



Evaluating
Contemporary
Needs for
Community
Hepatitis Services in
the ACT

Dr Jane Koerner & Ms Heilok Cheng

June 2018



© Hepatitis ACT 2018

Suggested Citation:

Koerner, J. & Cheng, H. (2018). *Evaluating Contemporary Needs for Community Hepatitis Services in the ACT*. Hepatitis ACT, Canberra.

Hepatitis ACT Inc.
PO Box 6259
O'Connor, ACT 2602
Phone: (02) 6230 6344
Email: info@hepatitisACT.com.au
www.hepatitisACT.org.au

Acknowledgements

This study was funded by ACT Health. The authors would like to thank the people who participated in interviews for providing their time and experiences, and extend appreciation to Mr John Didlick and Dr Jack Wallace, who provided comments on earlier drafts of the report.

Table of Contents

ACRONYMS AND GLOSSARY.....	4
EXECUTIVE SUMMARY	5
INTRODUCTION.....	9
AIM AND METHODS.....	13
SYSTEMATIC REVIEW OF LITERATURE ON COMMUNITY BASED INFORMATION AND SUPPORT FOR PEOPLE WITH HEPATITIS B AND HEPATITIS C	13
INTERVIEWS TO IDENTIFY THE INFORMATION AND SUPPORT NEEDS OF PEOPLE WITH HEPATITIS B AND HEPATITIS C IN THE ACT	14
OUTPUTS AND STAKEHOLDERS	14
ETHICAL CONSIDERATIONS	15
FINDINGS	16
FINDINGS: SYSTEMATIC REVIEW OF LITERATURE ON COMMUNITY BASED INFORMATION AND SUPPORT FOR PEOPLE WITH HEPATITIS B AND HEPATITIS C	16
FINDINGS: INTERVIEWS TO IDENTIFY THE INFORMATION AND SUPPORT NEEDS OF PEOPLE WITH HEPATITIS B AND HEPATITIS C IN THE ACT	25
DISCUSSION	43
RECOMMENDATIONS.....	45
REFERENCES.....	46
APPENDIX 1: PARTICIPANT INFORMATION AND CONSENT FORM AND INTERVIEW GUIDE	50
APPENDIX 2: TABLE OF FINDINGS OF SYSTEMATIC REVIEW OF LITERATURE ON THE INFORMATION AND SUPPORT NEEDS OF PEOPLE WITH HEPATITIS B AND HEPATITIS C	56

Acronyms and Glossary

ACT	Australian Capital Territory
ACT Health	ACT Government's Health Directorate
AMC	Alexander Maconochie Centre (ACT's adult corrections facility)
AOD	Alcohol and other drugs
ASHM	Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine
BBVs	Blood-borne viruses, including hepatitis B, hepatitis C and HIV
CAHMA	Canberra Alliance for Harm Minimisation and Advocacy
CALD	Culturally and linguistically diverse
DAA	Direct Acting Anti-viral treatments for hepatitis C – new treatments that became available through Medicare in Australia in March 2016, and which have higher cure rates with fewer side effects than previous interferon based medications.
PWID	People who inject drugs
NSP	Needle and Syringe Program
PBS	Pharmaceutical Benefits Scheme, administered by the Australian Government Department of Health, which subsidises medication for people eligible for Medicare.
PHN	Primary Health Network. PHNs were established across Australia in 2015, to improve coordination of care. PHNs work with general practitioners, primary health care providers, secondary care providers and hospitals to facilitate improved outcomes for patients. For more information, see: http://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Background
Primary care	The first (primary) layer of services in the health care system. Most Australians receive primary health care through their general practitioner (GP). Primary health care providers also include nurses (including general practice nurses, community nurses and nurse practitioners), allied health professionals, midwives, pharmacists, dentists, and Aboriginal health workers. For more information, see: http://www.health.gov.au/internet/publications/publishing.nsf/Content/NPHC-Strategic-Framework~phc-australia
STI	Sexually transmissible infection

Executive Summary

In Australia, hepatitis B and hepatitis C are significant but preventable health problems. In 2016, it was estimated that 233,034 people were living with chronic hepatitis B and 227,306 people living with chronic hepatitis C (1). In the Australian Capital Territory (ACT), 4,036 people were estimated to be living with hepatitis B, indicating a prevalence of 0.98%, and 3,557 people were estimated to be living with hepatitis C, a prevalence of 0.87% (2) (3). Of people with chronic hepatitis B in the ACT, 16.8% were receiving guideline-based monitoring and care, indicating there were 3,358 people with hepatitis B not in care. Of the people with chronic hepatitis C in the ACT, 21.5% of people had undertaken treatment and there was an estimated 546 people with severe fibrosis or cirrhosis related to hepatitis C (1).

In the ACT, Hepatitis ACT is the primary community based hepatitis organisation, and receives funding from ACT Health. Hepatitis ACT aims to deliver a comprehensive range of programs and services to help prevent viral hepatitis transmission, reduce associated morbidity and mortality, and minimise the personal and social impacts of living with hepatitis. These outcomes are achieved through: design and delivery of a range of targeted health promotion and education activities and information resources; a program of broader community awareness and education to raise understanding of viral hepatitis; advocacy, support and referral for people affected by viral hepatitis; training and development for organisations and workers providing support and care for priority populations; and the provision of a secondary NSP.

Hepatitis ACT has experienced a significantly increased demand for services in the last 5 years, including requests for a needle and syringe program, workforce development, community education and health promotion (4). This led the organisation to seek a small grant from ACT Health to conduct an assessment of the information and support needs of the approximately 7,000 Canberrans living with viral hepatitis. This needs assessment aims to identify the information and support needs of people with hepatitis B and hepatitis C in the ACT. Findings will assist Hepatitis ACT and its funding partners to better understand and respond strategically to contemporary needs for community hepatitis services in the ACT.

Hepatitis B is preventable primarily through vaccination, and hepatitis C through sterile injecting. Hepatitis viruses are transmitted through contact, usually with blood or other body fluids of someone who is infected. Exposure to hepatitis B or hepatitis C can inflame the liver, leading to chronic liver disease. This may put people at high risk of liver cirrhosis, liver failure and liver cancer. Contemporary literature identifies the need for improved awareness and education, diagnosis and access to care for priority populations. Priority populations for hepatitis B in Australia include people living with hepatitis B, people from culturally and linguistically diverse backgrounds particularly those born in countries where hepatitis B is endemic, Aboriginal and Torres Strait Islander peoples, children born to mothers with chronic hepatitis B, and unvaccinated adults. Priority populations for hepatitis C include people living with hepatitis C, people with a history of injecting drug use, and people in custodial settings. Barriers to treatment for hepatitis B and hepatitis C include access to

health care, the asymptomatic nature of the infections, not being diagnosed, and lack of awareness of options or opportunities for treatment. These barriers are exacerbated by stigma and discrimination, poor health literacy, language and cultural complications, and an increased demand for treatment (5-7).

Recently, hepatitis treatments have changed, globally and in Australia, particularly in relation to hepatitis C. New anti-viral treatments for hepatitis B have become available and there has been increased awareness of the need for closer management of people with hepatitis B. New hepatitis C treatments that are more effective and with much fewer side effects than previous treatment options have become available which has led to the possibility of around 95% of people with hepatitis C being cured.

Methods

The methods used in the study include:

- A systematic review of the national and international literature relating to the community-based information and support needs of people with hepatitis B and hepatitis C
- Interviews with 5 people in the ACT with hepatitis B and hepatitis C and with 5 representatives from health organisations who support clients with hepatitis B and hepatitis C in the ACT

The Bradshaw typology for conceptualising need was employed in this study, to identify the information and support needs of people with hepatitis B and hepatitis C. Need for available services and service gaps was investigated through Bradshaw's lenses of 'normative need' that is, needs identified by experts and 'felt need' which are those identified by affected individuals (8).

Key findings

Findings were largely consistent between the systematic review and interviews. While the systematic review provided an overview of the relevant literature in relation to information and support needs of people living with hepatitis, the interview findings provided additional data, specific to the ACT context.

Key information and support issues and needs, specific to the ACT, include:

- People with hepatitis require specific information, including about where to go for hepatitis testing, management, care and support. There is a need to connect the large numbers of undiagnosed and untreated people to testing, management, care and support.
- People with hepatitis rely on accessing information and support through word of mouth, such as friends and people that they know.
- There is a concern that current services are at capacity. Alternative models of service provision proposed by interview respondents and supported by broader literature include: community based testing and clinical services, one-stop shops for testing and treatment, and increasing the role of peer organisations and peer-driven approaches.

- Aboriginal and Torres Strait Islander people require specific information and support needs, through targeted resources and services.
- There is a need to increase opportunities in general practice, through migrant services, and CALD community networks to link people with hepatitis B to testing, ongoing monitoring, and treatment, including providing information and support options for people without access to Medicare.
- Specific information and support needs were identified in relation to new hepatitis C treatments, including information on medication regimes, tests required before, during and after treatment, side effects, options available for people who do not respond to treatment, re-infection, and life-after cure.
- There is a need to connect to people who are currently and have previously used injecting drugs, including those who have already been diagnosed but not been linked into care. Suggested approaches include the use of drug user and peer networks to link people into care.
- People with hepatitis C in prison were receiving information, testing and treatment at an advanced stage of disease progression, and opportunities for prevention were being missed through the lack of NSP.
- Experiences and fear of discrimination and stigma are barriers to seeking and accessing information and support from health professionals. As a priority, workforce development and training for health and community workforce is needed to improve understanding and skills in relation to hepatitis B and hepatitis C information and support provision.

Recommendations

Recommendations based on the findings of the needs assessment include:

1. Hepatitis ACT continues to develop and distribute accessible hepatitis B and hepatitis C prevention and treatment resources, and to provide support to people at-risk of, or impacted by, hepatitis B and hepatitis C.
2. Hepatitis ACT continues to work with community organisations and to increase distribution and availability of written and Internet resources to promote ACT specific hepatitis testing and treatment services, including contact details.
3. Hepatitis ACT continues to work with relevant stakeholders to develop and distribute information about the treatment options for people who are not eligible for treatment under Medicare.
4. Hepatitis ACT continues to work with ACT Health to ensure that hepatitis B and hepatitis C information provided by ACT Health agencies is current and relevant.
5. Hepatitis ACT continues to work with GPs, primary health care providers, community workers and others to increase their knowledge of viral hepatitis and how to support people with or affected by hepatitis B and hepatitis C.
6. Hepatitis ACT continues to work in partnership with community and clinical partners to increase opportunities for community outreach based interventions in relation to vaccination, screening, testing and support.

7. Hepatitis ACT and Capital Health Network investigates the feasibility of implementing workforce development around testing and treatment of hepatitis B and hepatitis C for general practice, including on stigma, with a focus on creating greater community-based treatment options, and growing the pool of GPs who have the capacity to provide high quality treatment for viral hepatitis.
8. The ACT Government progresses the establishment of a Needle and Syringe Program at the Alexander Maconochie Centre.
9. The ACT Government and community organisations, including Hepatitis ACT, investigate models of treatment and care such as community based testing and treatment services, one-stop shop models of care, and peer-driven approaches.
10. Hepatitis ACT continues community development and outreach to priority populations, including to the Alexander Maconochie Centre, with Aboriginal and Torres Strait Islander community populations, and with culturally and linguistically diverse groups.

Introduction

In Australia, hepatitis B and hepatitis C are significant health problems. In 2016, it was estimated that 233,034 people were living with chronic hepatitis B and 227,306 people were living with chronic hepatitis C (1). It was estimated that only 63% of people with hepatitis B, and 81% of people with hepatitis C, had been diagnosed. Hepatitis B and hepatitis C are both viruses, which are transmitted through contact, primarily with blood or other body fluids, and can lead to chronic liver disease if untreated, putting people at greater risks of liver cirrhosis, liver failure and liver cancer. Hepatitis B is preventable primarily through vaccination, and hepatitis C is preventable through access to sterile injecting equipment.

