts and concepts communicated during face-to-face discussions. Participants described how they would review printed resources multiple times and share them with family and friends to ensure the information was understood. Publications such as the quarterly magazines produced by Hepatitis Organisations and Drug User Organisations were noted as being more current, because the information was regularly updated, compared to other printed resources.

The Council magazines are really good … the Hep C Review, Hep C Council of SA newsletter, Good Liver … they have articles from all over the world about what is happening with hep C – Russia, China, new treatments, other people’s stories about their experiences, herbal remedies, little sections of info I can relate to – information that the general population is not interested in – it gives me a little trigger to explore more information.

Printed resources are great – but I get most of my information from readers’ stories from publications like Good Liver and Hep C Review because they reflect real life.
The physical presentation of printed resources was important to participants. In order to attract an individual’s attention and motivate them to pick up a resource from a display rack, participants suggested that the resource should be targeted in terms of its appearance.

I’d pick information up at an NSP or GP if it looked a certain way. Like “User’s News” and “Whack” – it’s about how you present it … if you present it in a way that we think looks good, then we’d pick it up. The pamphlets have to be targeted. If I can tell that when a resource has been written by users, for users, then it’s something I want to read.

Access to printed resources in public places was discussed among participants. The risk of being publicly identified when collecting hepatitis C information was a significant barrier for many participants accessing hepatitis C information in both metropolitan and rural Australia.

I saw a pamphlet [on hepatitis C] in the chemist, and there was a whole stack of them there, but no one ever takes them because what if someone sees you take it …

Several participants indicated they would pick up printed resources in a public setting if the front cover of the resource clearly indicated its content.

Half the time I can’t work out which pamphlet I need … I’m reading the covers, trying not to let anyone see me do it. So if I saw something that had “hepatitis C treatment” on the front cover, then I’d know what it’s about and I’d be more likely to pick it up.

There was significant variation of attitude among participants with regard to accessing resources on public display. The location of the displayed resources determined participants’ access. For example, participants attending NSPs or methadone clinics were more likely to collect resources, whereas participants attending mainstream GP clinics or health clinics in custodial settings were more reluctant. The stigma associated with accessing resources in a public place highlighted the importance of targeted presentation of resources and appropriate distribution of resources. One method of avoiding the stigma would be to
individually distribute printed information. Ideally, resources would be provided to people living with hepatitis C during a consultation with a health professional, or distributed confidentially either automatically on diagnosis, or upon request.

There is a stigma attached to seeking hepatitis C information … this is a major barrier. All the information in the racks in waiting rooms, there is always going to be someone else in the waiting room, probably watching what information you’re taking from the rack … therefore, I have a tendency to think that people won’t necessarily go for it, which is why I think if the information is given by the GP him/herself it’s more confidential.

Unfortunately, relying on health professionals to distribute printed resources assumes they are aware of the resources and understand the purpose and target group for each resource. Targeted distribution of the contact details of Hepatitis Organisations to GPs, NSPs, liver clinics and community health centres could improve referral rates and subsequently access of people living with hepatitis C to information resources.

**KEY POINTS: Results of the focus groups and interviews**

**Preferred methods of obtaining information**
- Participants’ preferred methods of obtaining hepatitis C information were face-to-face and printed resources.
- The internet allowed participants to access information anonymously.
- Printed resources were a vital method of obtaining information which allowed participants to reinforce information obtained face-to-face.
- Hepatitis Organisation and Drug User Organisations’ quarterly newsletters were identified as a popular way to keep up-to-date.
- Participants were reluctant to pick up resources displayed in public locations because of the stigma associated with hepatitis C.
Valued sources of hepatitis C information

Participants described a variety of valued sources of hepatitis C information including peers, printed resources and the internet. Participants described accessing a combination of these sources, while a smaller proportion preferred to rely on one source for all their information needs.

Peer education

The type of information required was the most significant predictor of participants’ preferred source of information. When participants were making hepatitis C management or treatment decisions, they valued the opportunity to speak to another person with hepatitis C who could provide a personal perspective on the information.

It would have been useful to talk to someone who had had the treatment before I started just to know what I could expect from the treatment.

It’s taken me 5 years of trying to understand what it’s like to endure treatment to make the decision myself … to talk to people face-to-face who have had treatment, talk to people on the internet through the forums and really get to know them … so now I have a really good idea of what it’s like and so I feel more confident in what I’m doing in my management decisions.

Hearing other people living with hepatitis C tell their stories either face-to-face or through printed resources was highly regarded. There was general consensus that the quarterly magazines produced by the Hepatitis Organisations and Drug User Organisations were a comprehensive and reliable source of up-to-date information and were commonly identified as an important source of peer education because of the personal stories. In particular, the Hep C Review was repeatedly identified by name across Australia as a valued source of hepatitis C information and support.

I get a lot of information from the Hep C Review because I class that as being valid information. I really like the personal stories in the Hep C Review because they make
me feel as though I’m not so alone. And there’s always lots of information that’s easy to understand about new treatments.

I rely on the information provided in the “Users news” magazine. I get it sent to me once a month and I find it really useful. There’s also a Melbourne newsletter ... Whack ... I like it because it is for people who use drugs or have used drugs. It’s targeted and it’s relevant. These magazines have got people’s stories and there’s also lots of information about hep C and interferon ... new treatments ... there’s a lot of information. I can also relate to the stories that I read about other people ... there are hopeful stories and sad stories. Both types.

It is worth noting that access to Hepatitis Organisations’ quarterly magazines and publications often preceded contact with a Hepatitis Organisation. In a focus group including nine people in rural NSW, seven people had read the Hep C Review, however, none had been in contact with the Hepatitis C Council of NSW. Participants had accessed the Hep C Review through methadone clinics, NSPs and health centres, though none had ever seen it in a drug and alcohol rehabilitation facility. Participants recommended that resources should be more readily available through all services working with people who inject drugs.

State and Territory Hepatitis Organisations
The Hepatitis Organisations of NSW, Queensland, SA, Victoria and WA were repeatedly identified as important resources for people living with hepatitis C in Australia. The strengths of the Hepatitis Organisations were the expertise of their workers and the printed resources. The workers were an important source of accurate information and advice about living with hepatitis C. One participant explained:

When I need information or I have a question about hep C, I always ring the Hep C Council ... For example, I didn’t know what bridging fibrosis was ... the lady at the Council didn’t really know either, but she asked lots of people and got back to me ... it was really fantastic .... because I trust her. There’s never any rush to get off the phone if I need to talk. They’re brilliant.
The printed resources produced by Hepatitis Organisations were critical to many participants' understanding of hepatitis C.

The information I first received was from the … Hepatitis Council … was fairly explicit. It even went as far as to recommend which herbs from health care stores you should avoid … but I found there was a magazine produced in NSW that was very useful … because it actually gave me a blow by blow description of someone who had been on the treatment and had been successful with it and was now free of the virus. So it was encouraging in that sense. Mind you, there were also a couple of stories in there where people weren’t successful … Having said that, the magazine provided a really balanced view, so when I went on treatment I had a feeling of what it could be like.

Several participants also discussed the value of Hepatitis Organisation libraries and resource centres. The latest information is located in the one place, so it is a one-stop-shop for new information. The concept of information being contained in one place was highly valued by participants as it reduced the time involved in searching for trustworthy and useful information. Several participants identified the ‘green book’ – the National Hepatitis C Resource Manual, as very useful, because it contained all the information in one resource.

That green book with the white spiral has been very useful – one stop shop for information – it’s all in the one place!

The green book with the spiral, that was really useful. It’s like a one stop shop for all the information you need. I think it should be given to people when they are diagnosed. It’s hard to throw away because it’s big and thick! But some of those other pamphlets get lost or chucked out.

Although this resource was produced for health professionals, it has been accessed by people living with hepatitis C across Australia, and many participants reported that it was very useful.

Disclosure of hepatitis C status was a barrier to accessing information; however, public education forums offered by Hepatitis Organisations were repeatedly identified by participants as valued sources of information. The education forums were valued because they provided participants with the opportunity to gather information directly from a range of experts.
A watershed moment for me, was when I attended a seminar at the NSW Hepatitis Council and they had different medical practitioners and a couple of nurses and a naturopath, and I learnt so much … that was just fabulous … the nurses talked about their experiences of helping people through treatment and that gave me so much knowledge about what to expect.

The importance of providing factual information, in contrast to opinion, was evident from one participant’s description of attending an education forum.

I attended a community forum on hepatitis C run by [organisation name] and it was very useful but the presenter was very biased … because he left me with the message don’t touch the treatment with a barge pole. He started talking about the worst case scenarios and the mental health impact of the medication. It was really irresponsible of him … I didn’t go to hear his opinion, I wanted information. I left the session feeling very anti-treatment and fearful of the treatment.

Educators must be aware of the powerful influence they have on an individual’s interpretation of information. Developing clear, evidence-based messages is critical to maintaining the trust and respect of people living with hepatitis C.

The internet
The internet was used by participants to explore hepatitis C generally, as well as to gather information on specific topics such as anti-viral treatment.

When I’m on the internet I just go here and there and basically anywhere. I just google hep C or treatment, or whatever and see where it takes me. I particularly take notice of university studies and hospital studies. They’re the ones I rely on.

Concern about trusting information on the internet was regularly raised by participants. While some participants had developed their own checklist for assessing the trustworthiness of information on the internet, others remained confused.
For information on the internet, I check the source to see where it comes from and I find the date to see how current the information is before I read any further.

Younger participants tended to be more trusting and less discerning about the trustworthiness of information on the internet. However, they described methods of testing the accuracy of the information, such as talking to a health professional.

I have been on the internet a couple of times, I just google it ... and that’s good. I don’t know what to trust – that’s funny I haven’t actually thought of that before ... I guess I just read it and because it’s written there I just assume it’s true. If it sounds really weird I will check it with my doctor.

Therefore, while the internet was a valuable source of information because it allowed participants to seek information anonymously, the content was often viewed with scepticism. Participants described a tendency to ‘stick close to home’ with regard to the sites they accessed.

You’ve got to be careful with what you’re looking at on the internet. I tend to stick to Australian sites, because I don’t trust the American or other international sites. I think sometimes the internet is full of information that isn’t correct, but people believe it because it’s written down and looks professional. And there’s a lot of information out there that people just make up ... and some of it can be quite frightening and some of it can be quite dangerous.

Criticism of Australian websites focused on their generic content. Many participants acknowledged that while they trusted Australian websites, they were frustrated by the lack of detailed information and breaking news.

I find the Australian websites very generic, you can go to any of the sites in Australia and you will find the same information. Whereas if you go to other international sites you’ll find new information, and you also get access to information and research as it’s happening. Australian sites are ... not updated. I would imagine that is largely because of funding – I imagine it costs a lot of money to constantly update sites.
Participants described how they were ‘forced’ to search for breaking news and the latest development ‘off shore’, which they perceived exposed them to potentially untrustworthy sources. Internet websites based in the United States were perceived to be particularly untrustworthy, because many were misleading or potentially biased. For example, several participants described accessing websites that were professionally presented, but were posted by an individual and provided opinion rather than fact. Websites funded by pharmaceutical companies were also perceived to provide biased information.

The Hepatitis Australia website and the AIVL and Victorian Drug User Organisation websites were identified by name as trusted sites because they were Australian, and participants recognised the organisation name and/or logo. The links listed on these websites were trusted because of their association with the organisation.

Now I know the good internet sites, after years of checking and double checking the information, I know which ones to trust … generally it’s the Council [Hepatitis Organisation] websites and links.

Maintaining the currency of the information contained on websites is a costly and time consuming exercise. Enhanced funding may be required to develop the capacity of Hepatitis and Drug User Organisations to develop and maintain the content of their websites.

**Health professionals**

Health professionals, specifically liver specialists and liver clinic nurses were trusted sources of hepatitis C information. However, GPs were frequently identified as lacking hepatitis C knowledge, which supported the questionnaire findings. Nonetheless, GPs were an important and preferred source of information for people living with hepatitis C. Participants discussed their desire to access information and support from their GP, because they were a familiar human resource, and in most cases, easily accessible. Participants provided encouraging examples demonstrating the willingness of some GPs to learn and be involved in managing patients with hepatitis C.
When I first went on treatment, my GP knew nothing about it, but as I was getting information about it from my specialist, I passed it on and he wanted information to be given to him, so I took all these brochures down to him, he didn’t have any idea … but he wanted to learn.

There was a lack of shared care and lack of interaction between my GP and the hospital [liver clinic] – I walked in at the end of my treatment and said to [my GP] ‘I don’t want to go back to the hospital, can you do my tests?’ … it was only then that I realised that he could have done a lot more of that along the way and that would have been great – remove the hassle of driving and parking at the big hospital … but he didn’t have the knowledge.

The role of GPs in providing information and support is critical; however, there were significant concerns that GPs had inadequate knowledge that prevented people living with hepatitis C from accessing information through their preferred pathway.

**KEY POINTS: Results of the focus groups and interviews**

**Valued sources of hepatitis C information**

- Participants valued the opportunity to interact with other people living with hepatitis C, particularly when they were trying to make decisions about their health.
- The term ‘peer’ specifically referred to other people living with hepatitis C.
- The NSW publication - The Hep C Review, was frequently named as a highly valued source of information and appeared to be accessed nationally.
- Participants relied on the quarterly newsletters because they relayed the most current information and developments in hepatitis C and they felt supported by the personal stories.
- Access to the quarterly newsletters often preceded participants’ contact with the Hepatitis Organisation.
- The support and information services such as telephone services, support groups and resource libraries, provided by Hepatitis Organisations were highly valued and respected by participants.
• Public education forums providing the opportunity for people living with hepatitis C to listen to expert speakers was a popular concept.
• The internet was used by approximately a quarter of participants to seek information and support.
• Participants were concerned about knowing what information to trust on the internet. Australian sites were generally regarded as more trustworthy, however, they were criticised because the content was too generic.
• Liver specialists and liver clinic nurses were trusted and respected sources of hepatitis C information.
• Participants wanted to access information from their GP; however, many were concerned about their GP’s hepatitis C competence.