Of those in Australia living with chronic hepatitis B, it was estimated that 22% were born in Northeast Asia, 18% were born in Southeast Asia, and 11% were Aboriginal and Torres Strait Islander people (1). Some 20 to 30% of people with chronic hepatitis B will develop advanced liver disease (including liver failure, liver cancer and death) if the virus is left untreated (9). The hepatitis B and hepatitis C mapping reports provide geographic estimates of the numbers of people diagnosed, in treatment and in care. In the ACT in 2016, there was an estimated 4,036 people living with hepatitis B, including 87 people diagnosed in 2016. This accounts for a 0.98% prevalence in the ACT, similar to the national prevalence (2). Of these, 38% were not diagnosed, 6.4% were receiving antiviral treatment, and 16.8% were receiving guideline-based monitoring and care, representing 3,358 people with hepatitis B not in care.

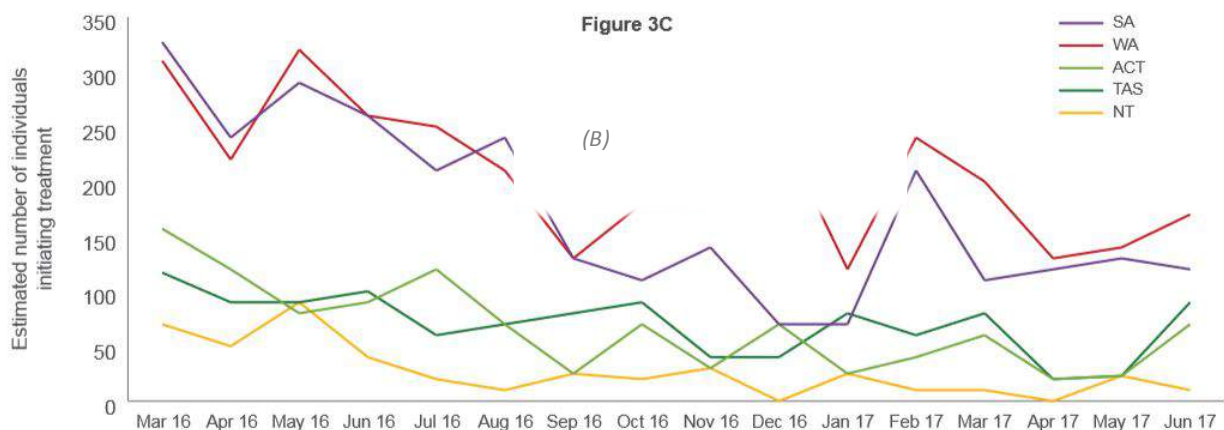
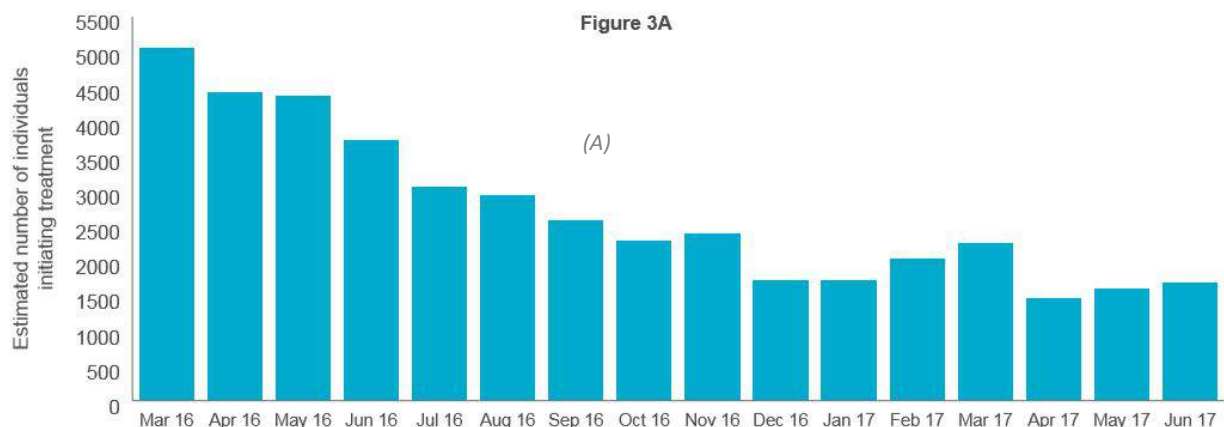
The primary form of clinical management for hepatitis B is of regular, usually annual, monitoring to identify the possible progression of liver disease. For a minority of people with hepatitis B, approximately 25% will require pharmaceutical treatment. There is no cure for hepatitis B and treatment using anti-viral medication is recommended for people with chronic hepatitis B whose blood tests show that they have indicators of liver damage (10). Anti-viral medications, which are funded through the Pharmaceutical Benefits Scheme (PBS) for people who are eligible, aim to stop the hepatitis B virus from causing liver damage and in most cases, will need to be taken daily for the remaining duration of life. Nationally agreed targets are for 15% of all people living with chronic hepatitis B to be receiving treatment. In 2016, it was estimated that less than half, 7% of all people living with hepatitis B were receiving treatment in Australia (1).

In relation to hepatitis C, in the ACT in 2016 there were 3,557 people estimated to be living with this virus, including 147 people diagnosed in 2016. This indicates a prevalence of 0.87%, which is slightly below the national rate of 0.94% (3). 21.5% of people with hepatitis C had undertaken treatment and there were an estimated 546 people in the ACT with severe fibrosis or cirrhosis related to hepatitis C (3) (1). Of concern, is that the national rate of new diagnoses of hepatitis C in Aboriginal and Torres Strait Islander populations (172.7 per 100 000) is five times greater than in the non-Aboriginal and Torres Strait Islander population (noting that ACT specific data is not available) (11).

Recent developments in hepatitis C treatment have led to the availability of direct acting antiviral (DAA) treatments, which became available on the PBS from March 2016. These treatments have revolutionised treatment efficacy and access. In 2016 14% of Australians living with hepatitis C were

treated and 93% of these were cured, indicating a high rate of success in curing the virus when people receive appropriate treatment (12). Changes were also made to the PBS to allow the prescribing of treatment through General Practitioners (GPs). Treatment uptake prior to the release of DAAs was low, at 1 to 2% per year. At the end of June 2017, this has risen to 19% since DAAs have become available (12). However, the decline in treatment uptake numbers, nationally and in the ACT since DAAs became available, is of concern (See Figure 1) (12). According to the Hepatitis C Mapping report, at February 2017 there were 2,794 people with hepatitis C in the ACT who had not received treatment (3).

Figure 1. Estimated number of individuals initiating DAA treatment in each month during March 2016 to June 2017 in Australia (A), and Jurisdictions SA, WA, ACT, Tas, NT (12)



NSW: New South Wales; VIC: Victoria; QLD: Queensland; SA: South Australia; WA: Western Australia; ACT: Australian Capital Territory; TAS: Tasmania; NT: Northern Territory

In light of the availability of highly effective DAAs to treat hepatitis C, there is a critical need to increase knowledge and capacity for undiagnosed people to seek or be offered testing, to understand their diagnosis, and to undertake treatment. It has been suggested that new models of care to test and treat people outside of specialist settings are required to meet the increased need for treatment. Information and support to people with undiagnosed, and diagnosed but untreated, hepatitis C is essential, to facilitate opportunities to increase uptake of DAA treatment. Community-

based organisations and peer groups have been identified as essential mechanisms to support this facilitation (7, 13).

The national policy direction for prevention and management of hepatitis B and hepatitis C in Australia is outlined in the Second National Hepatitis B Strategy, the Fourth National Hepatitis C Strategy, and the Fourth National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy (5- 7). These national strategies provide a framework for the national public health response relating to prevention, testing, management, care and support, workforce, protection of human rights, surveillance, and research and evaluation, in relation to hepatitis B, hepatitis C, and Aboriginal and Torres Strait Islander people.

The strategies identify the need for improved awareness and education, diagnosis and access to care for priority populations. For hepatitis B, priority populations include people from culturally and linguistically diverse backgrounds, particularly those born in countries of medium and high prevalence; as well as Aboriginal and Torres Strait Islander peoples; children born to mothers with chronic hepatitis B; and unvaccinated adults. Priority populations for hepatitis C include people already living with hepatitis C; people with a history of injecting drug use; and people in custodial settings. Key barriers to treatment for hepatitis B and hepatitis C include stigma and discrimination, poor health literacy, language and cultural complications, health care access and inability of services to meet demand, the asymptomatic nature of hepatitis, lack of clinical diagnosis in affected people, and lack of awareness of treatment options and opportunity for treatment (5- 7).

In the ACT, priorities and targets for BBVs and STIs are outlined in the Hepatitis B, Hepatitis C, HIV and Sexually Transmissible Infections ACT Statement of Priorities 2016-2020 (14).

ACT targets regarding hepatitis B (by 2017) include the following:

- Achieve hepatitis B childhood vaccination coverage of 95%
- Increase hepatitis B vaccination coverage of priority populations
- Increase to 80% the proportion of all people living with chronic hepatitis B who are diagnosed
- Increase to 15% the proportion of people living with hepatitis B who are receiving antiviral treatment

ACT targets for hepatitis C (by 2017) including the following:

- Reduce the incidence of new hepatitis C infections by 50%
- Increase the number of people receiving antiviral treatment by 50% each year

Hepatitis ACT is a community hepatitis organisation, funded by ACT Health to deliver a comprehensive range of programs and services that help prevent viral hepatitis transmission, reduce morbidity and mortality, and minimise the personal and social impacts of living with hepatitis in Canberra. These outcomes are achieved through the design and delivery of:

- a range of targeted education activities and information resources, featuring contemporary evidence-based written materials (including in languages other than English), for priority populations
- a program of broader community awareness, health promotion and representation to raise the profile of viral hepatitis commensurate with its prevalence, incidence and burdens of disease and mortality
- advocacy, support and referral activities
- training and development for organisations and workers providing support and care for priority populations, and,
- secondary needle and syringe program (prevention) services.

Hepatitis ACT has experienced a significantly increased demand for services in the last 5 years, including requests for NSP, workforce development, community education and health promotion (4). This led the organisation to seek a small grant from ACT Health to conduct an assessment of the information and support needs of the approximately 7,000 Canberrans living with viral hepatitis. This needs assessment aims to identify the information and support needs of people with, and those affected by hepatitis B and hepatitis C in the ACT. Findings will assist Hepatitis ACT and its funding partners to better understand and respond strategically to contemporary needs for community hepatitis services in the ACT.

Aim and Methods

This study aims to identify the information and support needs of people with, and affected by, hepatitis B and hepatitis C in the ACT, as well as organisations working with these groups. The findings will assist Hepatitis ACT and funding partners to better understand and respond strategically to contemporary needs for community hepatitis services in the ACT.

The methods undertaken to conduct the study, included a systematic review of the literature relating to the information and support needs of people with hepatitis B and hepatitis C, interviews with people living in the ACT with hepatitis B and hepatitis C, and interviews with representatives from organisations that support clients with hepatitis B and hepatitis C, including community based organisations and medical treatment services.

The Bradshaw typology for conceptualising need was employed in this study, to identify the information and support needs of people with hepatitis B and hepatitis C. Need for available services and service gaps was investigated through Bradshaw's lenses of 'normative need' that is, needs identified by experts and 'felt need' which are those identified by affected individuals (8)

Systematic review of literature on community based information and support for people with hepatitis B and hepatitis C

A systematic search of scientific databases and review of literature was conducted in November 2016 of databases including: MEDLINE, CINAHL, ScienceDirect, PubMed, PSYCIInfo, Cochrane Library, Scopus, ProQuest, Web of Science, EBM Reviews, Embase, Global Reviews, Informit and SocINDEX. Search words and terms included: hepatitis B virus, hepatitis C virus, needs assessment, information needs, support needs, care needs, barrier to treatment, underserved populations, community health services, and health service needs and demands. A grey literature search was also conducted through the Google search engine using the same keywords. Search results were limited to English language and studies published from 2000.