Information sources with limited value
Participants identified several information sources that had limited value because the information could not be trusted or was difficult to comprehend.

General practitioners
As highlighted previously, GPs were a valued source of information because of their accessibility, though many participants expressed disappointment about their GP’s lack of knowledge, interest, concern and motivation to support them in living with hepatitis C.

GPs are the worst. Not necessarily because their information is worse or anything like that but … because you think you can trust them – they’re doctors, for crying out loud! If you can’t trust them, who can you trust?

The problems associated with GP’s knowledge were exacerbated in rural areas.

Being in the country there’s a lack of medical knowledge and the GPs themselves, so they don’t seem to keep up with the information … even though there is a fairly reasonable prevalence of hepatitis C in rural areas, they just don’t seem to have the medical knowledge to be able to cope with it.
The issue of GP involvement in the care of people living with hepatitis C and their role in providing hepatitis C information and support is an ongoing challenge.

**Printed resources**
Although printed resources were regarded as one of the most useful information sources, participants raised some concerns about their content. Similar to discussions about the generalised content of Australian internet sites, printed resources were also at risk of presenting a generalised perspective.

*It’s hard to go into specifics in those generalised type of brochures ... but that’s what you need. The brochures are written for the average person with hep C, but I don’t know whether the average person actually exists?*

Although not a common complaint, several participants raised concerns that the language used in some printed resources was too technical and difficult to comprehend. In addition, poorly targeted resources that attempted to provide all the information in ‘one hit’ were identified as potentially damaging.

*A lot of written information that you get is very medically based, or it’s focused on how you contract it and how its spread which is too basic ... It needs to be simple information that is accessible to anybody, because I think people fear it, and sometimes the medical slant of the information makes it sounds even more scary.*

*All the information they try to condense into one pamphlet does nothing but alarm you...*

Printed resources produced by state and territory Hepatitis Organisations and Hepatitis Australia, were considered a cornerstone of information and education activities, because the topics and content were appropriately targeted.

**Peer education**
Participants acknowledged the value of peer education initiatives; however, they also cautioned others to interpret the advice and information with care. Peers did not always provide accurate or unbiased information.
Personal stories are not always representative of the ‘real’ situation.

In particular, several participants raised concerns about the validity of personal stories on internet chat rooms and forums.

I tend to avoid forums or crap like that, I wouldn’t bother with them, because that’s just full of people’s life experiences ... and you can’t take too much out of them because you don’t know the people and you don’t really know what’s happening there, in their lives. On those forum sites, all the people are essentially housebound and they just spend all day on the internet, but they’re not the whole picture. The ones who are still fit and healthy, they’re all out and about, so you don’t hear from them.

Preferences regarding peer support are based on personal choice. Participants who were wary of peer support were most concerned that the information was biased, and came from unregulated and unidentifiable sources. Information obtained from peers tended to be interpreted as personal opinion rather than factual information.

**The internet**

Participants acknowledged that access to the internet remained limited for many people in Australia, which restricted its value as a source of hepatitis C information, therefore, it was suggested that Hepatitis Organisations and Drug User Organisations could help improve access to the internet by offering drop-in centres.

Maybe if you can’t access the internet, that’s a service that should be made available by the Councils – a drop in centre for people to use the internet.

People working with CALD communities indicated that the internet had a limited role for their clients because older community members were not familiar with the internet, though younger members of CALD communities were more likely to use the internet. Websites targeting CALD communities may need to be specifically targeted towards the demographics of the users.
With regard to internet sites, I wonder if it is a resource more for workers. I find the [NSW HIV/Hepatitis C Multicultural Health and Support] site very, very valuable and access it all the time. But I wonder which CALD groups would be accessing the internet ... I think young people from CALD backgrounds would access the internet quite a lot but I don’t think it would be common among older people ... therefore, if the internet is being accessed mainly by younger people it raises the issue for me that the information should probably be in English, because many young people can’t read their community language.

Limited access to the internet and concern about the trustworthiness of the information found on many international websites were discussed at length as significant barriers to relying on the internet for hepatitis C information. The general consensus among internet users was that Australian organisations needed to invest in maintaining the currency of the information on their websites, but also needed to ensure the internet did not become the main distribution pathway for hepatitis C information, because access to the internet was limited for some people living with hepatitis C.

**KEY POINTS: Results of the focus groups and interviews**

**Information sources with limited value**

- Uninformed GPs, and family and friends, along with international websites and non-Hepatitis Organisation printed resources were most frequently noted as the worst sources of hepatitis C information.
- Poorly targeted printed resources were not useful. Use of medical jargon and complicated language, and generic content reduced their value.
- Some participants did not trust the information provided by other people living with hepatitis C, because it represented opinion rather than fact.
Unmet information needs

During the course of the focus groups and interviews, participants identified a variety of topics for which they required additional information. Many of these topics were consistent with the needs identified by questionnaire respondents. Participants believed there was a lack of information on anti-viral treatment, particularly pre-treatment preparation, managing side effects and life after treatment. A young Vietnamese woman discussed her uncertainty about accessing hepatitis C treatment:

I heard through another junkie that there is treatment [for hepatitis C]. I thought about going on to it but I don’t know how to get it, where to go or how much it would cost. How do I actually start treatment? I don’t know.

A lot of the available treatment-related information was produced by liver clinics and pharmaceutical companies, which were acknowledged as important resources, although potentially biased. Participants discussed the importance of having access to unbiased information about treatment, preferably produced by community organisations, because they were perceived to be impartial to the politics of treatment. Resources focusing on life after treatment were scarce, in particular, detailed information on resolution of side effects after treatment, coping with non-response or relapse after treatment and, reinforcing self-management strategies in the absence of other treatment options were needed.

More detailed information about self-management strategies was requested by many participants who either could not access, or did not want to access anti-viral treatment.

A lot of the written information that’s produced is focused on the preliminary information, like transmission and treatment. But it doesn’t address all the information needs of people living with hepatitis C across the spectrum in Australia. And one thing it doesn’t tell you is how to avoid being one of the ones who goes on and gets sicker… like me – as it turns out. It seems to me that people think it’s obvious – how to avoid getting sick – but it isn’t.
More detailed information about the symptoms of hepatitis C, including the extrahepatic manifestations of hepatitis C and symptom management is also required. However, participants acknowledged the difficulty associated with compiling information on symptoms into a printed resource, because the experiences of symptoms vary between individuals. While participants described needing validation of their symptom with factual information, they also realised that peer support and talking to their GP or specialist would be the most appropriate source of information.

Assistance in interpreting clinical information was associated with understanding treatment, symptoms and self-management. The chronicity of hepatitis C emphasised the importance of being involved in their medical management, however, participants expressed concern that because they did not understand clinical terminology and concepts, they lacked the control they desired.

I’ve needed a lot of interpretation about the medical things that were happening to me ... I’ve really needed interpretation of the long words – what do they mean? The doctors are talking about my body when they use these words, but I don’t know what they mean. For example, the liver function test, they look at them and they know what they mean but they don’t explain it. I would love a little dictionary of all the terms they use, at least I could understand what they’re saying.

Overall, the breadth of topics covered by the current printed resources was commended by participants, however, additional needs were highlighted that focused on clinical topics such as anti-viral treatment and management of hepatitis C. Hepatitis Organisations were the preferred source of these specific resources because they were considered impartial and had the appropriate expertise.
KEY POINTS: Results of the focus groups and interviews

Unmet information needs

- Participants believed there was a lack of information on anti-viral treatment, particularly pre-treatment preparation, managing side effects and life after treatment.
- Treatment information produced by community organisations was important because it was believed to be impartial from the politics of treatment.
- More detailed information about self-management strategies was requested by many participants who either could not access, or did not want to access, anti-viral treatment.
- More information was needed on managing the symptoms and extrahepatic manifestations of hepatitis C infection.
- Participants indicated they needed additional resources to assist them to interpret clinical information associated with treatment, symptoms and self-management.

Impact of hepatitis C-related stigma on accessing information

Hepatitis C-related stigma and discrimination were identified as significant barriers to accessing hepatitis C information and support. The impact of perceived or actual discrimination was widely discussed as a serious impediment to disclosure, which prevented participants from openly and freely accessing information and support. Educating health professionals and the general public was crucial to improving the community’s awareness of hepatitis C and reducing stigmatising behaviour.

More education now ... less stigma at a later stage. The more education we give the general community ... the more they will know and then that will mean that people with hepatitis C out there will not have to deal with as much stigma in the general community. Then I can take a pamphlet on hep C in my GP’s waiting room or at the local pharmacy without people giving me funny looks.

There’s no point in giving information to people with, or at risk of hep C, without giving information to people in the general community, that’s the only way we’re going to stop discrimination.
It is generally accepted that the stigma attached to hepatitis C is associated with injecting drug use as a route of transmission. According to professionals working with CALD communities, the aetiology of hepatitis C-related stigma varies between CALD communities, but primarily evolves from misinformation, in comparison to association with injecting drug use.

I think the issue of stigma is an interesting one in CALD communities ... and we have to be aware of the differences between cultures. For example, there is stigma associated with hep C in the Cambodian community because they are very concerned about gossip, and they are really scared about what other people are going to say. In Australia, the stigma is about injecting drug use. Whereas, the stigma in CALD communities tends to be more focused on misinformation.

Hepatitis C-related stigma and discrimination significantly affects the quality of life of people living with hepatitis C. The result of this project also confirms the barrier created by actual and perceived hepatitis C-related stigma on seeking information and support. Overcoming stigma is a profound challenge, and will require a multi-faceted approach.

KEY POINTS: Results of the focus groups and interviews

Impact of hepatitis C-related stigma on accessing information

- Hepatitis C-related stigma was a barrier to disclosure, which subsequently impeded participants’ access to information.
- Raising community awareness of hepatitis C was critical to reducing hepatitis C-related stigma.
Summary

Obtaining information about hepatitis C and remaining up-to-date with new information was described by participants as a life-long process. Overall, participants described a multifaceted approach to obtaining information which involved accessing a combination of human, printed, and/or electronic resources. The general depiction was that information was more readily available now than in the past, when many participants were diagnosed with hepatitis C. Participants’ information needs evolved as they experienced the spectrum of hepatitis C infection, including diagnosis, development of symptoms, and management of symptoms, and the desire to prevent, or slow the progression of the disease through self-management activities and/or anti-viral treatment.

Participants preferred to access information face-to-face from health professionals and other people living with hepatitis C (peers), however, printed resources produced by Hepatitis Organisations were the cornerstone for hepatitis C information. The Hepatitis Organisation and Drug User Organisation quarterly magazines were revered, because they contained current and accurate information, as well as personal stories that provided participants with support. The internet was a source of information; however, there was also recognition that access to the internet was limited for many people. Australian websites were the most trusted, but the content was criticised for being too generic.

Barriers to accessing information included poorly informed health professionals, specifically GPs, inappropriately targeted resources, and experiences of actual or perceived hepatitis C-related stigma. In order to improve access to information for people living with hepatitis C; awareness of hepatitis C must improve in the general community.
Hepatitis C support needs

Participants’ hepatitis C support needs were more consistently themed than their information needs. Support from other people living with hepatitis C or peer support was frequently identified as a preferred source of hepatitis C support. Overall, participants’ need for support was triggered by consideration, or commencement of anti-viral treatment. Participants preferred to access hepatitis C support face-to-face, however, telephone and internet services and printed resources that included personal stories were also valued sources of support.

What does support mean?

Participants were asked to consider what support meant to them. It was generally considered that support involved having someone to talk to and depend on who had a shared understanding or experience.

*Support means looking at things from the same point of view that I look at it, and assisting me with the things I think I need to do or I need to find out, rather than being told what to do.*

Several participants also indicated that support involved the provision of accurate information and the opportunity to validate individual experiences. Support did not just involve emotional assistance, but also included practical, physical assistance with activities of daily living.

*For me, support is having someone to talk to, no matter how stupid the things I say sound; a support person can allay fears and provide as much information as possible. Also, support includes help with the practical things, like providing a lift to get to a hepatitis forum so I could meet other people with hepatitis C, or a lift to a doctor’s appointment.*

Ideally, support is free of stigma and judgements, which is why participants preferred to receive support from other people living with hepatitis C (peers). Health professionals were a supportive resource, particularly liver clinic nurses. However, health professionals’ capacity to provide support was impeded by time constraints and for some their stigmatising attitudes about
injecting drug use. Family and friends were identified as preferred sources of support, but once again, participants discussed feeling disappointed by their lack of insight into the impact of hepatitis C and their limited ability to empathise, because they did not share their lived experience.

The ones who are closest to me, are the ones who can’t give me the support I need … close friends who haven’t got hep C, no matter how much they read and how much knowledge they get, they can’t give me the support I need. I get the best support from other people with the illness, strangers with a common bond.

Support involved emotional and practical assistance which improved participants’ experience of living with hepatitis C.

**KEY POINTS: Results of the focus groups and interviews**

**Hepatitis C support needs**
- Support involves having someone to talk to and depend on, who has a shared understanding and experience.
- Support includes validation of experiences, especially hepatitis C symptoms.
- Support is free of stigma and judgement.

**Preferred sources of support**
Participants discussed numerous methods of accessing support, including face-to-face, on the telephone, and on the internet. Other people living with hepatitis C were the preferred source of support because they demonstrated the greatest empathy. Practical assistance with activities of daily living was also an important, although not common, expression of support.

**Peer support**

The majority of participants indicated they would appreciate the opportunity to talk to another person living with hepatitis C, and in
itself that would provide them with support. Whether the contact was initiated through a support group, telephone service, or the internet, depended on the individual’s personal preference; however, the supportive impact was equally as significant.

I feel like I don’t have enough people to talk to and to kinda of say … I’m really scared … and to be validated by other people who have lived through it.

I speak to lots of people with hepatitis C on the net, but I don’t actually physically know anyone with it … I got into the forums when I was on treatment because no one else listens to you whinge and no one else really “gets” what it’s like. But the people on the net did “get it” because they’ve all got the same problem … It was really helpful.

Peer support was closely linked to seeking information about hepatitis C, because anecdotal information was highly regarded. Validation of symptoms and treatment experiences was a particularly valuable aspect of accessing peer support.

I find it really useful to talk to other people who attend the support group who may have tried something or heard about something that can help with symptoms … talking to people who understand is so important.

Of note, professionals working with CALD communities described the need for people living with hepatitis C to be formally linked with a peer from the community for hepatitis C support. However, there was concern about members of emerging CALD communities being identified because the community was small, so professionals discussed the need for peer support services to link peers from different geographic regions, to maintain their confidentiality.

We have people who have just found out that they have hepatitis C or they just mention that they have it, and there are a lot of unanswered questions, a lot of “I don’t know what’s going on with my body, it never used to be like this”. So we would like to be able to offer the opportunity for our clients to speak to other people with hepatitis C so they realise it’s not a unique experience and there are other people who have these experiences as well. It’s a way of reducing people’s isolation.
Discussions indicated that use of telephones was a barrier for some people from CALD communities accessing telephone-based information services, so, a telephone support service would have to be just one aspect of a more comprehensive support program for CALD communities.

Although face-to-face was the preferred method for obtaining hepatitis C support, participants were also supported by the personal stories included in printed resources, and Hepatitis Organisations and Drug User Organisation quarterly magazines. Printed resources were highly valued, because participants could access peer support while remaining anonymous. The stories provided a context for factual information and often made the information easier to interpret.

The best pamphlet is the Hep C Review … I read it front to back, every time I get it. Although you read that there’s a 51% chance of being cured, I wasn’t [cured] after 48 weeks of treatment … But you read stories about people who do get cured. It’s fine reading about the statistics, but when you read about people who actually have been cured that makes it real.

Peers were universally preferred as a source of hepatitis C support because they shared a common understanding of the experiences of living with hepatitis C.

**KEY POINTS: Results of the focus groups and interviews**

**Preferred sources of support – peer support**

- Many participants preferred to access support from other people living with hepatitis C, because it was perceived they were empathetic to their situation.
- Face-to-face was the preferred method of obtaining hepatitis C support.
- Written personal stories were a highly valued source of support.
- Telephone services were a barrier for people living with hepatitis C from CALD communities accessing support.
Treatment-focused peer support

Consideration of, or commencing on, anti-viral treatment was a common trigger for participants to seek peer support. Deciding whether or not to commence treatment was identified as a time when participants valued the opportunity to speak to another person with hepatitis C who had experienced treatment.

It’s really important to have the opportunity to speak to other people with hepatitis C who have been on treatment … I know every one is different and we all react differently, but I think it’s really important to know what you could be in for. So, you can develop strategies that will help you prepare.

The majority of participants were not aware of the NSW Hep Connect telephone-based, treatment peer support service; however, participants’ description of their ideal support service for people on anti-viral treatment closely resembled the Hep Connect program. Participants described their desire to have a telephone-based service that linked people on treatment, or thinking about treatment, with other people who had completed treatment and therefore create a treatment ‘buddy system’.

I think everyone who goes through treatment should adopt someone else.

Participants did not want to gather clinical information about anti-viral treatment through the ‘buddy system’, but were more concerned with gauging the impact of potential side effects, gathering anecdotal side effect management tips and, strategies to cope with non-response or relapse after treatment.

KEY POINTS: Results of the focus groups and interviews

Preferred sources of support – treatment-focused peer support

- Consideration of, or commencing anti-viral treatment was a trigger for many participants to seek peer support.
- Participants wanted to talk to peers about their experiences on anti-viral treatment, particularly side effect management.
Internet-based peer support

The evolution of the internet has led to a variety of new strategies for accessing peer support. As has been discussed, the internet is an important source of information for people living with hepatitis C; however, there were concerns about the accuracy of the information. In addition to seeking information on the internet, many participants also sought peer support. The internet was a safe and anonymous source of support which did not require disclosure. Considering this, it was interesting to learn that many participants who accessed internet chat rooms and forums chose to relinquish their anonymity and establish close friendships with the people they met online, which sometimes involved telephone and/or face-to-face contact.

I have exchanged contact details with people I have met on the hep C forum ... so now I've got all these phone numbers ... So I can talk to them online and also on the phone. A couple of us have also met ... we met for a picnic lunch one day.

Participants’ experiences of internet chat rooms and forums varied from extremely positive to negative. One participant described a positive support experience from using a hepatitis C forum while on anti-viral treatment:

I use the internet, particularly the hep C forum all the time, because you have to talk to other people who are going through it or else you will go crazy... I just fell in love with the people I met online because I met people who were one month ahead of me, 6 months ahead of me and one month behind me on treatment. We had our own support group online ... my hand was held virtually by three people while I was on treatment and that’s all that got me through.

While another participant described a different experience of internet-based support:

I disregard the [internet sites] with testimonials from people with hep C, because I’ve talked to friends with hep C and I trusted their judgement more than strangers. Anyway, listening to other people whinge and complain isn’t as useful as getting the factual information.
Although it was not universally accessed, the internet was an important source of support for some participants.

**KEY POINTS: Results of the focus groups and interviews**

**Preferred sources of support – internet-based peer support**
- The internet was a preferred source of support because participants could remain anonymous and disclosure in a public setting was avoided.
- Internet-based support had evolved to include face-to-face and telephone contact for several participants.
- Reliance on the internet as a source of support varied significantly between participants.

**Role of support groups**

Similar to questionnaire respondents, a small proportion of participants had attended a support group and reported positive feedback about their experience. Participants had attended support groups organised by Hepatitis Organisations, liver clinics and Drug User Organisations. The benefits of attending support groups mimic the benefits of peer support; however, participants were assured of face-to-face contact.

*Face-to-face is always better to receive support. I’m sure everyone agrees with that ... And I think that everyone with hep C is probably going to end up in a liver clinic at some point, so I think they should offer support groups. So you can go and talk to other people with hep C, face-to-face.*

Several participants did not find attending a support group beneficial. For most participants, the need to disclose was a significant barrier to their involvement. Support group discussions need to be carefully facilitated to ensure the individual needs of participants are achieved. One participant commented that people with hepatitis C are diverse, and therefore their needs are diverse, so there is the potential for support needs to remain unmet.
One of the issues I found was … like any support group, just because you have hep C doesn’t mean you’re the same or have the same needs. So in the end it didn’t really work because the people were so diverse.

Following on from discussions about the diversity of the hepatitis C community, some participants indicated that many hepatitis C support services were targeted toward people who injected drugs, with whom they did not identify.

At that stage of my life [when I thought about attending a support group], I wasn’t using any substances, but I knew that because the support group was held at a certain place there would be people who were continuing to use drugs … and I just didn’t want to be a part of that because it’s not a part of me anymore.

The diversity of the hepatitis C community has the potential to complicate the delivery of support services, particularly in small or under-resourced regions where a range of support services may need to be developed. Hepatitis C prevention activities need to focus on people who inject drugs, which may result in organisations such as Hepatitis Organisations being perceived as servicing people who inject drugs. It may not be possible or realistic to offer more than one support service, at more than one venue, to encourage participation from a variety of target groups, but the impact of location, timing and membership of support groups should be considered.

For people who aren’t injectors or people who haven’t had a history of injecting … for people with hep C who don’t relate to that culture … there are no support services available. Many of the community organisations exclude people because that hasn’t been their experience. They don’t exclude us deliberately, but we’re made to feel uncomfortable by the focus of their activities.

Feeling alienated because individuals do not share the same route of infection is a concern for organisations providing support services, and must be acknowledged during the planning and delivery of services.
KEY POINTS: Results of the focus groups and interviews

Role of support groups
• Attendance at support groups was not widespread among participants.
• The benefits of attending support groups mimic the benefits of peer support, however, participants were assured of face-to-face contact.
• Disclosure was a significant barrier to participants attending support groups.
• Some participants described feeling ostracised because they did not identify with the injecting drug use culture and asked services to consider the diversity of the hepatitis C community.
• Support groups need to be carefully facilitated to avoid participant alienation.

Practical support for people living with hepatitis C
Participants encouraged Hepatitis Organisations and other community organisations to ‘think outside the square’ and develop new strategies for hepatitis C support. At the time of writing this report, the Hepatitis Organisation of QLD was conducting a review of treatment support services to determine if there is a need to provide practical and/or emotional/social assistance to people who are receiving anti-viral treatment. The findings of this Needs Assessment emphasise the need for local investigation of support requirements and the Hepatitis Organisations’ role in coordinating support services.

The need for practical support while on treatment, such as help with meal preparation, shopping and cleaning, was raised regularly by participants.

It would be really useful if ancillary services were available to people on treatment ... really practical issues and help such as Meals on Wheels, council services that come into your home and help out.

Meals on Wheels is a fantastic idea that would really help. When I was on treatment I just didn’t have the energy
to cook, I would just get up and fall back down again, therefore, my health suffered because I just couldn’t cook and wasn’t eating.

Both participants with, and without families and/or dependent children, expressed the need for practical support to achieve their activities of daily living. Hepatitis Organisations have an important role in advocating for access to these services for people living with hepatitis C in metropolitan and regional areas.

**KEY POINTS: Results of the focus groups and interviews**

**Practical support for people living with hepatitis C**
- The need for practical support including meal preparation, shopping and cleaning while people are taking anti-viral treatment was highlighted.
- Hepatitis Organisations potentially have a role in facilitating access to existing services such as meals on wheels.

**Role of health professionals in providing support**

The majority of people involved in the needs assessment wanted to receive hepatitis C support from health professionals; most frequently their GP, but also their liver specialist and liver clinic nurse if they were on anti-viral treatment. In reality, many participants did not have access to support before they were referred to the liver clinic.

*Prior to going on treatment, I didn’t have any support. The [nurses] at the clinic have been absolutely wonderful, and I think it would have been really good to have access to people like them when I was just trying to live with the hep C.*

For a range of reasons, anti-viral treatment elevated the priority attached to hepatitis C, and the time on treatment was particularly important in terms of needing access to support services. Participants praised the supportive role of the liver clinic nurses, and discussed their role in providing reassurance during treatment.
Do you C what I C? Report on the information and support needs of people living with hepatitis C in Australia

My nurse from the clinic, was an angel sent down to help me … she told me I could call her any time of the day or night … even in the middle of the night, which was just so amazing … of course I never rang her in the middle of the night, but it was so comforting to know she was there if I needed her.

Access to support after office hours was frequently linked with nursing support. Although the general consensus was that participants were reluctant to contact their nurse after hours, it was comforting to know they were available if needed. It is worth noting that liver clinic nurses are not reimbursed for providing after hours support. Frequently, nurses give patients their personal mobile phone number for after hours access, which means that the highly valued after hours support is unfunded.

Unfortunately, time constraints were identified as a barrier to accessing specialist nursing and medical support, because participants were aware they were not the only person wanting or needing support. Inadequate resourcing in liver clinics meant that support is often overlooked, because the staff are busy with their clinical responsibilities and the opportunity to ‘have a chat’ with patients is not prioritised.

My nurse was a lovely, lovely lady but you’re dealing with time restrictions when you’re in the hospital environment … you’re there to have blood tests and you get the rush through with the doctor, so by the time you might have the opportunity to talk to the nurse you may not be feeling as comfortable as you are at home on the phone, talking to a friend.

Several participants indicated they did not have access to a nurse during the course of treatment, so they were envious of other people who described the supportive role the nurse played in providing care.

I needed a good nurse … other people say ‘my nurse this and my nurse that…’ but I didn’t have any of that … I just had a really shitty doctor.

Participants reported that other health professionals, specifically GPs, had a limited role in providing hepatitis C support because of time constraints, limited knowledge, or discriminatory attitudes.
Support is not easy to find, if you really seek it out it might be there, but it’s not just there. Particularly not GPs, they’re not very helpful and they don’t seem to know a lot about hepatitis C and they don’t seem to want to … as soon as they know you’ve got hep C … you’re a junkie to them … and obviously junkies have got a pretty bad reputation.

Access to a GP is a big thing – even though they may seem supportive … unless you’re really lucky and find one that is really good, they either don’t know enough, or they still have a hang up in the back of their mind so they’re a bit judgmental, or they don’t offer you what’s available because they don’t always know what’s available.

The findings of the Needs Assessment highlight the importance of continued investment in building the capacity of GPs to manage and support people living with hepatitis C. General practitioners are the first point of contact with the health care system for most people living with hepatitis C, therefore, they need to be able to refer patients to support services, particularly if they are personally unable to empathise with the individual.

**KEY POINTS: Results of the focus groups and interviews**

**Role of health professionals in providing support**

- The majority of participants wanted to receive hepatitis C support from health professionals, most frequently their GP, but also their liver specialist and liver clinic nurse if they were on anti-viral treatment.
- Access to health professionals was often restricted due to time constraints.
- Support provided by liver clinic nurses was highly valued.
- GPs were inadequately skilled and resourced to provide support.