Search results were downloaded to Endnote X7 and coded for inclusion or exclusion. References were included if needs relating to hepatitis B and hepatitis C information, support or psychological care were addressed in a community setting. References were excluded where they focused on solely on: clinical care and treatment of hepatitis B and hepatitis C, including social support from family and friends and psychological support from psychologists during treatment; and needs of clinicians and health services, where needs of individuals with hepatitis B or hepatitis C were not discussed. Inclusion criteria were journal articles and grey literature that identified the needs of people with hepatitis B and hepatitis C. Two reviewers coded references for inclusion or exclusion and discussed suitability of references where disagreement occurred.

Literature describing qualitative studies, with use of interviews and focus groups, were assessed for quality using the Critical Appraisal Skills Programme (CASP) appraisal tool (15). The CASP tool was guided by assessments on the validity of the data, use of appropriate research design and methods,

ethical conduct and consideration of the relationship between the researchers and study participants.

Interviews to identify the information and support needs of people with hepatitis B and hepatitis C in the ACT

Between June and September 2017, semi-structured interviews were conducted with five people with hepatitis B or hepatitis C and five representatives from organisations that provide health related information and support to people with hepatitis in the ACT, including community based organisations and medical treatment services.

The purpose of the interviews was to identify the adequacies and gaps in information and support services for people with hepatitis B and hepatitis C in the ACT, and seek information on future directions. Recruitment was purposive, drawing on the networks of Hepatitis ACT. The interviews aimed to elucidate the sources of information and support for people with hepatitis B and hepatitis C; the types of information they require; satisfaction with information and support available; possible gaps, and reasons for why these gaps exist; and if a dedicated community-based organisation did not exist, whether people with hepatitis B and hepatitis C would access the information they require elsewhere (see interview guide at Appendix 1). A total of 516 minutes (8.6 hours) of interview audio data was obtained.

Interviews were recorded (with consent) using a digital recorder, and were conducted at a location convenient to the interview respondent, or by telephone. Interviews were transcribed and analysed using NVivo software.

Inductive thematic analysis was used to identify themes found in the literature review (Bernard 1994). Broad themes were identified, and findings reported against these themes. Interview data were analysed thematically to identify the needs, gaps, and future directions for the provision of information and support for people with hepatitis B and hepatitis C.

Outputs and stakeholders

The systematic review and interview data were described and summarised, with findings identified and presented in relation to the information and support needs identified by people with hepatitis B and hepatitis C, and professionals supporting people with hepatitis B and hepatitis C.

Outputs of the needs assessment study include:

- a research report with recommendations for service delivery (this report),
- meeting(s) with key stakeholders to disseminate findings and to help translate evaluation findings into policy and practice,
- a summary of findings for community members, and
- submission of a paper in a relevant peer-reviewed journal in the area of public health or health promotion.

Key stakeholders (presented in alphabetical order) include: ACT Health, ACT Health Multicultural Health, ACT Health Policy and Government Relations, AIDS Action Council of the ACT, Alcohol Tobacco and Other Drug Association ACT, Canberra Alliance for Harm Minimisation and Advocacy, Directions, Canberra Sexual Health Centre, Capital Health Network, Companion House, Corrective Services, Garran Medical Imaging, Interchange General Practice, Justice Health and Division of Medicine, Health Care Consumers Association, Hepatitis Australia, Hepatitis NSW, HIV/AIDS and Related Program (HARP) – Murrumbidgee and Southern NSW Local Health District, Karralika Programs, Migrant and Refugee Settlement Service, Red Cross Refugee and Asylum Service, Sexual Health and Family Planning ACT, and Winnunga Nimmityjah Aboriginal Health Service.

Ethical considerations

An ethical protocol was developed to guide the interviews and was endorsed by the Governance Board of Hepatitis ACT. The rules of the Helsinki Declaration were followed (16), including confidentiality of participants' participation and interview data provided, provision of information about the project and how respondents' data would be used, seeking informed consent, and provision of a clear process to retract participation in the study at any time.

Findings

Findings will be presented in the following sections:

- Systematic review of literature on community-based information and support for people with hepatitis B and hepatitis C
- Interviews to identify the information and support needs of people with hepatitis B and hepatitis C in the ACT
- Recommendations

Findings: systematic review of literature on community based information and support for people with hepatitis B and hepatitis C

Thirty-nine journal publications (37 journal articles, two case reports) and seven grey literature reports met inclusion criteria (Figure 2). Twenty-one studies were conducted in Australia, 11 in the United States of America, eight in the United Kingdom, two in Canada and two in South Korea. Research participants included 4,973 participants with hepatitis C, 367 participants with hepatitis B, 75 participants with HIV and hepatitis C, 88 participants with hepatitis B or hepatitis C, over 195 clinicians or health care workers, over 166 stakeholders working in hepatitis B, hepatitis C or vulnerable population-focused programs, 152 community members, 77 participants from vulnerable populations (drug treatment clinic attendees, recently released prisoners) and 5 people with partners who have hepatitis C. Twenty-seven studies collected qualitative data using face-to-face or telephone interviews, and 8 studies used focus groups. Fifteen studies used questionnaires or surveys and one study used roundtable discussions. Two publications were case reports that did not focus on primary data collection.

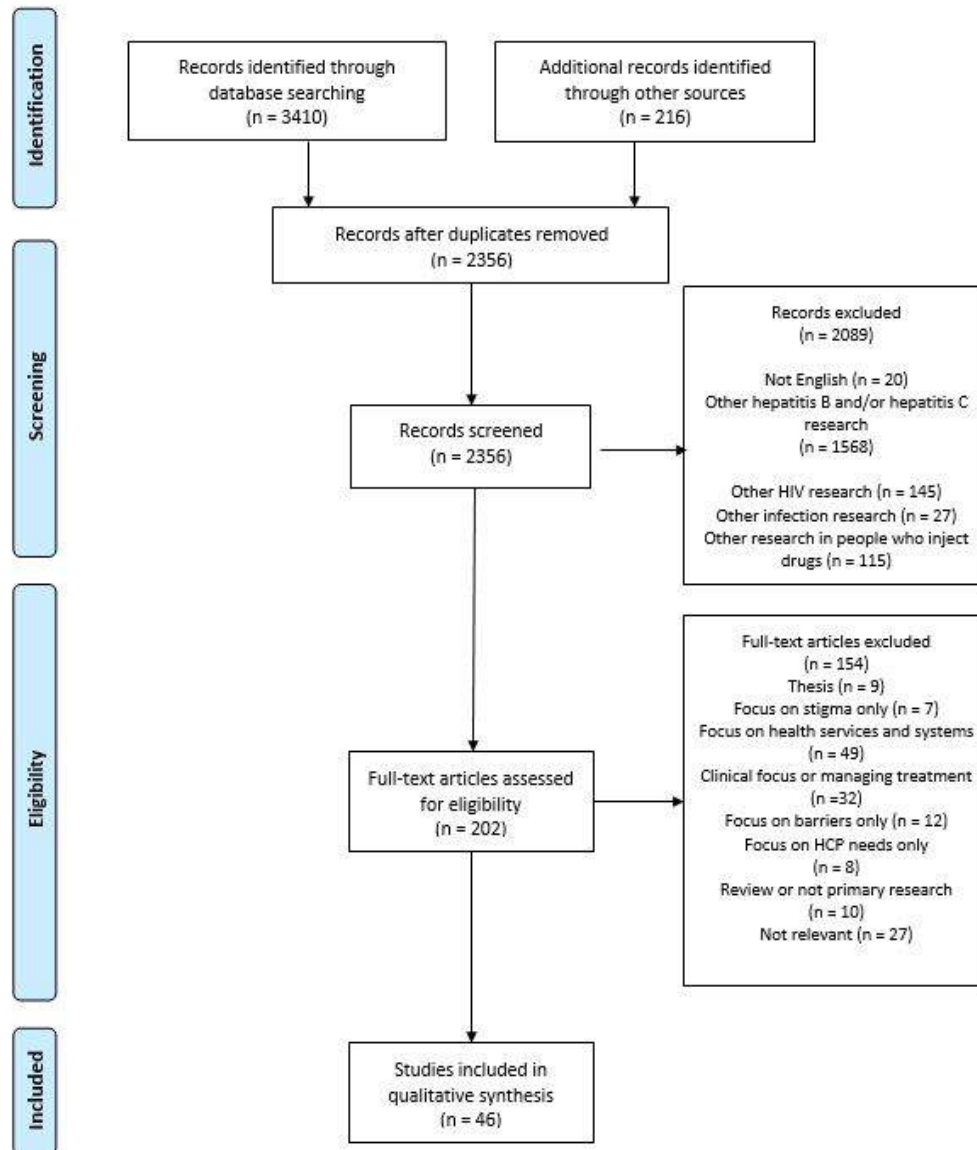
Sixteen studies were assessed to have good study quality using the CASP tool, eleven with unclear study quality and six with poor study quality. Fourteen studies were not assessed using the CASP tool, as they did not include a qualitative research element.

A majority of included studies focused on the self-identified needs of people with hepatitis B or hepatitis C, or their partners. Population groups included people from CALD populations; ex-prisoners; gay, lesbian, and bisexual people; people with a history of injecting drug use; and people in drug treatment. These studies found that information for people with hepatitis B and hepatitis C helped them to understand their condition and facilitated testing and care seeking (17-20). Inversely, lack of understanding of why hepatitis requires monitoring or treatment, the asymptomatic nature of hepatitis, and negative emotional responses to hepatitis due to inadequate education and understanding, prevented care seeking (21-25). Incomplete understanding of hepatitis care, including long-term assessment and monitoring prior to treatment, can lead to patient drop-out from, and non-attendance of, medical services (26).

Studies with clinicians and stakeholders were with health care professionals and community workers, such as clinicians, social workers, community health workers, and alcohol and other drug (AOD) treatment staff. These studies identified the need for targeted information and support for

Aboriginal and Torres Strait Islander people, programs to increase knowledge of hepatitis among community members and health service workers, and strategies to overcome the impact of stigma in inhibiting linkage to testing and treatment.

Figure 2: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram of included studies



Findings regarding information and support needs are presented for: prevention, testing, management, care and support; workforce and enabling environment, as per the priority areas for action outlined in the National Hepatitis B and Hepatitis C Strategies.

Prevention

Studies identified limited understandings of how to prevent hepatitis, and found that individual, community and primary health care information and support strategies were needed to address these.

a) Hepatitis B

There is limited understanding of hepatitis B relating to transmission, disease progression, prognosis and prevention (27-30). A United Kingdom study with community members in CALD groups, found that many were aware of hepatitis B and hepatitis C by name only, with minimal understanding of the impact and prognosis of disease, and the difference between hepatitis A, hepatitis B and hepatitis C (20). Community workers working with CALD groups in Australia reported that these groups conflated hepatitis A, B, C and HIV into the same disease with increasing severity (26). There was mixed awareness about transmission through injecting drug use (IDU), sexual activity, vertical (mother to child) transmission and blood (20). Misconceptions included beliefs about transmission related to poor hygiene and sanitation, alcohol and food, food sharing, and mosquitoes. Individual, primary care driven and community based strategies were identified as ways to address these information and support gaps (26, 28, 31).

b) Hepatitis C

Studies with people with hepatitis C found that they poor knowledge about the disease and its prevention, and people who inject drugs wanted more information on and access to harm minimization strategies including information and equipment for safe injecting (23, 32-34). In Australian studies, women reported information was needed on hepatitis C transmission through sexual activity, childbirth and shared use of household items (32, 35, 36). In one study, 38% of women said that they had received information about hepatitis C transmission in pregnancy, while 44 to 50% of lesbian, bisexual and heterosexual women in another study received information on women's health and safe sexual practices (37). Former prisoners in Colorado, USA recently released into the community were unaware of drug using and sexual practices that transmitted hepatitis C, and lacked information on accessing health care, medication and insurance after release (38).

Gaps were identified in terms of proactive support regarding prevention care. This included harm reduction education, awareness raising, safe injecting sites and environments to support marginalised groups by delivering health care, education, counselling, psychosocial support and NSP distribution and utilization of NSPs (34,39, 40). Other aspects of improving access to NSPs included involvement of trusted people to distribute sterile supplies; improved needle syringe supply distribution, without need to return used equipment; and improving awareness of harm reduction, the hepatitis C care pathway and hepatitis C knowledge in at-risk groups, such as young people; and expanding the reach of NSPs in prisons (34, 40).