**Role of family and friends in providing support**

Many participants wanted to receive support from their family and friends, but as has been discussed previously, many were disappointed by their close contacts’ lack of insight into their
experiences. The consensus was that support provided by family and friends was genuine and necessary for participants to live comfortably.

You don’t want someone who pretends to support you, you don’t want people you don’t know or who you know don’t care … you want real support, like your parents or siblings or closest friends … people you trust and know are really interested in you.

Hepatitis Organisations may have a role in supporting and educating family members and friends of people living with hepatitis C about the issues associated with living with hepatitis C. Printed resources specifically targeting family and friends need to be developed to provide information about hepatitis C in an appropriate context. Promotion of support services, such as telephone and internet-based options are also necessary, so family and friends can have access to accurate information and talk to trained professionals about their fears and concerns.

My Mum used the NSW phone line when I told her I had hep C. At first, I wasn’t allowed to wash my clothes with hers or eat with the same knife and fork, but after she talked to them on the phone, it was much better. She knew more about it and she was a great support.

Before I started treatment, my daughter got online to a hep C chat room and asked “my Mum is about to start treatment, what can I do to help her?” And someone responded that she needed to have thick skin because sometimes the interferon makes us quite angry. She has since told me that was very good advice.

Understanding the challenges facing people living with hepatitis C may not be instinctive to potential support people, thus, Hepatitis Organisations need to invest in educating and supporting ‘the supporters’, because people living with hepatitis C will benefit from their close contacts being informed.
KEY POINTS: Results of the focus groups and interviews

Role of family and friends in providing support

- Family and friends were a preferred source of hepatitis C support, however, they often lacked insight into the personal aspects of living with hepatitis C which affected their ability to empathise.
- Hepatitis Organisations potentially have a role in supporting and educating family members and friends of people living with hepatitis C about the issues of living with hepatitis C.
Summary

Participants described a variety of support needs that focused on seeking validation of their symptom experiences, assistance in making decisions about hepatitis C management and treatment, and the quest for information about hepatitis C. Peer support was undoubtedly the most valued form of support, and was accessed face-to-face through support group meetings, or on the telephone and/or the internet. Often individuals accessed peer support through a variety of these sources simultaneously. Participants wanted to be supported by family and friends, but reported that they often lacked understanding of what it was like to live with hepatitis C. Hepatitis Organisations could have an important role in providing targeted information and support to the ‘the supporters’ of people living with hepatitis C. Health professionals, specifically liver clinic nurses and liver specialists were also valued sources of support, however, time constraints restricted their accessibility. General practitioners were highly desired sources of support, but were generally thought to lack the capacity to provide adequate support. The role of GPs in providing support for people living with hepatitis C and ensuring that GPs have access to accurate information and referral points is a critical issue for future planning activities.

Thinking about, or commencing anti-viral treatment, was a trigger for participants to seek support. Treatment-related support was highly sought after, and participants described the need for a ‘buddy system’. The need for practical support such as assistance with meal preparation, shopping and driving, was also stimulated by experiences of treatment-related side-effects.
Information and support needs of priority populations

This section of the report details the specific information and support needs of people living with hepatitis C from priority populations. Focus groups and interviews were conducted with participants from priority populations for hepatitis C health promotion activities, including:

- people living with hepatitis C who inject drugs
- people living with hepatitis C from CALD communities (young Vietnamese people) *
- people living with hepatitis C in custodial settings
- Aboriginal and Torres Strait Islander people living with hepatitis C *
- people living with hepatitis C in rural and remote Australia
- young people living with hepatitis C.

* There was some crossover between the membership of these focus groups, for example, some young Vietnamese participants and Aboriginal and Torres Strait Islander participants identified as current injecting drug users. Several participants also disclosed that they had spent time in custodial settings.

The needs of people living with hepatitis C in custodial settings was explored from the perspective of custodial workers. In addition, professionals working with people living with hepatitis C from CALD communities provided insight into the needs of different CALD communities.

People living with hepatitis C who inject drugs

People living with hepatitis C who inject drugs identified specific issues regarding their information and support needs.

The role of peers in providing information and support

People living with hepatitis C who injected drugs wished to receive information and support through their peer network. This was repeatedly referred to as their preferred option as peers who had a similar lived experience of injecting and hepatitis C were considered much more credible sources of information.
Users are more likely to listen to us than people in an office because we’ve been there. What would office people know – they’re reading the information out of a text book, we’ve lived it.

Talking to each other is the best way to get information … because we’ve all been there and done it, so we know what we’re talking about.

Peer support was identified as being invaluable by people who injected drugs in rural areas, Aboriginal and Torres Strait Islander people who injected, homeless people and young Vietnamese people who injected drugs. All participants discussed the credibility of peer education and support, and their familiarity with accessing information through peers in the past. An Indigenous participant explained:

Peer support is so important … that’s where I learnt my drug using, that’s where I learnt about hep C, that’s where I learnt everything … through all my other brothers and sisters … them passing it onto me and me passing it back.

Many participants saw themselves as having a responsibility to educate young people new to injecting because they were more experienced.

Get ‘em young … you can mould them into young men and women … before they get stuck in their ways … before they get like me – I went in too hard and too young and now look at me … I’m really sick.

Although other people with hepatitis C were often identified by questionnaire respondents as providing inaccurate information, focus group participants discussed the role of peers in clarifying information.

How do you know what information to trust? You ask other people on the street, other people with hep C, and eventually you find out what the deal is.

Participants who had been trained as peer workers were apprehensive about the blind faith invested in untrained peers and emphasised the importance of formalised training programs. Many Drug User Organisations offer peer education training.
programs, which aim to educate people who inject drugs on hepatitis C and preventing transmission, so they can “spread the word” in their social networks. Providing outreach programs such as ‘train-the-trainer’ programs is an important investment, especially considering the value attributed to peer education.

Ensuring that accurate and relevant information is readily available from a variety of sources is critical. People who inject drugs need to be able to access hepatitis C information at a time and place that suits them, such as when they see their methadone doctor or attend an NSP or a drug rehabilitation facility. Accurate information needs to be widely distributed to locations that engage with people who inject drugs, therefore, workforce development must continue to be a focus of Hepatitis Organisations and Drug User Organisations.

Other methods of ensuring that people who inject drugs are engaged in hepatitis C education and support, is to include them in the development of resources.

> Resources need to be developed by working with people on the streets and actually asking them how things could be made better and easier for people to understand.

Acknowledging the priority attached to hepatitis C was important when trying to engage with people living with hepatitis C from priority populations. Participants discussed that hepatitis C was often a low priority because it was so common among their peers.

> When all your friends have hep C ... it’s just part of life.

Therefore, information needs to be practical and relevant, and acknowledge the context of hepatitis C in the individual’s life.

**Knowledge deficits**

During the focus groups, participants regularly discussed how they clarified information about hepatitis C, which revealed effective methods of providing information. Drug User Organisation magazines were frequently identified as useful sources of information. One participant described how information gathered from a Drug User magazine encouraged behaviour change.
I thought I was injecting cleanly ... I'm a grub apparently ... according to an article I read in “Whack”. I used to use the same syringe a fair bit ... I couldn't be bothered to go down the road to get some more. I cleaned it out and that, whatever ... but nothing compared to what you're supposed to do according to this pamphlet. I'm lucky I never got septicaemia or anything like that.

Participants identified topics that had been clarified by the information contained in the Drug User Organisation resources. Of note, many participants remained confused about transmission of hepatitis C, specifically transmission of hepatitis C through injecting paraphernalia.

When I'm using, I always use a tourniquet. But I never realised that if I got blood on my tourniquet and if I lent it to my friend ... they could catch hep C from that. I thought it was just blood to blood, I didn't realise ... I never thought about it ... that it could get into material and be spread like that.

I never knew that you could catch hep C from a spoon ... if someone has used a dirty syringe to mull up in the spoon and you go on and use a clean syringe, thinking you're doing the right thing ... I didn't know that.

Re-infection with other strains of hepatitis C was also highlighted during the focus group discussions as a confusing issue. Along with survival of the virus outside the body, participants were confused because of the inability to identify the correct answer.

I used to use the needle a few years ago ... and I was scared of getting another strain of hep C ... I learnt that from another junkie, that there were many strains of it ... and I didn't want to catch a double dose of it ... a junkie educated me on that. But I still didn't really know how to stop getting another strain.

I want to know the truth about ... if I cut myself and a drop of my blood gets on the floor or if it's on my tourniquet, how long is that virus alive for? Because I've heard so many different answers – seconds, minutes or hours ... I don't know what to believe.
Participants discussed the limited advice about how to live with hepatitis C and how to access treatment. Many participants knew someone who had received treatment, however, there was still confusion about how, where and when to access treatment services, and the impact treatment would have on their lifestyle.

I don’t know whether I should have the treatment or not, so I’m really up in the air ... what if it makes me really crook and I go back to using again?

There was universal interest in accessing hepatitis C treatment, but there was also recognition that even if they had all the information, many would not embark on treatment immediately because of their current life situation. Treatment was too difficult for many people to access because it was ‘hidden’ in big hospitals. One participant who had received treatment in a NSW prison, suggested a very proactive approach to disseminating information about treatment services:

I think there needs to be emphasis on treatment and getting treatment out there. You can get it – this is where ... You can start it next week. We can cut your dose if it’s too high so the side effects won’t be too bad. You can come “here” and get your shot if you don’t have a fridge ... it can be done.

KEY POINTS: Results of the focus groups and interviews

People living with hepatitis C who inject drugs

• People living with hepatitis C who inject drugs emphasised the importance of peer based education and support strategies.

• Peers were credible resources because they had experience of injecting and living with hepatitis C. Many participants described relying on peers for information and support over a long period.

• There is a need to ensure peers are trained, and have access to accurate and current information to support this method of information distribution.
• Participants identified knowledge deficits in safe injecting practices (transmission of hepatitis C through sharing injecting paraphernalia), hepatitis C re-infection and accessing hepatitis C treatment.
• Printed resources about hepatitis C prevention and safe injecting techniques produced by Drug User Organisations had an impact on injecting behaviour.

Summary
Distribution of information and support through peers was important for people who inject drugs. Many participants discussed that they learnt about injecting from their peers, and this was how they preferred to learn about hepatitis C. Resources developed by Drug User Organisations were particularly useful in understanding hepatitis C transmission and subsequently prevention, because the information was specifically targeted at people who inject drugs. Simplifying complicated information is an important technique to increase the priority attached to hepatitis C for people who inject drugs.

Homeless people living with hepatitis C
Four homeless people living with hepatitis C in Brisbane, QLD, participated in a focus group. While they share many of the same information and support needs of other participants, they also have specific needs related to their homelessness. Participants described hepatitis C as a significant burden.

I just don’t know how I’m going to end up. I could wake up tomorrow and have yellow eye balls … and be really sick. I’ve also got mental health problems. So the worry of hep C and other health problems, as well as not really knowing where I’m going to sleep each night … I have a lot of worries.

Not surprisingly, being homeless restricted participants’ ability to look after themselves and adhere to self-management advice such as reducing alcohol intake and eating a balanced diet.

You got to get yourself out of the situation of being homeless and using [drugs] and drinking … before you can really do
anything about the hep C … The only way the doctors and educators are going to be able to help you is if you help yourself, by eating well and watching what you put into your body and that.

When I was on the street, I used to eat real bad … lots of pies and chips and bad stuff, now I’ve got a place to live I try to eat better, drink water to flush my system and eat pasta with vegetables. Now I have made that step … I’m off the street, I can’t go back, because I know I feel better and my hep C is getting better now that I have somewhere to live.

Participants were well connected with street based services, and therefore may not represent the needs of homeless people in other parts of Australia. However, they indicated that developing the capacity of people working in homeless services around hepatitis C prevention and health maintenance information would be valuable, as these are their most trusted sources of health information.

Drop in centres, drug vans and other homeless shelters – you could make sure the resources are made available.

Nurses are available at a lot of shelters and homeless centres, they’re helping us with our homeless issues, so if they could know more about hep C that would be really useful.

KEY POINTS: Results of the focus groups and interviews

Homeless people living with hepatitis C

- Hepatitis C was a concern and burden for homeless people.
- Homelessness affected participants’ ability to self-manage their hepatitis C, achieve a healthy diet, and reduce their alcohol intake.
- Building the hepatitis C capacity of organisations working with homeless people would assist in the delivery of information and support.
Summary
Homeless people living with hepatitis C have a range of competing demands that need to be addressed. Based on the findings of this discussion group, there is a need to develop the hepatitis C capacity of the staff of services offered by organisations working with homeless people. Development of specific resources for homeless people was not considered necessary instead, appropriate distribution of existing resources for people who inject drugs and the general community was sufficient.

People living with hepatitis C from Culturally and Linguistically Diverse (CALD) communities
The needs of people living with hepatitis C from CALD communities were explored during a focus group with young Vietnamese people and professionals working with CALD communities from South East Asia and Africa (Sudan, Central and Western Africa). The latter discussion group provided an insight into the needs of CALD communities and emerging communities, particularly African communities, many who are arriving in Australia as refugees. There was not enough data collected during the focus groups to discuss the needs of emerging communities separately. Participants indicated that newly arrived refugees share many of the same needs as established CALD communities, though it is worth highlighting that due to competing social, financial and physical needs associated with settlement in Australia, people from emerging communities may be less likely to prioritise their health and hepatitis C. In this section of the report, data specifically referring to the needs of emerging communities is identified.

In addition to the information and support needs of the mainstream community, specific needs for people from CALD communities were identified. Primarily, the provision of information and support to CALD communities needs to utilise a multifaceted approach, because it is highly unlikely that one approach would reach everyone successfully.

There is no one single solution to providing information and support for CALD communities … we have bilingual workers who go out and actively access the community networks through community development approaches; we use ethnic media, written resources … it’s not a silver bullet but a range of coordinated approaches.
The need for a range of methods to provide information and support for people living with hepatitis C from CALD communities necessitates additional funding and investment in hepatitis C CALD services. The provision of human resources, in collaboration with printed resources and media strategies is costly and labour intensive, so further investment in these service delivery models is urgently required.

**Unique considerations for providing information to CALD communities**

Workers emphasised the importance of human resources when working with CALD communities, particularly bi-lingual workers. Bi-lingual workers provide information and support for CALD communities in a culturally appropriate manner, because they are a member of the community. The risk of information being misinterpreted is significantly reduced. People living with hepatitis C can also ask questions and receive answers in their own language, which improves the quality of the conversation.

*The way to provide information to CALD groups is face-to-face, which is very costly and time consuming. But no brochure will ever meet that need. It’s about sitting down with someone and taking the time to explain the purpose of monitoring and why they need to come to the liver clinic, and that’s really costly.*

Printed resources were an important adjunct to face-to-face provision of information. Similar to the mainstream community, printed resources provide a reference for the information and support the exchange of verbal information. Development of printed resources needs to be done in collaboration with the communities to reflect their specific needs.

*It’s important to have a language resource for back up and support with the provision of information, but it’s crucial to also be able to have the skilled people who can understand how we need to “sell” the resource, and what kind of follow up we need to give.*

The realisation that printed resources would not be effective for every CALD community was emphasised, however, they were identified as a good place to start delivering information. Unique
challenges were identified for producing CALD specific printed resources. Obviously, language was a significant consideration that facilitated accessibility of the resource to CALD communities. Workers discussed the proliferation of resources in Vietnamese, but there are gaps in services for emerging communities such as African communities.

There are communities whose languages are really well represented like the Vietnamese language; there is a lot of information around this area, and there are other communities that are not well represented like the African communities, and it’s usually when we get requests from these communities that we have to search for information ... we usually end up providing incomplete or inadequate info.

Workers advocated for CALD specific resources to be developed in the community language. The practice of translating the content of resources from English to the community language was outdated and inappropriate, particularly considering some phrases or words could not be translated and there are subtle dialect differences.

Some terminologies in English either don’t translate or have a different meaning in other languages ... For example, hepatitis A, B, C in India; they understand hepatitis, but not the “A, B and C". People know they have hepatitis, but which one – A or B or C – they don’t know. Another example is that in some African countries like Rwanda or Sudan, they don’t recognise the word “hepatitis". But if you say “jaundice" they understand. In the Middle East, you say “hepatitis" and once again they don’t understand. But if you say ... “yellowing" then that means liver disease.

Some of the African communities you can put under the umbrella of Arabic speaking but it’s really difficult to know, for example, the Sudanese community is represented by at least 19 different ethnic communities and a lot of them speak different dialects ... so even if you give them information written in Arabic, the Arabic they speak is often quite different to the Middle Eastern Arabic that many of the resources have been produced in.
In-language production of printed resources is vital to ensure the community accepts and uses the resource. In addition, the content of resources needs to be relevant and specific for each CALD community. For example, discussion of hepatitis C transmission that focuses on injecting drug use has the potential to alienate members of some CALD communities because this is not how they were infected.

A lot of people have great difficulty articulating that the information they’re hearing … and reading is relevant to them. The resources we have access to are written in the context of the Australian population and then translated. So we never write it in the context of that particular community. For example, older Vietnamese were more likely to have been infected through medical treatments in the home country, whether it’s dental care or small procedures or surgery or whatever, and that’s completely different to the new incidence to the infections here in Australia, which is related to sharing injecting equipment. Our education materials really need to articulate those practices and those contexts that are relevant to the community.

Importantly, younger Vietnamese participants indicated that their preferred language for written and verbal communication is English, but they suggested that older members of their community would still prefer to receive information in their community language.

Some kids don’t know how to read Vietnamese, so English is better. Vietnamese is for the parents, and English is for the users and the kids.

The age-dependent language preference in the Vietnamese community highlights the importance of consulting members of CALD communities before, and during, the development of printed resources, hence, allowing specific community requirements to be identified and incorporated into the resource.

As important as the language, dialect and content of printed resources, is recognition of the priority given to hepatitis C for people from CALD communities. Many people from CALD communities, and newly arrived refugees, are faced with significant stresses that impede their ability to digest information
about issues that are not causing immediate health concerns. The priority which should be attached to hepatitis C needs to be reflected in the resource.

Maybe even if you have resources that don’t aim to give too much information but at least help people to click and say … well I have been in that situation, relating to a photo of a Cambodian woman having cosmetic tattooing or a person having dental work … they relate and that makes them think ‘maybe I do need to go to a GP and talk about this’. The resource won’t provide everything, but if it stimulates people to realise they do need to seek health care from a community health worker, or a refugee health worker, or their GP about this, then that’s really good.

General information about the structure and function of the Australian Health Care system was identified by workers as being equally as important as the provision of hepatitis C information.

Many people from CALD communities and emerging communities were frightened to attend hospitals and liver clinics, because they did not understand how the system worked. Many community members believed they would have to pay for medication and appointments because they did not expect a free health system.

Our Refugee Health Service has just put out a DVD on the health system and accessing health care, we have shown it to some of our patients in the liver clinic so they can get some information that explains how things work. The DVD has information about using your Medicare card and things to ask on your first appointment and that it’s OK to ask questions. Really basic information that we just take for granted.

Information deficits in CALD communities

Several deficits were identified in the information available for people from CALD communities. There was consensus that most of the information was very generic, and there was a lack of information about treatment, the practicalities of accessing treatment and information about the importance of monitoring and health maintenance.
There is a lot of information about what hepatitis C is, I don’t think there is a lot of information in different languages about the treatment options, and I don’t think there is a lot of information about other issues like how does the family deal with this virus, nutrition, healthy lifestyle and things like that. So, depending on the topic, you will find that there is a lot of information about a certain topic compared to other topics.

There is a significant lack of information on self-management for people living with hepatitis C from CALD communities, specifically the importance of a low fat diet, exercise and alcohol reduction. In addition, the limited information available disregards the cultural context of self-management.

I have spoken to the hospital over and over ... because they keep on providing the man with information about nutrition because he is the one who has been diagnosed. But he does not do the shopping or prepare the meals. So it’s not until they give the information to wife or daughter or mother that the changes will be made. That is the culture.

Similar to the mainstream community, confusion about the difference between the various forms of viral hepatitis was common in CALD communities. Because hepatitis A and B are endemic in many developing countries, people from CALD communities are confused about how they are different from each other and indeed with which virus they have been diagnosed.

There is confusion about hepatitis B and hepatitis C and the confusion goes as far as people often don’t know which virus they have been diagnosed with, let alone the differences between the viruses themselves.

Support needs of people living with hepatitis C from CALD communities
People living with hepatitis C from CALD communities also have specific support needs because they are often confronted with a range of competing financial, employment and social issues, which reduces the priority attached to health.
Managing a chronic illness is really different and often difficult when you have so many competing issues and issues that feel more pressing than a health condition that may or may not be making you feel sick.

The chronicity and slow progression of hepatitis C infection means that it can be deprioritised because it is not causing immediate health concerns. Many people from CALD communities are employed in casual or non-professional positions, which generally make access to flexible working hours to attend liver clinic appointments difficult. In addition, they may feel reluctant to commence anti-viral therapy considering the side effect profile and potential for decreased work productivity. People from CALD communities need to be cared for holistically, and there must be collaboration between employment, settlement and health services, because these are all interlinked aspects of an individual’s life. Unfortunately, workers indicated there is a lack of service co-ordination and communication.

There are problems because the [refugee] settlement services and mainstream hepatitis C services are separated. So when the client is within settlement services they are seen from a settlement perspective, excluding their health issues. And when they are in the hepatitis C sector that’s all that they see – hepatitis C. And rarely do those two services interact and work together to meet the needs of the client.

Hepatitis C-related stigma is a significant impediment to accessing support service for the mainstream community. Interestingly, workers did not perceive that hepatitis C-related stigma was as pervasive or limiting in CALD communities, because the association with hepatitis C and injecting drug use was not strong. Workers identified misinformation about hepatitis C transmission as the most significant barrier to members of CALD communities disclosing their hepatitis C and subsequently accessing support.

The need for confidentiality and privacy was paramount for people from CALD communities, but was often threatened when they accessed specialist services because they needed to use interpreting services.
With our patients, there have been a couple of situations for people in smaller communities, where the interpreter is from their own community, which raises issues about confidentiality being breached. So we have to be very careful about reinforcing the policies around confidentiality.

Specialist services, particularly liver clinic nurses, rely heavily on the telephone to communicate and support their patients; however, reluctance to access telephone-based services means that the support options available to people from CALD communities are limited. Unlike the mainstream community, group support is not favoured by members of CALD communities; their preference was for individual, face-to-face support.

I think people rather prefer individual support, than the group support. We have tried to establish support groups but no one turns up. But to provide the individual support, you need to have the resources.

Similar to their information needs, support options were limited for people from CALD communities, though the important role of the family network in supporting individuals should be acknowledged, and strategies developed to assist families to understand hepatitis C.

**Preferred methods of obtaining hepatitis C support**

Participants acknowledged that people from CALD communities preferred to access health information and support through face-to-face contact with a professional, but opportunities to access information and reinforce information with an expert or support person is limited for many people from CALD communities, primarily because of language limitations.

People might be looking at you, nodding and listening, as you’re saying “blah, blah, blah”, but the problem remains there is nowhere for them to go or talk to, so they can reflect on the information they have just been told. The problem is you just don’t know what you don’t know… The assumption is made that they understand what’s going on, but they really don’t. But they’re either too afraid or too worried or too polite to ask.
General practitioners are often the first point of contact with the Australian health care system for newly arrived refugees and migrants, and other established CALD communities. General practitioners working with CALD communities often speak the community language, and are a trusted source of information and support. Investment in training and supporting CALD GPs is an important strategy to ensure accurate information is available for CALD communities.

We have conducted intensive training with Arabic and Chinese speaking GPs ... because CALD GPs are a really, really important source of information. It’s probably where they find out that they have hep C and it’s probably the main source of good and bad information. The GP is a really great place to influence the process because a Chinese speaking GP is able to influence an individual speaking the same language about their hepatitis C. If a patient gets crook because of their hepatitis C, they’re probably better off being able to go to their GP and describe in their own language how they're feeling and not have to fear their experience being lost in translation.

However, care must be taken not to over-invest in CALD GPs and expect too much of their service, because they are thinly stretched and access is often restricted in terms of availability of appointments and length of appointments.

It’s all very well to aim to work with the GPs, but we need to be mindful that GPs who work with migrants are over stretched and they honestly don’t have the time to sit down and explain and engage in a meaningful way with the client. So we can’t just rely on GPs.

While ensuring CALD GPs remain informed about hepatitis C; management is a key strategy, it should not detract from investment in other sustainable and accessible resources. Workers were enthusiastic about developing new strategies for working with CALD communities. Limited resources meant workers were often forced to think laterally about alternative methods of delivering hepatitis C information.
We really need to get out of our comfort zone and start thinking and working on developing new ways of engaging with CALD communities. We need to focus on putting hepatitis C in the day-to-day life of the community and not just look at hepatitis C as a task that we need to do. We need to get information about hepatitis C into the ESL [English as a second language] programs, so when people are newly arrived to Australia they can learn English and also information about hepatitis C.

The use of novel technologies including visual aids (DVDs and videos) was encouraged, because they can be watched with family and other support people, ensuring that everyone has access to consistent information.

A resource like “Everybody’s business” which is a video that they have taken the time to re-shoot the same scenario with different actors from different ethnic groups, I think that’s best practice. But it’s costly to make these resources.

Collaboration between CALD organisations and clinical and community organisations allowed pooling of resources and encouraged the use of more expensive technologies. A liver clinic nurse who cared for a high number of patients with hepatitis C from CALD communities discussed the collaborative development of a DVD about self-management and its use in reinforcing health messages.

In my liver clinic, we’re in the process of developing a DVD, so it’s something the patient can take home and show their support people, or they can use it to reinforce the information that has been given to them about their treatment, lifestyle changes, diet and alcohol and other choices … the list goes on.

Although the telephone has a significant role in the mainstream community, interactive telephone services were considered limiting for people from CALD communities because of concerns they would not be understood because of their accent and subsequently embarrassed. However, different strategies for using telephone-based services were supported by workers, including recorded information in community languages.
The telephone is a huge barrier for a lot of people with accents ... so I think accessing a telephone helpline that offers a recorded message, that you know is not going to ask you any questions, is actually quite safe. I can see people using that type of service and afterwards it might make them more likely to want to talk to someone.

KEY POINTS: Results of the focus groups and interviews

People living with hepatitis C from CALD communities

- Members of CALD communities prefer to receive health information and support face-to-face from bilingual workers including CALD GPs.
- General practitioners working with CALD communities often speak the community language, and therefore become a trusted source of information and support.
- Printed resources were an important adjunct to face-to-face provision of information, but they need to be developed in-language, to account for dialect.
- Content of printed resources needs to recognise the priority and context associated with hepatitis C for people from CALD communities. For example, many people from CALD communities have no experience of injecting drug use, and this needs to be reflected in hepatitis C transmission information.
- Printed hepatitis C resources also need to include information about how to navigate the Australian health care system in relation to hepatitis C.
- People living with hepatitis C from CALD communities may not prioritise hepatitis C because they have many competing and more immediate health, financial and social concerns.
- There is a major need for detailed treatment and self-management information to be made available in a range of priority CALD languages.
- In addition, smaller emerging CALD communities are particularly under resourced in terms of hepatitis C information and support services.
Summary
A variety of methods are required to provide hepatitis C information and support to people living with hepatitis C from CALD communities. Human resources are the preferred information and support option, though this can be expensive. Printed resources need to be developed in close consultation with community members, and can support human resources. Innovative methods of distributing hepatitis C information and support need to be continued.