A study of a group of gay and bisexual Australian men with hepatitis C or HIV and hepatitis C, found that 35% were unaware that hepatitis C could be sexually transmitted and 56% were unaware that being HIV-positive increased the risk of contracting hepatitis C (41). Eighty-one per cent had unmet

information needs and wanted further information on avoiding transmission, the impact of hepatitis C and HIV co-infection on health or treatment effects on each condition, effect of hepatitis C on health, accessing treatment or counselling and interpreting diagnostic results. Similarly, gay men with HIV and hepatitis C in the United Kingdom reported lack of awareness about sexual transmission risk of hepatitis C among men who have sex with men (42).

Testing

Multiple studies found that respondents felt they had been provided insufficient information and support regarding the need and reasons for hepatitis testing. Information about hepatitis, including the implications of being diagnosed, the meaning of test results, and what was required post-diagnosis; was poorly understood by respondents.

a) Hepatitis B

Following diagnosis, many people had poor understanding of what hepatitis B was, its impact, self-management, and the consequent elevated risk of liver cancer (26). Information provided by physicians and health care practitioners at the time of diagnosis may not be well understood by patients (29). In a hepatitis B needs assessment conducted in Australia, none of the people with hepatitis B interviewed received pre- or post-diagnosis counselling. Procedures around hepatitis B testing and diagnosis testing was opaque, with some respondents believing they were having routine blood tests and not understanding that they were being tested for hepatitis (26).

b) Hepatitis C

A national needs assessment as well as studies conducted in other settings identified the need for improved counselling and information provision at the point of testing and diagnosis. Low levels of counselling were reported at the point of testing, with 13% receiving pre-test counselling (43). Referral to support groups or clinical services for hepatitis care at time of diagnosis varied. Sixty-six per cent of respondents in a national Australian hepatitis C needs assessment were offered information and support, and 34% were referred local hepatitis councils (43). An Australian study found that 33% of lesbian, 46% of bisexual and 66% of heterosexual women with hepatitis C were referred to or given information about support groups, hepatitis C specialists and hepatology clinics after diagnosis (37). Women were more likely to be referred to specialists or clinics for hepatitis C care compared to men (44). Women with current or former experience of injecting drug use reported perceived discrimination by health care practitioners, resulting in inadequate referral to support and counselling after diagnosis (32).

Comprehensive pre- and post-diagnosis counselling for hepatitis C was required, to inform clients about hepatitis C status, methods of transmission and impact of hepatitis C on health. The literature also identified the need for delivery of health promotion to vulnerable groups; development of general life skills; education to avoid sexual, nosocomial and occupational transmission; encouragement of screening and treatment uptake; and hepatitis A and hepatitis B immunisation (39).

Information and support needs relating to management, care and support

Studies relating to the information and support needs for management, care and support identify gaps in service provision and delivery. The diverse needs of hepatitis B and hepatitis C affected populations require targeted approaches. Competition of resources for hepatitis B and C services was identified, with one condition seen as being prioritised over the other, or against HIV, blood-borne disease, and STI care.

a) Hepatitis B

People with hepatitis B identified the need for plain language and culturally appropriate resources, including in relation to the format of resources, instead of written pamphlets and brochures, to facilitate patient understanding of hepatitis. Examples of culturally appropriate information included visual and interactive resources for Koreans and Aboriginal and Torres Strait Islander people Australians; and education and treatment by clinicians from non-English speaking background (22, 45, 46). There was also a need for better explanations of 'hepatitis' beyond English, to other language resources, as the term 'hepatitis' was not well understood (20, 26).

For hepatitis B patients already seeking care, 84% wanted more information about hepatitis B, and only 52% were aware that effective treatments were available (29). Lack of information and resources provided at time of diagnosis prevented proper self-management on reducing alcohol intake, improving diet, undertaking physical activity and proactive discussions with GPs about ongoing monitoring and management (26).

Concerns reported by people with hepatitis B may indicate areas where information or counselling is needed, with primary concerns relating to prognosis, life expectancy, effect of hepatitis B on health, development of chronic hepatitis B to cancer, transmission, social stigma, workplace discrimination and costs of treatment (26, 29, 47). Among Koreans and Korean Americans, there was lack of understanding of hepatitis B as a chronic asymptomatic liver condition, its vertical and sexual transmission, and misunderstanding of the 'hepatitis B positive' as 'positive news' instead of an indicator of disease status (30, 45). Chinese Australians and Americans held misconceptions on hepatitis B being preventable through cooking methods and hand washing, or that hepatitis B was curable through traditional Chinese medicine (28, 29).

In an Australian study of people with hepatitis B, 18% of respondents did not talk to anyone, including health professionals, family, friends and work colleagues of community organisations or internet forums, about their hepatitis B status (29). Of the people with hepatitis B who relied on health care practitioners for emotional support, 78% had a hepatitis related concern or anxiety. In comparison 85% who relied on family, friends and colleagues had a similar concern. Needs of people with hepatitis B extend beyond biological clinical management and include psychological and social life needs. Strategies to address these include increasing culturally appropriate knowledge about hepatitis B and developing models of care that include counselling (27, 29, 46).

b) Hepatitis C

Similarly, information needs for plain language and culturally-appropriate resources were reported by people with hepatitis C (21, 26, 48). Examples of appropriate resources included visual, audio-visual and face-to-face peer education for Aboriginal Australians and Vietnamese and Cambodian Australians with mixed literacy; and education and treatment by non-English speaking background clinicians (18, 21, 46). Deficits in information on self-management and treatment options for CALD communities were identified (20, 43). In-group community members were considered as ideal contributors for resources targeted at CALD groups, or people who inject drugs (43).

In an Australian national hepatitis C needs assessment, only 17% respondents felt that they were consistently supported to manage their hepatitis C, and 23% of respondents currently or previously had attended a support group, with a further 28% indicating they would like to but did not know how to access these locally (43). In a survey of Australian lesbian, bisexual and heterosexual women with hepatitis C, few women were referred to counselling services, although about a third were offered information on support groups (37). Support was received from other people with hepatitis C inside and outside of support groups (37, 49, 50). The main reasons to attend support groups was to access information and support including information about treatment, diet, diagnosis, prevention, how to communicate with clinicians, professional organisations and vaccination; and validating and sharing experiences (43, 50). The preferred methods to access support were through face-to-face contact, support groups, telephone helplines and the Internet (43).

Community workers and medical professionals identified the need to establish a clear hepatitis C care pathway with health services and community resources, by assessing available resources; identifying if local health services are invested in providing hepatitis C and other injecting-related care to clients in this pathway; obtaining support to sustain and publicise a hepatitis C care pathway; and establishing and formalising partners (40).

Other information and support needs identified by people with hepatitis C included: psychosocial support from clinicians and social networks to manage living with hepatitis C (51, 52); support to manage capacity to continue paid employment (53); family planning (36); personal relationships (54); inability to drink socially (53); fear of transmission during sport employment (53); practical support to manage daily living including meal preparation, shopping, cleaning and childcare (32, 43); strategies to cope with barriers to hepatitis C care, (25, 46, 55, 56); access to housing (56); poverty (48); and geographical barriers to health care services, such as transport limitations that prevent being able to get to health care services (56).

Specific support needs were also identified by minority or marginalised groups. Sixty-seven per cent of gay and bisexual Australian men with hepatitis C or with HIV and hepatitis C wanted gay-specific hepatitis C services, such as a telephone helpline, support group and referral to treatment services. Similar proportions indicated they would like services delivered through hepatitis services, lesbian/gay/bisexual/transgender/intersex organisations, and HIV organisations (41). Aboriginal and Torres Strait Islander health workers and people with hepatitis C identified the need for gender-specific and age-specific support groups such as for parents and carers and broader community and

mainstream healthcare approaches, as well as services to provide culturally-appropriate information and support during diagnosis and treatment (21, 48). Peer educator support provided to individuals or targeted groups required objective, firm, non-discriminatory approaches for working with people who inject drugs to provide education and support about harm reduction techniques and health-seeking behaviours (13, 57). Additionally, individual and group peer support needs to be contextualized within issues that affect the lives of people with hepatitis C, such as managing family and other priorities, drug treatment attendance, mental health, financial support, housing, criminal justice and healthy lifestyle management (39, 48, 57-59).

Information and support needs relating to enabling environment

Experiences of stigma and fear of disclosure were barriers to individuals being proactive to seek information and support. Furthermore, wider structural issues were identified that impact on information and support provision for people with viral hepatitis, including low levels of strategic planning (34).

a) Hepatitis B

Reducing stigma encourages and enables testing, care-seeking, self-care, voluntary disclosure and better quality of life for people with hepatitis B (13, 20, 21, 26-28, 30, 32, 35, 38, 46, 52, 55, 56). Fear of disclosure was a barrier to people with hepatitis B connecting with others with hepatitis, to seek information and support regarding their experiences and how to manage shared problems (26).

Australian studies with clinicians and stakeholders to plan national approaches to hepatitis B care identified cultural stigma and fear of positive diagnosis as barriers that inhibited testing (20, 26, 29). Certain communities interpreted 'high hepatitis B or hepatitis C risk populations' as a negative judgement on their communities (20). Repeated screening invitations were suggested to stress the urgency and importance of screening attendance.

b) Hepatitis C

Studies indicate that information and support is needed to cope with stigma that is part of living with hepatitis C, including psychological interventions, increased provision of community based information dissemination (43), and wider strategies to reduce social stigma and discrimination towards people with hepatitis C (18, 32). Strategies to address stigma and discrimination experienced in health care settings and from health care workers included improved education and support for health care workers (32, 50), and provision of models that promote patient centred and holistic care (51). Several studies identified the need for improved community awareness of hepatitis C, in order to reduce stigma and discrimination, including among the general population, among CALD groups, and among gay and queer communities (42, 43, 46).

People working with homeless populations identified that self-management of hepatitis C was difficult when coping with chaotic lifestyles, and identified the need for information dissemination in shelters and homeless shelters (43). People working in prisons identified the need to improve hepatitis C education for prisoners, and provide workplace training, so that custodial staff can

identify hepatitis C treatment side effects in prisoners, such as aggression, without responding using retaliatory action (43). Social workers also identified that they could play a role with people in prison, by acting as a point of contact, providing accurate information about hepatitis C and access to local services; bridging gaps and providing referrals to services; and providing holistic support in addressing access to treatment and pre-existing needs, such as housing, employment, psychosocial needs, social support systems, and alcohol and other drug use (17, 19).

Comprehensive needs assessments of the hepatitis B and hepatitis C services in Australia, Quebec and Scotland have identified the need for improved coordination, targeted funding and alternative models of care, to address gaps in service delivery; health promotion; and the diverse needs of hepatitis B and C-affected populations (24, 26, 39).

Aboriginal and Torres Strait Islander people hepatitis information and support needs

Studies with Aboriginal and Torres Strait Islander people have reported the need for more information and support regarding prevention, transmission and management of hepatitis B (22, 26, 29) and hepatitis C (21, 29, 48).

The need for different approaches to health care was also identified. Addressing the sharing culture of Indigenous Australian communities is an important consideration in preventing transmission (43, 48). Aboriginal and Torres Strait Islander people also highlighted the need to separate hepatitis B and hepatitis C information into men's and women's health issues (48). Further, non-clinical Indigenous health workers did not always understand the hepatitis B messages that clinicians wanted them to convey or translate to patients, and non-Indigenous clinicians were found to inadvertently use culturally inappropriate examples as part of hepatitis B education (22).