People living with hepatitis C in custodial settings

Information needs of people living with hepatitis C in custodial settings
There was general agreement that there is a substantial amount of hepatitis C information available in custodial settings. Participants (both hepatitis C custodial workers and people living with hepatitis C with experience in custodial settings), described printed resources, videos/DVDs and formalised education sessions upon reception and release from custodial settings.

Videos are a good way of communicating health information, because they can be played on an automatic loop and there are no worries with literacy.

A young Vietnamese man highlighted that time in custodial settings allows people to prioritise hepatitis C, because the information is widely available and attendance at information sessions is often compulsory.

Most of the time when users from my community [Vietnamese community] go to prison, that’s when they get educated about hep C. It’s compulsory for everyone to go to the hep C and HIV prevention education ... so if you like it or not you have to sit there and listen to the whole thing.

The role of peer education and support was strongly advocated by workers, and has been formally acknowledged as an effective and proven method of decreasing the transmission of blood
borne viruses (BBV) in custodial settings. For example, Hepatitis C Victoria has a dedicated BBV worker for custodial settings. The focus of this program is training peer support workers on hepatitis C, so they can be a resource for other prisoners.

The peer support workers know much better than me the best way to deliver the information ... they know how best to say it and what other issues the information is competing with.

Peer education and support models harness the expertise of prisoners in terms of understanding their environment and the priority attached to hepatitis C. It also acknowledges the models of communication that exist in custodial settings, particularly ‘word of mouth’.

Word of mouth is powerful in prison; information travels fast ... whether it’s correct or not is another issue ... but often prisoners will hear things and that’s when they follow up.

Once again, the opportunity to clarify information with professionals was highlighted as critical to the provision of information. An Indigenous participant indicated that while it was valuable to receive information by watching a video, there was no opportunity to clarify information with a worker:

I saw a video when I went to prison about hep C ... and they said you could catch it from semen and faeces ... I think it was a hep B and C the video, but they said you could catch it from using someone’s toothbrush ... but I got real confused about what was hep B and what was hep C ... it was really bad ... the video was made by inmates because they’re the ones telling us about it. But you got to make sure the information is right and that there is someone to talk to about it.

Workers discussed the importance of investing in the infrastructure of the custodial setting to better cope with the hepatitis C needs of prisoners. Custodial nurses described that a significant focus of their role had become hepatitis C and anti-viral treatment, but hepatitis C remained just one component of their role. Participants believed there was a need for a specific BBV position in custodial settings to develop and maintain the profile of hepatitis C prevention, treatment and care. Prevention of
hepatitis C transmission is a highly politicised issue in custodial settings, and as such, participants believed it could be easier for a non-custodial employee to engage in these discussions with prisoners.

*I think there needs to be a specific hepatitis C worker who is separate from the prison system, from justice health and corrections. So they can work specifically with prisoners around hepatitis C, making treatment decisions and things like that.*

Interestingly, stigma was not considered by workers or people living with hepatitis C to be a significant issue in custodial settings among members of the peer group.

*Stigma is not an issue in prisons because almost everyone has hep C!*

Although stigma was not an issue between prisoners, disclosure of hepatitis C status to prison staff, particularly guards, was avoided because of concerns about stigma. Often prisoners preferred to access information about hepatitis C face-to-face, rather than through printed resources, because there was no record of their status and their confidentiality was maintained.

*Prisoners like to access information about BBVs quite discreetly, because they are concerned that the prison guards might find out and they might be victimised and the guards might seek them out to cause trouble. Therefore, pamphlets can cause problems, because what if a guard sees you with it, so I think they prefer to talk to people and access information that way.*

Concern around the barrier created by custodial workers and parole officers for prisoners accessing hepatitis C information and support was discussed at length and highlighted the need to educate custodial workers about hepatitis C, particularly means of transmission. Workforce development is a significant issue for all staff in custodial settings. Participants recommended that hepatitis C education and training be included into the orientation training for new staff, and updates should be provided through the course of their work in custodial settings. Training should also address attitudes and values toward hepatitis C.
Prison guards have a lot to answer for, they are a significant barrier to prisoners with hepatitis C and those on treatment … they need to be educated about the symptoms of hepatitis C and the side effects of treatment, so they stop disciplining prisoners thinking that they’re acting up or need to be reprimanded … when really they are just agitated or aggressive or moody because of interferon.

Hepatitis C information should be included in the training program when people first learn how to become a custodial officer. That would ingrain the understanding in their minds from the very beginning. They would be more likely to work with us and the prisoners around hepatitis C…

Developing the hepatitis C knowledge and skills of custodial workers is as important as making information and support accessible to the prisoners. The prevalence of hepatitis C in custodial settings is high, so both workers and prisoners need to understand transmission and prevention issues. Similarly, ensuring that information and support structures are available to prisoners on release is important to maintain the priority attached to hepatitis C.

I think the level of information and support within prisons is good … it’s much better than it used to be … but once the prisoners are released there is no information, no advice about how to access a hep C doctor or care or support.

One way of providing the link between custodial and mainstream services is to allow prisoners access to these services while they are incarcerated. The Hepatitis C Council of NSW has expanded access to the telephone helpline service to custodial settings, and other organisations are considering offering the same access.

In NSW, we have access to the Hep C Helpline for NSW prisons, whereby staff, family and friends of inmates and the inmates themselves can ring this number and access correct and up to date information on hepatitis C. So they can have their questions answered and have information sent directly to them.
Support needs of people living with hepatitis C in custodial settings

Both workers and participants agreed that health services were accessible, which was evidenced by the availability of hepatitis C treatment in custodial settings. Access to hepatitis C treatment in custodial settings is gradually improving throughout Australia. Participants with hepatitis C described their release from prison as chaotic, because they did not have a place to live and they had to re-establish family relationships, therefore, hepatitis C loses its priority. A person living with hepatitis C described some of the challenges experienced on release from prison.

When I was released [from prison] I was out on the street … I sometimes have trouble taking anti-depressants … I’ve smoked that much pot that I’ve got short term memory loss … so how would I remember to take the injection and tablets. I need someone to help me, to support me and to remind me when to take the stuff.

While incarcerated, people living with hepatitis C are able to focus on their health and access support services to ensure they finish a course of treatment. A custodial nurse summarised the benefits of receiving hepatitis C treatment while in prison:

I think prison is a wonderful time for people to be treated for hepatitis C. It is a completely supportive environment, medication compliance is closely monitored – so you get a good chance of ensuring you get all the medication. While they’re in prison they can focus on the treatment and not have to worry about outside pressures, like money and jobs and kids and families. It really is a great time for them.

Three participants had received anti-viral treatment while incarcerated and they were grateful for the nursing care they received. The workers also acknowledged that access to support was more widely available in custodial settings than in the general community.
Because the prisoners don’t have the support of their family, they come to rely very heavily on the nursing staff while they’re on treatment. A lot of them have not had a caring person to turn to, so it’s almost like they are transferring what they would have or like to have in the community – like friends and family support, to the nursing staff and perhaps a couple of prisoners, who then become their support networks.

One of my patients refused parole because he wanted to finish treatment while he was in prison. He realised that he was in a really supportive place. He had free access to me [nurse] whenever he felt worried or sick … he could use my office for a bit of time out … an escape.

In addition to health services, peer support had an important role in custodial settings. Similar to participants in the general community, the importance of peer support was emphasised by hepatitis C treatment. Deciding to embark on treatment and the subsequent concerns around side-effect management highlighted the need for peer support.

When prisoners approach us for treatment, generally they have already made up their minds that they want treatment. They have talked to their mates, got information from the bush telegraph!

One day I was talking to a prisoner who was interested in treatment … and he was very well informed about the side effects and management of the side effects, he knew what he was getting into! He told me that his cell mate had done the treatment last year, and he had supported him through it. On a couple of occasions, his cell mate was feeling very crook, so this guy went and did his job for him. They had struck a deal that they would support each other through treatment. There’s a lot of support in prison, and it’s different to the type of support you get on the outside, it’s far more personal, in many ways.
KEY POINTS: Results of the focus groups and interviews

People living with hepatitis C in custodial settings

- There is a substantial amount of hepatitis C information available to people living with hepatitis C in custodial settings, including printed resources, videos/DVDs and formalised education sessions upon reception and release.
- Peer education and support models harness the expertise of prisoners in terms of understanding the priority attached to hepatitis C in the context of custodial settings.
- Prison guards were perceived to be a potential source of hepatitis C-related stigma because they lacked knowledge about hepatitis C.
- People living with hepatitis C in custodial settings were reluctant to access printed information in case the guards found out and they were inappropriately targeted or victimised.
- People living with hepatitis C who had spent time in custodial settings and workers both described incarceration as an ideal time to prioritise health and access hepatitis C treatment. Peer support and the support of health professionals was more readily available than in the community.

Summary

Over time, hepatitis C information and support has become more widely available in custodial settings. People living with hepatitis C reported that custodial settings were a valuable time to have access to information and support because they were able to prioritise their health, if the stress of being incarcerated was managed. Workers described the proliferation of a variety of custodial specific resources including printed, visual and auditory resources, compulsory training and access to supportive health professionals. The attitude of some custodial workers and guards was identified as a barrier to prisoners freely accessing information and being provided with support, however, workers believed that targeted training may help to address these barriers.
Aboriginal and Torres Strait Islander people living with hepatitis C

Nine Aboriginal and Torres Strait Islander people living with hepatitis C contributed to the Needs Assessment through a focus group held in Canberra. All participants had previous experience with injecting drug use and several had spent time in a custodial setting. Hepatitis C was a significant concern for all participants because of the high prevalence in Aboriginal and Torres Strait Islander communities.

As Indigenous people, we are four times more likely to catch hepatitis C and six times more likely to be incarcerated so there is a need to get the information out there.

Participants discussed that it was important to understand why hepatitis C infection was spreading in Aboriginal and Torres Strait Islander communities in order to develop targeted and relevant information and support services for community members. Sharing was a very important aspect of the Aboriginal and Torres Strait Islander culture, even though sharing injecting equipment was acknowledged as a risk factor for hepatitis C transmission, cultural beliefs frequently exerted more power over behaviour. The high number of Aboriginal and Torres Strait Islander people in custodial settings was also a considerable concern for hepatitis C transmission, and custodial settings were identified as an opportunity to provide information and support.

We’re a very sharing community and a lot of rural communities don’t have needle and syringe programs so people share their gear ... and gaol is another big factor, you know most of the time there is only one fit in the gaol system for 3-4 months and that goes through shit knows how many people. Our young fellas who have not caught hep C before they go into gaol ... go in negative and come out positive ... the gaols are not testing them on release, and yet that’s their duty of care.

We’re very caring people, if you’ve got a brother who is sitting there sick ... hanging off the gear ... and you’ve only got one fit ... you give it to him ... you clean it out as much as you can, but you give it to him. It’s hard you know ... if you’re that sick and you’re hanging out, sometimes you just don’t care.
The provision of hepatitis C information and support must acknowledge the cultural context of sharing that exists within Aboriginal and Torres Strait Islander communities. Social research needs to explore the priority attached to hepatitis C by Aboriginal and Torres Strait Islander people to inform the development and delivery of services.

Participants believed that printed resources had an important role in providing Aboriginal and Torres Strait Islander people with information, however, the preferred source of information and support was face-to-face contact. There were a number of reasons why human contact was preferred, including low literacy and difficulty understanding complicated concepts.

Lots of Indigenous people have trouble with reading, so you need to use common language if you’re going to make written resources … sometimes the resources use quite big words, that are hard to understand.

You can read stuff on pamphlets and stuff but it’s not until someone actually explains it that it makes any sense … you get more insight if you talk to people.

Similar to the needs of other priority populations, information and support services for Aboriginal and Torres Strait Islander people need to be developed in close consultation with members of the community.

Indigenous- specific resources should be developed by getting in and talking to peers and hearing what information they want to have included in the resources. As we’ve all said, we’re more likely to listen to each other than other people…

Misinformation about hepatitis C was common in Aboriginal and Torres Strait Islander communities. In particular, there was a lack of information about hepatitis C transmission from mother-to-baby. Two female participants discussed their fear of not having the information when they were pregnant and, their concerns about giving hepatitis C to their baby being dismissed by their mainstream health providers.
There’s not enough information out there about transfer of the virus from mother to baby and then the treatment, like what happens if the baby does have it … it’s really stressful and there’s no information.

Participants with children demonstrated strong emotional reactions to hepatitis C transmission, which were embedded in their fear of passing the virus on to their children.

It’s really stressful … our daughter is of an age now where everything goes into her mouth … we are very careful people, but it’s come to the stage that we wash our hands so often … we try and do a good thing, that my hands crack and they bleed … so you know by being so careful we are actually putting ourselves and our daughter at risk … and that’s scary. We’re glove crazy and Dettol crazy …

KEY POINTS: Results of the focus groups and interviews

Aboriginal and Torres Strait Islander people living with hepatitis C

- Aboriginal and Torres Strait Islander participants were aware of the high prevalence of hepatitis C in their community and emphasised that hepatitis C services and resources needed to be developed in consultation with community members.
- Printed resources and peer support were the most important sources of hepatitis C information.
- There was confusion about hepatitis C transmission among participants. Access to hepatitis C treatment was limited, and self-management advice did not reflect the context of many participants’ lives.
Summary

The information gathered in this focus group emphasised the importance of having a comprehensive approach to providing hepatitis C information and support to Aboriginal and Torres Strait Islander people. Participants were frustrated by the high prevalence of hepatitis C in their community, particularly considering that it can be prevented through safe injecting practices and blood awareness. However, participants were fearful, because their lack of knowledge meant they were at risk of spreading the virus. A combination of human and printed resources was considered ideal. Concurrently, participants prioritised the need to build the hepatitis C capacity and infrastructure of Aboriginal and Torres Strait Islander health services, so information and support could be provided in a familiar and culturally appropriate service.

People living with hepatitis C in rural areas

People living with hepatitis C in rural areas were most concerned about access to support services. Participants’ information needs were similar to those already identified; however, access to support was impeded, because participants were reluctant to disclose their hepatitis C status. The reasons underpinning participants’ reluctance to disclose are not unfamiliar in the general context of living with hepatitis C, but they are exaggerated because of the rural context. An interviewee living in remote QLD explained:

> It would be nice if I was able to tell everyone with free abandon about the hep C, but the reality is, particularly in rural Australia, that people are probably unforgiving and would say ‘oh well you brought it all on yourself … and this is something you’ll die of because of what you did’.

Because of the association between hepatitis C and injecting drug use and fear of the ramifications of disclosure, participants were forced to develop elaborate explanations to disguise hepatitis C and its impact.
When I was thinking about going on interferon, I googled it and I found a British website that mentioned that interferon was actually used in cancer … it’s a treatment for people with kidney cancer. So instead of telling people the whole truth and nothing but the truth, I told everyone I had cancer of the kidney … because telling them the truth would mean that they would have pictures that I was some crazy narcotic addict or a criminal … so I told my friends, I told my daughter that and told everyone around me that …

KEY POINTS: Results of the focus groups and interviews

People living with hepatitis C in rural areas

• People living with hepatitis C in rural areas were most concerned about access to support services.
• Participants preferred to access support services face-to-face, but were prevented from doing so because of reluctance to disclose, and subsequent fear of discrimination.

Summary

Lack of confidentiality was part of the landscape in rural Australia and was a significant barrier to accessing hepatitis C support. Participants explained that information could be accessed anonymously through the internet or on the telephone, but participants preferred to access support through direct human contact.
Young people living with hepatitis C

Ten young people aged less than 25 years were involved in several focus groups. They provided a very limited insight into the information and support needs of young people living with hepatitis C. Overall, young participants were ambivalent about hepatitis C and its impact.

I really have not thought about hep C or spoken about it … since I was diagnosed. I haven’t wanted any information or thought about it at all … You asking me these questions has made me think about it more than I ever have!

Younger participants were not concerned about hepatitis C because they were not experiencing any symptoms, and therefore concluded that it was not a significant concern. All the younger participants involved in the project were currently injecting drugs, and each identified their drug use as a more significant priority than hepatitis C.

KEY POINTS: Results of the focus groups and interviews

Young people living with hepatitis C
• Young people living with hepatitis C involved in the needs assessment did not prioritise hepatitis C, because they were not experiencing symptoms and described other more important priorities such as drug use.

Summary
Generally, young people believed they did not have any needs regarding hepatitis C, because they were unaffected by it. Overall, they did not experience symptoms related to hepatitis C, so they surmised that it was not worth worrying about. Most had not sought information or support and could not understand why they would need to.
Considerations when using the Needs Assessment

When considering the findings of the Needs Assessment, limitations relating to the representativeness of the sample, the recruitment methods and the ability to generalise the findings must be acknowledged.

Participants

Despite all efforts to include as broad a range of people with hepatitis C as possible, it is acknowledged that the 327 people who were consulted may not be a representative sample of all people living with hepatitis C in Australia. Participants were conveniently recruited through Hepatitis Organisations, Hepatitis-related organisations and clinical services. It is difficult to determine whether people who access these organisations are representative of the population. Therefore, the needs of people not linked to hepatitis C services may not be accurately reflected in the results of the Needs Assessment. Accessing a truly representative group of people living with hepatitis C remains a significant challenge, because many people with hepatitis C are unaware of their infection and have not been diagnosed.

Participants were reimbursed for their involvement in the project which must be acknowledged as a potential limitation. It is possible that the offer of reimbursement falsely motivated people to participate and biased the findings. In addition, information about the number of people who were approached to participate in the project but refused is not available, which highlights a potential bias in the results.

Methods

Limitations associated with the questionnaire design are recognised. For example, question 15 asks participants if referral to a specialist was made at the time of diagnosis. Only those who answered ‘yes’ could answer the following question, which asked for further details about the timing of the referral. The wording of this question does not account for people who returned for follow up one to two weeks after diagnosis and who were then referred at this point. Therefore, the data is potentially misleading.
Data was collected over a short time, which may have limited the number of participants and therefore the depth of the findings.

Only small numbers of participants were involved in the focus groups, which is a characteristic of this methodology. It is critical to highlight that it was not the purpose of the focus groups to gather representative information, rather to explore in-depth the needs of people from priority populations.

The inability to include a greater representation of people living with hepatitis C from culturally and linguistically diverse communities and people living with hepatitis C in custodial settings was addressed by conducting focus groups with professionals working with these priority populations. However, this is a weakness of the data, because professionals may not share an accurate understanding of the needs of these priority groups.

Results
Considering the limitations associated with the representativeness of the sample, the findings of the Needs Assessment should not be generalised. The use of a convenience, self-selected group of people living with hepatitis C enabled the identification of the salient information, education and support needs for this group of affected people and therefore provides evidence to plan, develop and deliver services.

The triangulation of methods used to collect information in the Needs Assessment has resulted in some repetition of themes in the report. Focus group and interview data is used to support and expand on the questionnaire findings, therefore, repetition is unavoidable, however, it is hoped the presentation of the findings in this way provides the reader with a deep understanding of the needs of people living with hepatitis C.

Recommendations
It is beyond the scope of the Needs Assessment to advise about the implementation of the recommendations. The recommendations are intended to highlight the most critical findings of the Needs Assessment and strategically influence the planning, development and delivery of future education and support programs.
Major Recommendations for action

The National Hepatitis C Needs Assessment 2008 provides a rich source of information for organisations and individuals providing services to people with hepatitis C. It is expected that many organisations will review the Needs Assessment, gain insights and adapt their practice as needed. The following recommendations were developed after consultation with the management and staff of Hepatitis Organisations throughout Australia and professionals working in the sector who attended a forum on the Needs Assessment held at the 6th Australasian Viral Hepatitis conference in October 2008. The recommendations focus on the areas where a more coordinated effort across the sector is required.

Time of Diagnosis

The findings of both the questionnaire and the focus groups indicate that diagnosis was a time of concern and stress for many participants. Most people knew little, if anything, about hepatitis C prior to diagnosis, and indicated that the process of diagnosis did not improve their knowledge. Participants highlighted the need to provide self-management information at diagnosis as well as information on preventing further transmission, when to disclose, and treatment options. The National Hepatitis C Testing Policy requirements for a pre-test discussion appeared to be rarely followed and referral for support to a community organisation at the time of diagnosis was also lacking.

Most participants were diagnosed by their GP, and the role of the GP is therefore of particular importance at the time of diagnosis. While GPs were identified as a preferred source of information and support, lack of knowledge limited many GPs’ ability to provide information or support.

1. Establish a national “Hepatitis C Time of Diagnosis Project” specifically targeting GPs to develop and implement best practice guidelines around the time of hepatitis C diagnosis.
Addressing Stigma and Discrimination

Participants repeatedly indicated that hepatitis C-related stigma and fear of discrimination were a barrier to seeking both information and support. The stigma and discrimination associated with hepatitis C, and the major impact it has on people with hepatitis C is well recognised. The National Hepatitis C Strategy 2005-2008 lists six priority action areas to address stigma and discrimination, however, no significant progress has been made to date which has made a difference to the lives of people with hepatitis C. The impact of stigma and discrimination is all pervasive and must be addressed as a top priority in the next iteration of the National Hepatitis C Strategy.

2. Implement a well designed hepatitis C public education campaign which dispels the myths and misconceptions around hepatitis C and reduces the negative impact of stigma.

3. Develop effective partnerships with anti-discrimination agencies to guide further action to address hepatitis C-related discrimination.

Information Needs

Overall, 60% of survey participants indicated they had additional unmet information needs on a range of topics. Many of the hepatitis C information resources available were noted to be generic; participants desired more specific and detailed information in many cases.

Participants expressed a strong preference for receiving information face-to-face from health professionals to allow instant clarification of any issues of concern. Great value was also placed on interaction with another person with hepatitis C and reading the personal perspectives of a person with hepatitis C in hepatitis organisation magazines. However, some people expressed concern that peers with hepatitis C could be a source of biased or inaccurate information unless they were well trained.
Internet access was noted to be limited for some people; however, others often turned to the internet for hepatitis C information. For these people, websites were a preferred source of information, as information could be accessed confidentially. The paucity of breaking news stories on Australian websites often forced participants to go to international websites to learn about new developments. Concern was expressed over the veracity of international websites in particular. The ability to assess the quality of a website was viewed as an important skill for people seeking hepatitis C information on the internet.

4. Hepatitis organisations and specialist clinical services consider strategies to increase access to quality interactive information services incorporating hepatitis C peers and health professionals.

5. The National Hepatitis C Resource Network (run by Hepatitis Australia), reviews the results of the National Hepatitis C Needs Assessment as part of their planning process for new consumer resources.

6. Hepatitis-related organisations facilitate timely consumer access to information on new developments in hepatitis C and methods of assessing the quality of international websites.

Support Needs

Many participants had not experienced specific hepatitis C support prior to commencing treatment and the majority had unmet support needs.

Access to other people with hepatitis C was considered a major source of support, particularly when considering treatment. Peer education and support networks were particularly important to people who inject drugs and to people in custodial settings.

Participants wanted to be supported by family and friends but reported that they often lacked understanding of what it was like to live with hepatitis C.

A quarter of respondents indicated they would like to belong to a support group but the majority did not know how to go about accessing a local support group.
7. Hepatitis and clinical organisations consider strategies to facilitate improved access to support groups across the country.

8. Hepatitis-related community organisations extend the reach of peer based support programs, including treatment specific programs.

9. Hepatitis-related community organisations promote their support services widely to incorporate family and friends of people living with hepatitis C.

Future action

The next stage of the Needs Assessment involves implementing the findings of the Needs Assessment. The implementation phase will involve disseminating the findings of the Needs Assessment throughout Australia to all interested parties, and consulting with the staff of Hepatitis Organisations, Hepatitis-related community organisations, clinical services and people living with hepatitis C, about creative options to address the recommendations arising from the project.

10. Hepatitis Australia consults with Hepatitis Organisations, Hepatitis-related community organisations, clinical services and people living with hepatitis C about the Needs Assessment findings and the strategic development of hepatitis C information, education and support services in Australia.
Conclusion

It is recognised that meeting the information, education and support needs of Australians with hepatitis C requires a collaborative effort by a wide range of people and organisations.

It is hoped that each organisation which provides information, education and support to people with hepatitis C will review the full report of the National Hepatitis C Needs Assessment and gain insights into the broad spectrum of education, information and support needs of people with hepatitis C.

Gaps in information, education, and support provided to people with hepatitis C have been identified in this report. Coordinated and concerted effort will be required to make significant progress. Two levels of action are required. The results of this Needs Assessment can be used by a range of organisations to inform their future service delivery to better meet the identified needs of people with hepatitis C. In addition, several areas will require coordinated government action to effect the changes required. For example, the impact of hepatitis C stigma and discrimination and poor levels of hepatitis C knowledge amongst GPs have been recognised and reported for many years. Successfully addressing these issues will require a significant investment of both time and funds. We hope that this challenge will be taken up.
Appendix 1 – Questionnaire

The National Hepatitis C Needs Assessment

Welcome to Hepatitis Australia’s National Hepatitis C Needs Assessment survey. People living with hepatitis C in Australia are invited to complete this survey. It should take between five and ten minutes to complete.

The purpose of the Needs Assessment is to document the information, education and support needs of people living with hepatitis C in Australia.

The results of the Needs Assessment will be widely distributed across Australia and will help guide the planning and delivery of education and support services for people living with hepatitis C, through Hepatitis Councils and other community organisations around Australia.

Please consider telling other people you know living with hepatitis C about this survey and encourage them to complete it as well. We greatly appreciate your participation in the Needs Assessment!

Thank you for your time.

Please return this survey by **Friday 27th June 2008** to:

Hepatitis Australia
National Hepatitis C Needs Assessment
PO Box 716
Woden
ACT, Australia, 2606.
Part 1. Information about you

Please tick (✓) the most appropriate box.

1. In which Australian state or territory do you live?
   □ Australian Capital Territory
   □ New South Wales
   □ Northern Territory
   □ Queensland
   □ South Australia
   □ Tasmania
   □ Victoria
   □ Western Australia

2. How would you describe where you live?
   □ Inner city
   □ Suburban
   □ Regional or rural

3. What is your gender?
   □ Female
   □ Male
   □ Transgender
   □ Other (please specify) _______________________________

4. What age are you?
   □ 0 - 18 years
   □ 19 - 30 years
   □ 31 - 45 years
   □ 46 - 60 years
   □ 61+ years
5. Do you identify as being:
   □ Aboriginal
   □ Torres Strait Islander
   □ Aboriginal and Torres Strait Islander
   □ None of the above

6. Which country were you born in? _______________________

7. What is the primary language you speak at home?
   □ English
   □ Other (please specify) _______________________

8. In what year were you diagnosed with hepatitis C? _______

9. How long do you think you have been living with hepatitis C prior to the diagnosis?
   □ Less than one year
   □ 1 – 5 years
   □ 6 – 10 years
   □ 11 – 20 years
   □ More than 20 years

10. Who diagnosed your hepatitis C?
    □ Drug and alcohol worker
    □ General practitioner (GP)
    □ Nurse
    □ Sexual Health clinic worker
    □ Specialist doctor
    □ Other (please specify) _______________________
11. Did you know about hepatitis C before you were diagnosed?
   □ Yes
   □ No
   □ Uncertain
   If yes, where did you get most of the information about hepatitis C?