Stakeholders identified the need to address cultural concepts through counselling, including sharing of household paraphernalia and injecting equipment, which carries hepatitis B and hepatitis C transmission risk; and shame, which can deter people from asking questions about hepatitis C, disclosure, care-seeking, and interacting with health care professionals (43, 48). Sensitivity in language, such as using 'bug' instead of 'infection' or referencing hepatitis C as part of women's and men's health care instead of sexual health, were suggested to improve patient-provider communication. Potential service changes were identified to provide culturally-appropriate hepatitis B and hepatitis C care, to be proactive in encouraging people to seek and maintain care, and to adapt to situations where Indigenous Australians had cultural imperatives and responsibilities, such as mourning practices, which prevented clinic attendance; and mobility between health localities (22, 26).

People from culturally and linguistically diverse groups hepatitis information and support needs

Studies conducted with CALD groups identify the need for community involvement to legitimise hepatitis awareness and educational messages (27). Professional local expertise was also recommended by Vietnamese and Cambodian Australian groups, who preferred information from GPs, liver clinics, and NSPs, through written English and Vietnamese language resources and internet

sources (18). Privacy issues with CALD-group translators and health workers were also identified. Attending certain health centres and working with translators and health workers from the same CALD communities as patients carried a risk of stigma, personal conflict of interest for staff, and the possibility of unintentional disclosure to other people personally known to clients accessing the same service (43).

Access to care was inhibited by language and cultural difference barriers that prevented understanding of screening, monitoring and treatment purposes among patients (25, 26, 29, 46, 57). Language barriers included challenges for people from non-English backgrounds to read and understand information about tests, and test results, written in English (20, 26, 29, 55, 57). Cultural barriers included shame or norms of not discussing illness, a lack of non-English speaking clinicians, financial and time constraints for booking interpreters (20, 29).

Health care workers and community workers used their practice experience to identify both the needs of clients and how their own role contributed to care delivery. Australian community workers working with CALD groups, including South East Asian and African Australians, identified client need for development of multilingual resources in community languages, instead of translating resources from English; audio instead of written resources; clarifying differences between the hepatitis A, hepatitis B and hepatitis C conditions and transmission methods; separate resources for chronic hepatitis B and chronic hepatitis C, instead of interchangeably using hepatitis resources; and explaining differences between treatment and 'cures' for hepatitis (18, 26). Further considerations that need to be taken into account when developing CALD-appropriate care and resources, explanations of hepatitis and disease management a need to consider cultural concepts that are different to Western biomedical concepts of 'virus' and 'liver health' (18, 26, 34].

Summary

The systematic literature review indicated that people with hepatitis B or hepatitis C experience information and support gaps related to testing, diagnosis, and referral to support systems, including health care. Studies identified information and support provision needs to be tailored to gender, sexual orientation, race and cultural background, and experience of injecting drug use.

People from multi-ethnic and non-English speaking backgrounds particularly demonstrated poor understanding of hepatitis B and hepatitis C, with these populations wanting more information about their condition, and how it is transmitted to other people. Surveys indicated that information about the impact of disease, transmission prevention and lifestyle management were inconsistently provided, and in situations where it had been provided, was sometimes poorly understood due to a range of barriers. Stigma was identified as a significant barrier to individuals and communities in accessing information, testing and care.

Understanding the impact of hepatitis B and hepatitis C is essential, for people with hepatitis to initiate testing or care seeking. Incomplete or insufficient understanding of chronic hepatitis management and treatment pathways can lead to people never initiating care or dropping out from

medical services. Referral to individual and group support to manage and share experiences on living with hepatitis B and hepatitis C is essential for self-management.

National needs assessments for hepatitis B and hepatitis C undertaken in Australia, Canada and the United Kingdom, indicate a need for consistent, national approaches, with hepatitis B and hepatitis C care pathways established, integrated and clearly reported in the health care system. This includes accessibility of hepatitis C care and NSPs in prison and AOD settings; improved hepatitis B and hepatitis C screening and communication about diagnosis across settings, including immigrant health, primary care, prisons and AOD settings; and educating a multidisciplinary health care workforce in effective screening, counselling, treatment and care of hepatitis B and hepatitis C.

Findings: Interviews to identify the information and support needs of people with hepatitis B and hepatitis C in the ACT

Demographics of interview respondents are presented first. This is followed by findings on where people with hepatitis B and hepatitis C access information and support, and their information and support needs in relation to prevention; testing; management, care and support; workforce; enabling environment; and surveillance, monitoring, research and evaluation.

Table 1. Demographic information of interview respondents with hepatitis B and hepatitis C; and representatives from organisations that provide health related information and support to people with hepatitis in the ACT

Interview respondent demographic information				
Gender (n)				
Female	Male	Other		
2	7	1		
Age group (years)				
Under 19	20 to 29	30 to 39	40 to 49	50 and above
0	0	1	3	6
Years of work in the area or living with hepatitis B or hepatitis C				
Less than 1 year	1 to 2 years	2 to five years	More than 10 years	
0	0	1	9	

Sources of information and support for people with hepatitis B and hepatitis C

Respondents identified several sources of information and support that people with hepatitis B and hepatitis C access in the ACT. These varied depending on the background of the person (including language and culture), and their purpose for seeking information and support (including experience of the medical system, and their stage in the treatment journey).

Respondents from organisations that provide health related information and support to people with hepatitis identified a range of services which information or support people with hepatitis in the ACT, including Winnunga Nimmityjah Aboriginal Health Service, migrant health services, the Liver Clinic and the broader ACT AOD sector. As well as a range of community-based organisations and treatment services, respondents also identified the internet, written information, newspaper, radio and events, including the Multicultural festivals and World Hepatitis Day, sources of information. Respondents with lived experience identified organisations as sources of information including hepatitis treatment services, including the Sexual Health Service and Liver Clinic at the Canberra Hospital, and Hepatitis ACT.

a) Word of mouth

People with hepatitis identified friends and other people they know, as a key source of information for people with hepatitis.

Most of what I have done is talked to friends. (Person with hepatitis)

However, one lived experience respondent highlighted that word of mouth can lead to the provision of incorrect information.

But it's not so much about what's real and true, it's about what people say to each other about things. (Person with hepatitis)

b) The National Hepatitis Information Line

People with hepatitis and from health organisations noted the importance of the National Hepatitis Information Line as a source of information. This national phone number diverts callers to the community hepatitis organisation in the jurisdiction from where the call is made. However, in the ACT, callers are diverted to the Hepatitis NSW phone-line operators. One interview respondent explained that they had called the information line to get contact information for an appropriate GP, following an experience of discrimination with their current GP. However, for reasons not explained by the respondent, the telephone information line was not able to provide local contact details of GPs who could provide treatment.

Often people go to GPs and they come out and call the phone line because although they nodded their head, they actually didn't understand anything. (Person from health organisation)

c) Written sources of information

Both health organisation respondents and people with hepatitis noted the importance of written information. People with hepatitis stated they had obtained written information in the form of the

newsletter published and distributed by Hepatitis NSW, and in particular, a health organisation respondent noted that this was an important source of information for people in prison, and expressed regret about the change of format from a mail out paper version to a digital version distributed by email list. People with hepatitis stated that they had also picked up pamphlets from the Liver Clinic at the Canberra Hospital.

I've also got information from Hepatitis NSW in the form of a newsletter. So I still get that. (Person with hepatitis)

It's very informative and provides a range of levels of information. So, there's some really high-level information, but also some very basic, ground-building, kind of foundation-building information. And I think the decision, whatever that decision was, of Hepatitis New South Wales, to stop printing the Hepatitis Review, I think it was a bold step too soon. (Person from health organisation)

d) Internet

Several respondents identified the Internet as a major source of information about hepatitis, and identified benefits and problems associated with its use. The Internet was widely discussed by health organisation respondents as providing opportunities to present generic information, but that this could not replace service delivery. They articulated that general information should be complemented with information specific to the local context, particularly in terms of how to access treatment. A health organisation respondent noted the digital divide between the 'haves' and 'have nots' regarding internet access – that internet access was a luxury for people who do not have stable living situations, including people who are couch surfing, in prison or in other unstable situations.

Internet has a lot of potential but we're not quite getting there in terms of potential. I don't think we could replace community-based or peer-based approaches by running an India-based call centre. (Person from health organisation)

People with hepatitis acknowledged the ready availability of generalised information through the Internet, but were concerned about the accuracy of the information within the large volume of information available. A clear understanding of the technical language, the date of when the information related to, and region that the information was applicable to, was often not clear. People with hepatitis noted the problems with getting relevant information about treatment services and medications available in Australia, and that there was still a great deal of information that related to Interferon based medications, which are now out-dated. A person with hepatitis said that he had not spent time looking for information on the Internet at all and had relied mainly on people he knew for information.

So, a lot of that information that's available internationally, it doesn't translate to local context. (Person with hepatitis)

There are new drugs and there is a lot of information being published every week, which is very technical. I don't know if a lot of people find it accessible. So, there are problems and benefits with the Internet. Person with hepatitis

e) General Practitioners

People with hepatitis and organisational respondents noted the importance of information and support from GPs, particularly regarding testing and treatment. This relies on the ability to connect with a clinician who is competent and confident with hepatitis testing and treatment; however, respondents stated that the quality of GP services was variable – with inconsistent levels of knowledge of testing and treatment protocols.

The current system relies on the patient bringing up the issue and being confident to ask what they need. But time pressures, money pressures, I think, mitigate against GP's opening up the conversation with people, even if they have some awareness of circumstances or lifestyle factors that may contribute to an increased risk or an information need around hepatitis. (Person from health organisation)

People with hepatitis and organisational respondents also identified the struggle with getting referrals to hepatitis specialists. Furthermore, people with hepatitis raised their experiences of stigma and discrimination as barriers to obtaining information from GPs such as not feeling welcome, being asked too many questions about why they were requesting a hepatitis C test, or being given a test and feeling that they were being rushed out of the surgery, all of which unhelpful. Stigma and discrimination will be further discussed in the interview findings, under Enabling Environments.

They seem to fall into two camps. They're either really try to work out why something's happened and ask you questions, or else they're just interested in fixing or giving you a test. And both are kind of, at least in experience, both are not ideal, usually. (Person with hepatitis)

Although, to actually get tested and stuff like that, you could go to a doctor, but that shame kind of puts it off for people. ... So, if you're not feeling sick, and you don't necessarily want to admit to your doctor that you've done something risky. (Person with hepatitis)

f) Alcohol and other drug (AOD) services

Both people with hepatitis and organisational respondents noted the importance of information and support from the AOD sector in providing information about potential exposure to hepatitis C, testing and treatment information to clients. While AOD services were places where people with hepatitis C could access information about prevention and treatment, organisational respondents raised concerns that people were not getting adequate information relevant to management of their hepatitis from AOD services. An organisational respondent questioned whether opiate substitution services were the right place to be talking about treatment due the punitive nature of these services. A person with hepatitis also commented that the provision of hepatitis treatment through GPs at Directions (AOD service) was important for treatment accessibility.

To be really honest, even the needle and syringe programme in the middle of town.... That's a real lost opportunity... [AOD] treatment workers don't seem to know much about prevention of hepatitis and treatment. (Person with hepatitis)

g) Correctional settings

The Alexander Maconochie Centre (AMC), the ACT's adult periodic detention centre, and the Bimberi Youth Justice Centre were identified as important venues to provide information, given the high prevalence of hepatitis C among people who have been, or are in prison. People with hepatitis and organisational respondents identified the Health Service at AMC as a good source of information and treatment. Interviews revealed that most people getting information, support and treatment about hepatitis in jail had been living with the virus for a long time. Despite their liver disease being advanced in many cases, they had not been previously exposed to information and opportunities for treatment through their pre-jail contact with AOD and health services. Several respondents commented on the lack of progress in the implementation of an NSP at AMC, which was seen to be about punishing people in prison for their behaviours rather than ensuring the health and well-being of people in prison and the wider community. Furthermore, Hepatitis ACT's outreach services and Hepatitis NSW's Hepatitis magazine was seen to be a useful format for people in prison.