12. Before you were diagnosed with hepatitis C, did you have a pre-test discussion about what it meant to have hepatitis C?
   □ Yes  → Go to question 13
   □ No   → Go to question 14
   □ Uncertain  → Go to question 14

13. If you had a pre-test discussion about hepatitis C, were you told about: (choose all the answers that are relevant)
   □ How hepatitis C is spread?
   □ The impact and progression of hepatitis C disease?
   □ Possible treatments?
   □ Where to get more information and support about hepatitis C?
   □ Referral to a Hepatitis Council?

14. When you were given the hepatitis C diagnosis, were you given the impression that it was:
   □ A fatal disease?
   □ A serious disease that could be treated?
   □ A relatively unimportant and unthreatening disease?
   □ Other (please specify) ________________________________
15. Were you referred to a specialist doctor or liver clinic at the time of diagnosis for further tests and treatment?

☐ Yes → Go to question 16
☐ No → Go to question 17

16. How much time went by between being diagnosed with hepatitis C and being referred to a specialist clinic?

☐ Immediately at diagnosis
☐ Within 12 months of diagnosis
☐ 1 – 2 years after diagnosis
☐ 3 – 5 years after diagnosis
☐ over 5 years after diagnosis

17. Have you received interferon-based treatment for your hepatitis C?

☐ Yes → Go to question 18
☐ No → Go to Part 2

18. What type of hepatitis C treatment have you taken?

☐ Interferon (3 times a week injections)
☐ Interferon (3 times a week injections) and Ribavirin
☐ Pegylated interferon (1 injection a week)
☐ Pegylated interferon (1 injection a week) and Ribavirin
☐ Other (please specify) ____________________________
Part 2. Hepatitis C information and education needs

Please tick (✓) the most appropriate box.

1. Over the past few years, do you believe you have had enough information to make informed decisions about your hepatitis C?
   - □ Always
   - □ Most of the time
   - □ Sometimes
   - □ Rarely

2. How would you prefer to receive hepatitis C information?
   - □ Face to face
   - □ Internet chat rooms and forums
   - □ Internet websites
   - □ Over the telephone
   - □ Written printed resources
   - □ Other (please specify) ____________________________
      __________________________________________________
      __________________________________________________
      __________________________________________________
      __________________________________________________
5. **Who** have been the worst sources of hepatitis C information?
(Please choose up to 3 sources)
- Another person with hepatitis C
- Community worker from a Drug user organisation
- Community worker from a Haemophilia Centre
- Community worker from a Hepatitis Council (including telephone information and support workers)
- Drug and alcohol worker
- Family member and friends
- Your general practitioner
- Your liver clinic nurse
- Your liver specialist
- Other (please specify) ____________________________________________________________________

_____________________________________________________________________________________

6. **What** have been the worst sources of hepatitis C information?
(Please choose up to 3 sources)
- Hepatitis C Council telephone service
- Hepatitis Council website
- Hepatitis Council written, printed information
- International internet website
- Internet chat room or forum
- Support group
- Written, printed resources (non-Hepatitis Council)
- Other (please specify) ____________________________________________________________________

_____________________________________________________________________________________
3. **Who** have been the best sources of hepatitis C information?
(Please choose up to 3 sources)
- Another person with hepatitis C
- Community worker from a Drug user organisation
- Community worker from a Haemophilia Centre
- Community worker from a Hepatitis Council (including telephone information and support workers)
- Drug and alcohol worker
- Family member and friends
- Your general practitioner
- Your liver clinic nurse
- Your liver specialist
- Other (please specify) ____________________________

4. **What** have been the best sources of hepatitis C information?
(Please choose up to 3 sources)
- Hepatitis C Council telephone service
- Hepatitis C Council website
- Hepatitis C Council written, printed information
- International internet website
- Internet chat room or forum
- Support group
- Written, printed resources (non-Hepatitis Council)
- Other (please specify) ____________________________

__________________________
7. What topics would you like more information on?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Part 3. Hepatitis C support needs

Please tick (✓) the most appropriate box.

1. Do you believe you have been given adequate support to manage your hepatitis C?
   □ Always
   □ Most of the time
   □ Sometimes
   □ Rarely

2. How would you prefer to receive support for hepatitis C? (Please choose up to 2 options)
   □ Individual face to face contact
   □ Internet
   □ Internet chat room or forum
   □ Support group
   □ Telephone
   □ Other (please specify) ________________________________________________
   ______________________________________________________________________
3. Who have been your best sources of support for hepatitis C?
   (Please choose up to 3 options)
   □ Another person with hepatitis C
   □ Community worker from a Drug user organisation
   □ Community worker from a Haemophilia Centre
   □ Community worker from a Hepatitis Council (including telephone information and support workers)
   □ Drug and alcohol worker
   □ Family member and friends
   □ Partner
   □ Your general practitioner
   □ Your liver clinic nurse
   □ Your liver specialist
   □ Other (please specify) ________________________________

4. What have been the best sources of support for hepatitis C?
   (Please choose up to 3 sources)
   □ Hepatitis C Council telephone service
   □ Hepatitis C Council website
   □ Hepatitis Council written, printed information
   □ International internet website
   □ Internet chat room or forum
   □ Support group
   □ Written, printed resources (non-Hepatitis Council)
   □ Other (please specify) ________________________________
5. Who would you like to receive hepatitis C support from?
(Please choose up to 3 sources)
- Another person with hepatitis C
- Community worker from a Drug user organisation
- Community worker from a Haemophilia Centre
- Community worker from a Hepatitis Council (including telephone information and support workers)
- Counsellor
- Drug and alcohol worker
- Family member
- Friend
- Partner
- Support group
- Your general practitioner
- Your liver clinic nurse
- Your liver specialist
- Other (please specify) __________________________

6. Do you belong to, or have you attended, a hepatitis C support group?
- Yes  → Go to question 7
- No  → Go to question 8

7. Did you find that you hepatitis C support needs were met by attending a support group?
- Always
- Most of the time
- Sometimes
- Rarely
- Other (please specify) __________________________
8. Would you like to belong to a support group?
   □ Yes → Go to question 9
   □ No → Go to question 10
   □ Uncertain → Go to question 9

9. If you are not a member of a support group but would like to join one, what has stopped you?
   □ A support group is not available in my area
   □ I do not want to disclose I have hepatitis C
   □ I do not know how to find out about support groups in my area
   □ Other (please specify) ________________________

10. Who have you told about your hepatitis C?
    □ I have chosen to be open with everyone about my hepatitis C status
    □ I have chosen to tell only a small number of people I trust
    □ I have chosen to tell people that I have a liver disease or blood disorder (instead of naming hepatitis C)
    □ I have chosen to tell no one about my hepatitis C
    □ Other (please specify) ________________________

11. Have you accessed the services offered by the Hepatitis Council in your home state or territory?
    □ Yes
    □ No
    □ Uncertain
12. How do you think the Hepatitis Councils should advertise their services?

- Community radio
- Community television
- GP clinic waiting room
- Mainstream radio
- Mainstream television
- Public hospitals
- State, local and regional newspapers
- Others (please specify) ________________________________

Thank you!

Thank you for participating in the National Hepatitis C Needs Assessment. The information you have provided will help inform future hepatitis C education and support activities around Australia.

If you would like to obtain the group results of this questionnaire or a copy of the needs assessment, please contact Hepatitis Australia on (02) 6232 4257. It is anticipated the Needs Assessment report will be available in early 2009.

Please return this survey by **Friday 27th June 2008** to:

Hepatitis Australia
National Hepatitis C Needs Assessment
PO Box 716
Woden
ACT, Australia, 2606.
Appendix 2 –
Focus group questions

Please note the questions listed below represent the general format followed during the focus groups. Questions were slightly focused towards each priority population as needed.

Introduction
I am a consultant for Hepatitis Australia, which is the ‘parent’ organisation for the Hepatitis C Organisations – community organisation. I am conducting focus groups in: Victoria, WA, SA, QLD and ACT.

The purpose of the focus group is to explore your hepatitis C information, education and support needs. Hepatitis Australia is very keen to know what you need, so they can help advise the state based Organisations to develop and implement programs and strategies that are needed.

- All information that is discussed and collected will be kept confidential
- Is it ok to tape record the discussion?
- Introduce the scribe... if relevant
- Location of bathroom.

Does anyone have any questions about the format of the focus group?

Information and Education Needs
- Do you think you have always had enough information to make correct decisions about your hepatitis C (e.g. whether to have treatment or how to look after yourself)?
- Who or what has been the best source of information?
- Provide examples of good resources
- Who or what has been the worst source of information?
- Provide examples of bad resources
- Who or what would be most useful to keep you up to date and well informed about hepatitis C?
  - Types of information
  - Delivery of information
  - Accessibility?
• What would have been most useful when you were first diagnosed?
• How do you prefer to get information about hepatitis C now?
  • How often do you seek information?
  • Are there any triggers that stimulate you to seek information?
  • How do you prefer to receive information – written, visual or auditory?
• What is the easiest way to access information?
• Have you had any difficulties accessing information?
• What sources of information do you trust?
  • How do you assess whether you can trust information?

Support Needs

General
• What does support mean to you?
• Please tell me about the types of support which are important to you.
• What type of support do you need?

Diagnosis and support
• When you were diagnosed, were you given any: (i) advice; (ii) counselling; (iii) information about your infection; (iv) referral to a specialist; or, (v) referral to a support agency [e.g., a hep C council]?
• Do you feel you have been given adequate support in dealing with your hepatitis C [e.g., someone to talk to]?

Disclosure issues
• Who did you first tell you had hepatitis C?
• How was this information received?
• Who have you told that you have hepatitis C?
• Who reacted badly to this news?
• If you have not told anyone about your hepatitis C, how do you go about getting support when you need it?
• How have your children coped with the news about your hepatitis C?
Support groups
• Are you in a support group for hepatitis C? If so, what do you think about support groups?
• Please tell me how your support group has been helpful or unhelpful in coping with your hepatitis C.
• What do you want most from a support group?

Other support sources
• Since you were diagnosed, who has given you the most support?
• Where do you go to seek help with making decisions about:
  • (i) recommended changes to diet;
  • (ii) symptom relief;
  • (iii) alternative and complementary therapies;
  • (iv) interferon-based treatments?
• Are you aware of state-based hepatitis C telephone helplines? If so, have they been a useful form of support for you?
• Do you use hepatitis C Internet sites? If so, have they helped you to gain support?
• Do you have a case manager, social worker or medical professional (doctor, nurse, specialist physician) that you can talk to about your hepatitis C? If so, please tell me how they have provided support for you?
• Who or what has been the best source of support?
• What information and services about hepatitis C would you like to see?
Appendix 3 – Interview questions

The interviews were semi-structured; therefore, the questions listed below provide an overview of some of the topics discussed.

Introduction

I am a consultant for Hepatitis Australia, which is the “parent” organisation for the Hepatitis C Organisations – community organisations. I am conducting interviews with people living with hepatitis C from across Australia.

The purpose of the interview is to explore your hepatitis C information, education and support needs. Hepatitis Australia is very keen to know what you need, so they can help advise the state based Organisations to develop and implement programs and strategies that are needed.

• All information that is discussed and collected will be kept confidential.
• Is it ok to tape record the discussion?

Interview questions

Information and Education Needs

• Do you think you have always had enough information to make correct decisions about your hepatitis C [e.g. whether to have treatment or how to look after yourself]?
• Who or what has been the best source of information?
  • Provide examples of good resources
• Who or what has been the worst source of information?
  • Provide examples of bad resources
• Who or what would be most useful to keep you up to date and well informed about hepatitis C?
  • Types of information
  • Delivery of information
  • Accessibility?
• What would have been most useful when you were first diagnosed?
• How do you prefer to get information about hepatitis C now?
  • How often do you seek information?
• Are there any triggers that stimulate you to seek information?
• How do you prefer to receive information – written, visual, or auditory?
• Have you had any difficulties accessing information?
• What sources of information do you trust?
• How do you assess whether you can trust information?

**Support Needs**

**General**
• What does support mean to you?
• What type of support do you need?
• Do you feel you have been given adequate support in dealing with your hepatitis C (e.g. someone to talk to)?

**Diagnosis and support**
• Can you describe what happened when you were diagnosed with hep C?

**Disclosure issues**
• Who have you told about your hepatitis C?
• How was this information received?
• If you have not told anyone about your hepatitis C, how do you go about getting support when you need it?

**Rural and remote issues**
• What are the issues for people living with hepatitis C in rural and remote Australia?
• Can you access information and support for hep C?

**Support groups**
• Are you in a support group for hepatitis C? If so, what do you think about support groups?
• Please tell me how your support group has been helpful or unhelpful in coping with your hepatitis C.
• What do you want most from a support group?
Other support sources

- Since you were diagnosed, who has given you the most support?
- Are you aware of state-based hepatitis C telephone helplines? If so, have they been a useful form of support for you?
- Do you use hepatitis C Internet sites? If so, have they helped you to gain support?
- Do you have a case manager, social worker or medical professional (doctor, nurse, specialist physician) that you can talk to about your hepatitis C? If so, please tell me how they have provided support for you?
- Who or what has been the best source of support?
- What information and services about hepatitis C would you like to see?

References