[People in prison's access to information is] Inconsistent. From absolutely nothing, to being very well-informed. And I suspect the critical thing was access to that magazine, the Hepatitis Review. Because it would sit around and be passed around. I'd see dog-eared copies of it. (Person from health organisation)

Hepatitis ACT have been present at the jail, and very effective advocates, and also service deliverers, for at least I'd say two to three years. And I think that's the time when far too many people, far too late in their disease progression, are getting primary-level knowledge. (Person from health organisation)

h) Community based organisations

Hepatitis ACT and other community-based organisations were identified as sources of information and support by both people with hepatitis, and organisational respondents. Community organisations specifically identified included Hepatitis ACT, Companion House, sexual health services, refugee and migrant resettlement services.

Hepatitis ACT, which is grounded in a community-based response which draws from the direct experiences of people living with Hep C and Hep B. You can't go past that for the reputable, reliable and good understanding of the entire Hepatitis C or Hepatitis B epidemic impact on people. (Person from health organisation)

Companion house is doing some marvellous work particularly in the hep[atitis] B space. (Person from health organisation)

i) Needs of Aboriginal and Torres Strait Islander people

People with hepatitis and organisational respondents noted that Aboriginal and Torres Strait Islander people need information and support specifically targeted to a diverse range of needs. While Winnunga Nimmityjah Aboriginal Health Service was identified as a service providing targeted information and support for people from Aboriginal and Torres Strait Islander backgrounds, an organisational respondent noted that some Aboriginal and Torres Strait Islander people may not want to access Winnunga due to stigma and shame surrounding hepatitis, particularly hepatitis C. Some Aboriginal people may prefer mainstream health services.

[People can obtain information and support from] Aboriginal community controlled health services, although some people may not want to access these due to stigma and shame surrounding Hep C in particular but sometimes Hep B, so some Aboriginal people may prefer mainstream health services. (Person from health organisation)

j) Needs of people from CALD groups

People from CALD groups were also identified as requiring specific information and support. Organisational respondents identified services for migrants and refugee settlement services as providers of information, and the policy work of ACT Health's Migrant Health Unit and the work of Companion House were identified as providing good services for these groups. A person with hepatitis from a CALD background was unaware of migrant services, apart from their university health services.

People from health organisations respondents acknowledged that second and third generation CALD communities are likely to be connected into the mainstream health system, but that more recent migrants or refugees will be reliant on settlement and migration services. History and experience, language and cultural barriers, including distrust of medicine, were factors impacting on CALD populations' access to information. Respondents also acknowledged that information provision should go beyond availability of information, to connecting people to primary care and treatment.

My biggest concern for gaps in information provision for recently migrated refugees, families and communities are the needs go beyond translation of pamphlets. ... What is required for migration settlement services, communities they serve, is a bridge that helps them to talk about what can be difficult conversations. We need to bring the skills around how to sensitively explore information needs with people that don't make them uncomfortable. (Person from health organisation)

Information and support needs regarding prevention; testing; management, care and support; workforce; enabling environment; and surveillance, monitoring, research and evaluation

a) Prevention

The critical importance of providing prevention related information was discussed by people with hepatitis, as well as organisational respondents. In addition to increased awareness of prevention strategies including NSP and vaccination for prevention of hepatitis B, respondents noted the need for information that assists people to identify that they have been exposed to the virus. People with hepatitis identified that prevention for young people, particularly young people who are using drugs, was a particularly important information and support need.

But, yeah, huge amounts of confusion out there between hep A, hep B, hep C ... keep going ... and what the different transmission rates are, and who is and who isn't vulnerable, and people thinking they've had their shots for hep C. (Person from health organisation)

Young people who have just started using know almost nothing about viral hepatitis, and when they get access to information, it is almost always too late – such as through prison. (Person with hepatitis)

b) Testing

Information and support needs regarding testing and monitoring were identified by people with hepatitis, as well as organisational respondents. People with hepatitis indicated that it was not clear where to go for testing and that they were not aware that they could get testing through a GP.

Despite all the efforts of different organisations, hep B or hep C is not known about in the general public, so when something might have happened that's put them at risk, I don't think it's immediately clear where you would go. (Person with hepatitis)

For me and people I knew, was not knowing, genuinely, where to actually get tested, that you could go to a doctor. (Person with hepatitis)

Organisational respondents noted the importance of providing information and support to understand test results and processes for ongoing monitoring, in particular for people who have cirrhosis and advanced liver disease. People with hepatitis described the difficulty in understanding test results, and indicated that they wanted written information about what tests were required and what the results mean.

Especially something like relatively life changing like that. You want to be sure that you've got the terminology right. And it's really more about like, "Okay, so you got a positive result for hep C. It's very easily mistaken for, 'That's a good result.' As in you don't have it." (Person with hepatitis)

In relation to hepatitis B specifically, organisational respondents identified that testing was a key issue, given the large numbers of people who are undiagnosed.

In view of the fact that 40% of the 232,000 Australians living with hepatitis B don't know that fact yet and this is a huge number of undiagnosed people. It takes cognisance of their understanding of health, cultural background and sensitivities to reach out to these people and communities who don't know they have it yet. (Respondent from health organisation)

While the importance of connecting people with hepatitis B to testing and subsequently to care was recognised, organisational respondents discussed the missed opportunities for testing. Suggestions provided to overcome these missed opportunities included more active identification of people from countries of medium and high prevalence by providers, and follow-up of families by public health units.

Why are GPs and migrant health services not actively connecting people to care – there are many missed opportunities. And if they're from a high-prevalence country, why are GPs, why are migrant health services, not really actively pursuing that and doing testing? (Person from health organisation)

The other big issue with testing for hep B, we missed so many opportunities. If you diagnose one person in a family with hep B, then we should be having a system whereby public health units are actually doing follow-up with all our families, all their contacts, their intimate contacts, so that they're offered testing. Hep B is a family issue, and every time if a chronic infection is diagnosed, there's no follow-up, and public health units have been worried about being overburdened with the follow-up. Well, when you only have a diagnosis rate nationally of about 65%, what you're doing is condemning people to death if you don't diagnose, and so where is the priority here in public health units? (Person from health organisation)

c) Management, care and support

Management, care and support information and support needs were identified, including the need to link people with hepatitis to care, as well as specific needs in relation to DAAs.

The capacity of primary care, including GPs, and specialist services to deliver management, care and support was seen as critically important to meeting the management, care and support needs of people with hepatitis. Respondents identified several opportunities and problems.

In relation to primary care and GPs, several organisational respondents stated that this sector needed to increase its engagement with people with hepatitis to increase the numbers being treated. Issues identified by respondents included capacity issues in primary care to meet the demand for treatment, and the reliance on people with hepatitis to initiate conversations about past exposure. Variability in the quality of information provided by GPs, and difficulties in being referred to specialist hepatitis services was also seen as problematic.

Current services, like TCH [The Canberra Hospital] and IGP [Interchange General Practice], are at capacity. (Person from health organisation)

GPs' knowledge [of hepatitis] in the ACT is very variable unless you are connected to one of the high-volume practices that see a lot of people with hep b and hep C. (Person from health organisation)

Every GP needs to know the basics of where to go, when to refer, and what tests. (Person from health organisation)

Health promotion strategies around GPs work effectively when there is push from both ends – prime and incentivise the GPs to respond, and raise the issue at the community level. (Person from health organisation)

d) Hepatitis B specific management, care and support needs

Hepatitis B treatment issues identified by respondents included the need for to connect the vast numbers of undiagnosed and untreated people to care as well as the need for ongoing monitoring. Challenges were acknowledged in communicating with people with hepatitis B that they would need to be engaged with medical services over their lifetime, given that hepatitis B is not curable and requires regular monitoring.

The importance of engaging with GPs and migrant health services to achieve increased access to monitoring and treatment was highlighted by organisational respondents. While the work of Companion House, ACT Health's Multicultural Health Policy unit, and Hepatitis ACT in conducting community outreach and education targeting hepatitis B priority populations was valued, respondents also acknowledged the need to do more to link people with hepatitis B into ongoing management.

It's fantastic that Hepatitis ACT and Hepatitis New South Wales and all the other states and territory Hepatitis groups have some money, limited money but we're doing work in this regard, in Hep B. It's targeting the communities who it aims to serve, it's relevant to their needs, it's developed in consultation with them and in many cases by them. (Person from health organisation)

Organisational respondents highlighted although there was now greater understanding of when to treat people with hepatitis B, it was difficult to link people to ongoing monitoring for a range of reasons. For recently arrived migrants and refugees, this included that they have other more pressing priorities, different understandings of disease, and lack knowledge about where to go and how to negotiate the health care system.

For hep B, the critical issue is that people need to understand with hep B is that it's lifelong, and you need to really just get used to that and make sure that it becomes a routine thing. If you miss your six-monthly follow-up, the implications can be devastating, because most people feel well until their liver starts not to function. The real critical issue in hep B are the dangers of not monitoring, so that you can access treatments as needed, so that you don't get the more severe complications of disease, including liver cancer, and end-stage liver disease in many, many cases. (Person from health organisation)

Options suggested by respondents, to remove these barriers, included the implementation of nuanced approaches, with GPs, and stronger partnership approaches with the ACT Government and stakeholders.

e) Management of people without Medicare access

The discrete issues for people with hepatitis B and hepatitis C who cannot access subsidised treatment through Medicare and the PBS was also raised, and for these people, knowing how to access medications, including generic and imported medications was critical.

For people who are ineligible for Medicare, we have a responsibility to advise them of the options for treatment such as importation of generics, or compassionate access – that it has been very difficult to organise this. Generics really are the only option really for people who are Medicare ineligible. (Person from health organisation)

A respondent with hepatitis B, described that living close to the Hepatitis ACT office, facilitated access to information on treatment. As a person not eligible to Medicare, he was not sure where to go. Through the organisation, he could connect to a GP that could assist with accessing medications through other sources.

For people not able to get treatments who are not entitled to Medicare - how to get generic medications. Also process for importing generic and hepatitis B medications from one's mother country. This kind of information is really difficult to work out process. (Person with hepatitis)

Hepatitis ACT helped me actually to link up to the hepatitis C group who actually they have been importing the generic drugs. So, they actually helped me which are the websites that actually are reliable. I think I mainly actually go through Hepatitis ACT because I think they have the knowledge who are the doctor who are actually specialised in hepatitis B. (Person with hepatitis)

f) Hepatitis C specific management, care and support

In discussing the information and support needs in relation to new DAA treatments for hepatitis C, respondents were overwhelmingly supportive about the significant opportunities offered, due to the availability of these treatments at this time in history. Respondents identified information and

support needs in relation to promoting treatment, treatment regimes, side effects, non-responders, reinfection and living post-cure, and models to increase linkage to care.

We're in an area, time and place area, that's ground breaking. And it's kind of the promise to the world, is where we're at. Let's get going. (Person from health organisation)

This positivity was tempered by concerns that the availability of the treatments has led to bureaucrats and parliamentarians thinking that this meant that hepatitis C treatment issues were now solved. Respondents acknowledged that while take-up rates of DAAs had been very encouraging, many of those who had taken up treatments were motivated people who were aware of their hepatitis C status and treatment options.

There is a thinking among many health bureaucrats and MPs, parliamentarians, that hep C is done. We've got the cure, check, done. While there has been fantastic uptake of new treatments, it is the people who were ready and waiting who have been treated. Already there is a decline of monthly treatments, compared to the peak. (Person from health organisation)

Respondents stated that they believed much more action was required to link undiagnosed and untreated people with hepatitis C to treatment. This was important, to ensure that hard to reach and untreated people were not left behind.

If we don't think about what the ongoing community information and support connection needs are, general practice will default end up being what governments think is the answer to a now-much reduced burden of Hepatitis in the community and none of the questions [will be answered] around, "Who's left who didn't get treated?" (Person from health organisation)

Models suggested to increase linkages to management and care include: increasing the role of peers, including through organisations such as CAHMA. The benefits of using peer networks for information and support provision were raised in most of the interviews with organisational and lived experience respondents. Several respondents believed that peer networks were the key to rolling out treatment of new DAAs, beyond the highly motivated people who have already been treated.

CAHMA has to play a more assertive role now, because they are the ones with the trust of user networks. Provision of information about treatment needs to go hand in hand with overdose prevention and opiate replacement. Should be promoted as a triangle, and promoted systematically. (Person from health organisation)

As far as peer goes, it doesn't really matter how you access them. I think there's a forum by text, by app, by anything, so as long as there's a way to build trust. (Person with hepatitis)

The role could be particularly helpful in reaching people who are not accessing services, as well as overcoming misinformation that is held by people, such as about treatment side effects.

It's more about the people who don't access those services. There's a lot of those out there. ...I think that where peers would really work well, is actually getting deeply into networks. (Person with hepatitis)

The need for a general population targeted information campaign was suggested by a smaller number of respondents, although others disputed this idea.

Part of me thinks a massive awareness campaign is the only way to get to people who don't know that they're at risk, or don't know whether they have hepatitis C or B. But then, the other part of me goes, I think we need targeted campaigns run by organisations that know their community really well. (Person with hepatitis)

Absolutely clear that a public awareness campaign is not needed – I have no confidence that this would be the right delivery. What is needed is simple clinical input ... The antecedents to this are peer advocacy, not public education – I am absolutely clear on this. (Person from health organisation)

Respondents noted that the current models of hepatitis management create barriers to linking people to care. What is required currently is for a person with hepatitis to present to a GP to order a test, then returning for results, and receiving further referral to the Liver Clinic for a liver scan. This needs to be replaced with a one-stop shop where everything is accessible in a community-based location. A one-stop shop was an effective way to engage with people who are not linked into primary health care.

You can't have someone state that they want treatment, see a doctor, the doctor then sends off a pathology, just sends off an ultrasound, a Fibroscan, expects the person to come back, take a script, go to the pharmacy. That doesn't sit with that decision process. (Person from health organisation)

And now we have to get people to self-refer their friends and have an easy way for people - because it might be a decision, spur of the moment, so we need to get CAHMA, Hepatitis ACT, to get people fast-tracked onto treatment. So, identify those key places. Which would necessarily be Interchange [General Practice], the jail, and Winnunga. Get a few pharmacists onside. I don't think it's rocket science. (Person from health organisation)

Community-based outreach clinical services, with suggestions that this could be conducted at Hepatitis ACT, was also raised by people with hepatitis and organisational respondents.

Hepatitis ACT could set up clinics within their organisation if they wished, if they had the funds to do it. Other hepatitis organisations are doing that. They're doing testing. They're having us practitioners coming in doing Fibroscans. They have GPs coming in to commence people on treatment who don't have a regular GP ... We obviously don't want to disconnect people from their regular GPs. But there are a number of people with hep B and C who don't have a GP, where do they go? How do we make sure that they have access to everything else? (Person from health organisation)

They [Hepatitis ACT] need to be the hub. They need to be where everyone in the ACT can refer people and know that they're going to get a really good service. But to be the hub, you've got to actually put some dollars into that. To be the go-to place requires promotion, requires the capacity within the organisation to actually deal with the issues that come through the front door when they come, and that's a concern. (Person from health organisation)

Furthermore, networking, resources and better use of local level networks such as public health networks (PHNs) were ways to better target people with hepatitis C, and improve service access to people who are not currently engaged with treatment.

We need to find the access point to communities (which community organisations know how to do), but they aren't able to do the clinical testing – it is a clinical resources question to actually get people to the communities to do the testing. (Person from health organisation)

There needs to be ways of bringing those organisations together to make sure that the PHNs know what the burden of disease is, and actually apply that funding appropriately and give some priority. ... We need to find people, we need to connect them, we need to support them, we need to do it on their terms not the health services' terms. (Person from health organisation)

Just what do we need to do? This is where the partnership approach and strategic planning meetings are so important. (Person from health organisation)

While the new DAAs offered new opportunities in terms of high cure rates, respondents identified several information and support needs that will need to be addressed to increase uptake of the new treatments. This includes the need for information to overcome the history of interferon-based treatments and their side effects.

A lot of people with hepatitis C have been living with hepatitis C for a long time and they have heard the horror stories of interferon-based treatments, and this frames their thinking about treatments. We have to do quite a bit of work in terms of turning around how people look at treatment for hep C and how these new drugs are different and what the difference is in terms of side effects and length and ease of treatment. A lot of information is needed in terms of these. (Person from health organisation)

The old treatment experience still kind of echoes for people, still comes through. It's still people remember the fact that their friend had a really awful time, so they can't quite believe that these treatments have as few as side effects as there are. The other thing is that a lot of people don't believe there's a cure rate that's so high. So, I mean, there is an element of needing to reinforce that over and over again with people. (Person with hepatitis)

A person with hepatitis reported that their doctor had dismissed the side effects that he experienced while taking the new DAAs. While there are fewer side effects associated with the new DAAs, in comparison with the previous interferon-based treatments, people taking them do experience side-effects and these need to be communicated clearly.

You know when you go to the doctor they say, these are all fantastic and they have no side effects when in fact the experience of people taking them is a little to the contrary. I tried two different drugs. But the first one, I had a lot of insomnia and slightly aching legs and joints and the second one I had lots of aches and pains, but no insomnia, and overall it was better. It would've been nice to have been better informed as to what side effects might have been. What to expect. (Person with hepatitis)

Furthermore, respondents with hepatitis identified a need for information about the process for getting onto treatments, about which regimen is needed for different genotypes, and what monitoring and testing is required during treatment.

People want to know things like, the processes for getting signed up to go on these regimes, what the processes are for working up, for example, whether they need ultrasounds, or biopsies, or liver scan. (Person from health organisation)

They want to know about interpreting test results as they come through, including four-week tests if they get them, or 12-week tests, end-of-treatment tests, or 12-week follow-up tests and how reliable these tests are, and how much they can feel that a 12-week SVR is a reliable result. (Person with hepatitis)

A pamphlet would be really good that says if you have type one B and you're on this treatment and you're tested this number of months after the treatment is finished, then you have, whatever the

percentage is chance that it will never return without re-contracting the disease. I'd like to know that. I actually don't know what the answer is. (Person with hepatitis)

Organisational respondents noted the need for ongoing monitoring for people with cirrhosis.

In offering a hundred people direct-acting antivirals, we have three people who have Cirrhosis, who will need ongoing surveillance. They know about that as part of their treatment work-up. That's not high-yield for public relations. (Person from health organisation)

For the smaller number of people who have been treated and who have cirrhosis, will need ongoing surveillance. (Person from health organisation)

g) Non-responders to treatment

Expert respondents noted the devastating effect of receiving a post-treatment result that the new DAA treatments had not been successful. Resistance to the new treatments is an issue that needs further investigation. While an organisational respondent noted that there are new anti-viral medications in the pipeline that can offer hope for these people in the near future, the information and support needs of this group of people need specific management now.

I think there's support needs in relation to that, particularly if there's treatment failure. Also, the co-infection issues and the reinfection issues in terms of people getting it again because they haven't used the right preventative measures not to. They're still out doing whatever they're doing that enabled them to get it in the first place, in relation to Hepatitis C. (Person from health organisation)

h) Re-infection

Re-infection is an issue that was raised by several expert respondents and a person with hepatitis. Reinfection has emerged as an issue particularly for people in jail where there is unregulated needle and syringe distribution, and for others who have limited access to injecting equipment.

Support people who have been treated effectively, to maintain that status. (Person from health organisation)

Messaging [is needed] around how you can be cured, and then have an injecting experience and then get re-infected. (Person with hepatitis)

Furthermore, DAAs will challenge the assumptions of people who have been living with hepatitis C, once they are cured.

I think just that getting on with life afterwards is often an issue for some people as well, particularly people who are still injecting, or injecting has been a big part of their lives and they've lived with hepatitis C for a long time. Moving on from that can be quite scary and, I guess, forces a focus on other areas of their life, which also they may or may not want to focus on. (Person with hepatitis)

i) Workforce

Information and support needs in relation to workforce development were identified as a key issue in improving treatment and linkage to care.

The health workforce needs to step up and play a bigger role – first workforce development and then to practice discussion in their GP and other settings. (Person from health organisation)

The health workforce needs to be scaled up, I'm talking here GPs, I'm talking nurses in public settings, nurses in private settings. I'm talking community health centres, I'm talking about migrant resource centres. They all need to be skilled up and be able to provide a basic level of understanding and awareness of what Hep B and in cases Hep C. (Person from health organisation)

Organisational respondents identified the need for more workforce development to skill up GPs to become prescribers and initiators of hepatitis B treatment. The role of ASHM (Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine) in up-skilling GPs to become prescribers and initiate early treatment was highlighted.

We actually need some of that directed to workforce capacity building, not just to provision of services, because the situation we're in at the moment, it's just changing rapidly, and we need to make sure that the workforce is prepared for that. And by that, I mean the community workforce as well as the health care workforce. (Person from health organisation)

Anyone on the front line of human services needs to understand questions of stigma, shame as barriers to seeking information and support around hepatitis, but also blood borne viruses, sexual and health infections, and STIs in general. Ongoing programme of professional learning to understand these, and the role that front-line people can have in connecting them to information and supports. (Person from health organisation)

Furthermore, an organisational respondent noted that community organisations in the ACT that have clients with hepatitis B and hepatitis C need printed information and up-skilling so they can refer people to treatment.

It would be really good if we had some fact sheets or training even, because here we come across so many people who do have infection, they're asking about it, they want more information. We want to be able to give them the right information. So, it would be good if we had some skilling up of our staff and also just some information handouts that we could give to people that pointing them in the right direction. (Person from health organisation)

j) Enabling environment

People with hepatitis and organisational respondents identified several structural issues that facilitated and hindered access to information and support. These included broad factors such need for greater leadership, funding gaps and the short funding cycle, and the need for service reconfiguration. The effect of stigma and personal factors as barriers to information and support acquisition were also discussed.

Unfortunately, there are affected communities here that are not politically powerful and are small. So, we're tied to acceptable deaths, basically, is what we've had with Hepatitis. Some people are allowed to die from chronic conditions that we wouldn't tolerate anywhere. (Person from health organisation)

The need for greater leadership within the ACT Government to address hepatitis information and support related policy and programming was discussed by several organisational respondents. A respondent identified that while the Sexual Health Committee (SHARD) had been on message in

providing advice to the health minister, the Chief Health Officer could do more to grapple with the policy responses to hepatitis B and hepatitis C.

Organisational respondents also described funding and resource gaps, with a respondent describing Hepatitis ACT is as the most poorly funded community-based hepatitis organisation in the country, while others noted that funding levels provided were not commensurate with the number of people affected by hepatitis and the numbers of people requiring linkage to care, particularly in comparison to other BBVs, such as HIV.

My issue would be that it's completely lopsided the amount of information and public awareness and funding, I suppose. (Person from health organisation)

And I would say the ACT Government really needs to have a long, long hard look at the disparities in funding between the AIDS Council [AIDS Action Council of the ACT] and Hepatitis ACT. I think it's bordering on discrimination. (Person from health organisation)

An organisational respondent stated that extraneous to levels of funding, the short funding cycle prevented community organisations from strategically planning for long-term needs.

I think this is something that's common with all non-government organisations, that it's not just about the amount of money that's received from government, it's about the certainty and the timeline of those grant processes as well. If you're in a secure environment, you can do that blue-sky thinking of, okay, hep C's changed, we need to move from this to that. (Person from health organisation)

Working in partnerships was also seen as a way to get more resources and support.

I think working together in partnership has to be the answer to that [i.e. getting more resources and support] and accepting each other's each sector's needs, barriers, strengths, opportunities. All of those things and working together instead of working in silos. And supporting each other's cause, politically. (Person from health organisation)

The need to reconfigure community and clinical services was discussed widely by organisational respondents. A respondent stated that there was adequate evidence about the scope of the problem and what is needed, but what was needed was courage to make difficult political and policy decisions to reconfigure health services to adequately meet needs, based on needs based planning.

Configuration of community and health services to meet needs is required. There is sufficient epidemiological information that identifies needs but there is a lack of courage to follow through on what this means in terms of the mix and balance of services required in the community. (Person from health organisation)

Needs-based planning needs to be understood better or else we see really poor decisions made. There's a pretence, then, that we're doing something evidence-based rather than actually acknowledging that the evidence suggests this and then we've got political and community needs in a democracy that play out. (Person from health organisation)

Locally, I don't see a great strength in the ACT Government's service planning, either in health or community services, from the notion of the continuum of services and care that's required. ... It's not just a government problem - organisations who deliver services have not been proactive around identifying

the gaps in the continuum and stretching or moving themselves to fill them when they've been comfortable to just sit with what we've always done. (Person from health organisation)

Once hepatitis C has been eliminated in the longer-term, changes will need to be made in the service landscape to match the change in prevalence. Further down the track, when hepatitis is less prevalent, service structures will also need to be reconfigured. An organisational respondent was concerned that if the on-going community information and support needs in the future are not identified and planned for, government will default to GPs who will not be able to actively conduct outreach to those who remain untreated, which could potentially lead to ghettoisation of infection in hard to reach groups, leading to further reinfections.

If we don't think about what the on-going community information and support connection needs are, general practise will default end up being what governments think is the answer to a now-much reduced burden of hepatitis in the community and none of the questions around, "Who's left who didn't get treated?" and their sense of access and support in general practice will be answered. And I think that looks dire because it's actually just going to even further ghettoise infection in hard to reach and disconnected people and communities... (Person from health organisation)

I think the game-changing bit of it is that fairly shortly, if we do this right, Hepatitis is going to be a much less prevalent, chronic issue that maybe doesn't need systems and service structures the way they have been structured in the past. And I think it's really tricky to try to prepare for this. It perhaps focuses a little bit more around what does the service landscape need to look like? (Person from health organisation)

Specific policy directions suggested by respondents included the establishment of a NSP in the jail, and called on the ACT Government to take leadership, with one respondent calling on the Human Rights Commission to progress the stalemate in negotiations about establishing a NSP at the jail.

There needs to be a needle exchange at the jail, in the light of cases of reinfection related to ongoing injecting. (Person from health organisation)

The abiding commitment to human rights and the dignity of men and women has not been demonstrated, so that's a huge disappointment. (Person from health organisation)

Beyond these structural issues, stigma and individual issues were also identified as barriers to creating enabling environments. This included lifestyle factors which 'get in the way' of accessing treatment, barriers caused by stigma, and the need for leadership, coordination and resources. At the broadest level, the fact that affected priority populations are small and not politically powerful was identified as one of the barriers to providing adequate levels of information and support to people with hepatitis B and hepatitis C.

k) Stigma

In relation to hepatitis C and association of hepatitis C with injecting drug use, respondents discussed the impact of stigma, shame, discrimination and negative experiences from medical professionals, and how this created barriers to accessing information and treatment. People with hepatitis elucidated the impact that shame has in creating barriers to accessing health services.

Shame kind of puts off people [going to see a GP]. (Person with hepatitis)

I actually rang the hepatitis info [line]... I wanted a doctor from them, and they were unable to give me that information. ...I wanted a doctor that I knew I could cut out the crap, if I could find one, [rather] than go through sort of five or six. I just wanted to find one who I knew wouldn't discriminate against me. (Person with hepatitis)

People with hepatitis described how shame and stigma isolates people, forcing them to rely on friends rather than expert advice, resulting in trying to ignore or 'put it out of their head'.

Speaking about hep C, in particular, but maybe it applies to B as well, because there is quite a bit of stigma around ... And related to hep C, it's really highly related to the fact that it's associated with injected drug use. That impacts, because some people, if they're really isolated, don't even know how to ask their friends. (Person with hepatitis)

That's why people speak to friends and worrying about those things, peers and stuff. Because they want to know that they've got a chance at being treated properly. They're gonna be honest. Because most people have had a really negative experience opening about, certainly, hep C. My diagnosis experience, for instance, pretty much put me off speaking to a medical person about it, for years. (Person with hepatitis)

People with hepatitis identified that a number of factors, including drug use and recent migration to Canberra, impacted on being in the right 'head space' to getting information and support, and to making decisions about treatment.

Not being in a space, in terms of my lifestyle, which meant that I couldn't make sensible decisions. (Person with hepatitis)

If you're a new migrant into ACT, you're trying to get a roof over your head, you got multiple other priorities. If you're a person who injects drugs, and you're not currently in a sort of stable living or stable employment or life is not easy, then it's about what needs to happen before treatment. (Person from health organisation)

Furthermore, for people who previously engaged in drug using who felt they had 'moved-on', re-engagement with organisations and the consequences of their previous drug use was felt to be more difficult.

My own experience and that of a lot of people that I know, is that of not having used drugs for a very long period of time, and so there would be a reluctance to engage with an organisation that is really catering more to an actively drug-using, at the moment, population. (Person with hepatitis)

In fact a lot of people just feel that they've left that behind him and so they don't want to go there. (Person with hepatitis)

Approaches suggested by respondents to overcome stigma included the need for tailored community-based and peer approaches, as well as better workforce training and protections on privacy. The social determinants of health, including education, socio-economic factors and linkages to supportive social networks were noted as systematic barriers, which prevented individuals and communities taking more active control over health.

Need to empower communities of people living with hep B and hep C to look after their own health – there are challenges because of a wide range of social determinants of health including various levels of education, poverty, relationships and social networks. (Person from health organisation)

There is a lot of stigma in some communities so peer support could be useful. What is clear is that we need to focus our attention on the communities affected. Hep ACT is doing their best to reach those communities but their resources are limited. (Person from health organisation)

You've still got this overarching attitude issues, stigma issues. There are information gaps partially because if you've got something that's highly stigmatised, how you get the information to reach the people easily is quite different from if you have a non-stigmatised condition.... Well, your strategies will not be the same. They need to be very tailored and really address those fears, so that takes a lot of time and effort. (Person from health organisation)

Systems are not there that make it easy to identify people with hep B and hep C, and people don't want to be identified as people with hep B and hep C unless they're sure that their privacy concerns are going to be protected, because otherwise they quite often have had quite stigmatising and discriminatory experiences of health care. (Person from health organisation)

1) Surveillance, Research and Evaluation

While surveillance, research and evaluation was not specifically addressed in interview questions, an organisational respondent commented on the surveillance, research and evaluation information and support needs for people with hepatitis. This respondent argued that adequate epidemiological data is available regarding target populations and the scale of the issues; however, translation of health promotion research to practice and advocacy to policy makers is required.

Need to articulate the robust evidence available from health promotion approaches and apply them. 'Research to practice' is needed to evaluate and understand what is required to develop the tools for to identify and respond to community needs – this needs to be sold up to decision makers. (Person from health organisation)

Discussion

This study identifies the information and support needs of people with hepatitis B and hepatitis C in the ACT. There are no known published reports and studies specific to the ACT. Furthermore, much of the published literature is not up to date considering the more recent focus on treating people with chronic hepatitis B prior to progression to advanced liver damage, and the availability of DAAs to treat hepatitis C.

Comparison of the systematic review of literature and the interviews indicates a significant consistency in themes, particularly regarding the need for clear treatment pathways, and information and support that meets the specific needs of a range of groups, including Aboriginal and Torres Strait Islander, CALD, injecting drug users and people who are not connected to health services. The interviews provided nuanced findings regarding the local context, particularly in relation to the lack of information on where to go for testing and treatment, and the gaps identified regarding the lack of strong government leadership to develop policy and planning for BBVs.

A number of information and support issues and needs, specific to the ACT, were identified:

- People with hepatitis require specific information about where to go for hepatitis testing, management, care and support. There is a need to link the large numbers of undiagnosed and untreated people with hepatitis to testing, management, care and support.
- People with hepatitis rely on information and support through word of mouth, such as through friends and other people they know.
- There is a concern that current services are at capacity. Alternative models of service provision were suggested, include: community based testing and clinical services, one-stop shops for testing and treatment, and increasing the role of peer organisations and peer driven approaches.
- Aboriginal and Torres Strait Islander people require specific information and support needs through targeted resources and services.
- There is a need to increase opportunities in general practice, through migrant services, and CALD community networks to link people with hepatitis B to testing, ongoing monitoring, and treatment, including providing information and support options for people without access to Medicare.
- Specific information and support needs were identified in relation to new hepatitis C treatments, including information on medication regimes, tests required before, during and after treatment, side effects, options available for people who do not respond to treatment, re-infection, and life-after cure.
- There is a need to connect to people who are currently and have previously used injecting drugs, including those who have been diagnosed a long time ago but have not been linked into care. Suggested approaches include the use of drug user and peer networks to link people into care.

- People with hepatitis C in prison were receiving information, testing and treatment at an advanced stage of disease progression, and opportunities for prevention were being missed through the lack of NSP.
- Experiences and fear of discrimination and stigma are barriers to seeking and accessing information and support from health professionals. As a priority, workforce development and training for health and community workforce is needed to improve understanding and skills in relation to hepatitis B and hepatitis C information and support provision.

Recommendations

Recommendations, based on the findings of the needs assessment, are as follows:

1. Hepatitis ACT continues to develop and distribute accessible hepatitis B and hepatitis C prevention and treatment resources, and to provide support to people at-risk of or impacted by hepatitis B and hepatitis C.
2. Hepatitis ACT continues to work with community organisations and to increase distribution and availability of written and Internet resources to promote ACT specific hepatitis testing and treatment services, including contact details.
3. Hepatitis ACT continues to work with relevant stakeholders to develop and distribute information about the treatment options for people who are not eligible for treatment under Medicare.
4. Hepatitis ACT continues to work with ACT Health to ensure that hepatitis B and hepatitis C information provided by ACT Health agencies is current and relevant.
5. Hepatitis ACT continues to work with GPs, primary health care providers, community workers and others to increase their knowledge of viral hepatitis and how to support people with, and who are impacted by, hepatitis B and hepatitis C.
6. Hepatitis ACT continues to work in partnership with community and clinical partners to increase opportunities for community outreach based interventions in relation to vaccination, screening, testing and support.
7. Hepatitis ACT and Capital Health Network investigates the feasibility of implementing workforce development around testing and treatment of hepatitis B and hepatitis C for general practice, including on stigma, with a focus on creating greater community-based treatment options, and growing the pool of GPs who have the capacity to provide high quality treatment for viral hepatitis.
8. The ACT Government progresses the establishment of a Needle and Syringe Program at the Alexander Maconochie Centre.
9. The ACT Government and community organisations, including Hepatitis ACT, investigate models of treatment and care such as community based testing and treatment services, one-stop shop models of care, and peer-driven approaches.
10. Hepatitis ACT continues community development and outreach to priority populations, including to the Alexander Maconochie Centre, with Aboriginal and Torres Strait Islander community populations, and with culturally and linguistically diverse groups.

References

1. Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report 2017. Sydney; 2018.
2. ASHM. Hepatitis B Mapping Project: Estimates of geographic diversity in chronic hepatitis B prevalence, diagnosis, monitoring and treatment-National Report 2016. Darlinghurst; 2018.
3. ASHM. Hepatitis C Mapping Project: Estimates of geographic diversity in chronic hepatitis C prevalence, diagnosis, monitoring and treatment - National Report 2016. Darlinghurst; 2018.
4. Hepatitis ACT. Hepatitis ACT Annual Report 2016-2017. 2017.
5. Australian Government. Fourth National Aboriginal and Torres Strait Islander Blood-borne Viruses and Sexually Transmissible Infections Strategy 2014-2017. Department of Health, Canberra. 2014.
6. Australian Government. Second National Hepatitis B Strategy 2014-2017. Department of Health, Canberra. 2014.
7. Commonwealth of Australia. Fourth National Hepatitis C Strategy 2014-2017. Department of Health, Canberra. 2014.
8. Bradshaw J. A taxonomy of social need. In: McLachlan G, editor. Problems and progress in medical care: Seventh series NPHT/Open University Press.; 1972.
9. Dore G, Wallace J, Locarnini SA, Desmond P, Gane E, Crawford D. Hepatitis B in Australia: responding to a diverse epidemic. 2008.
10. ASHM. HIV, viral hepatitis and STIs: A guide for primary care. Darlinghurst: Australasian Society for HIV Medicine; 2014.
11. Kirby Institute. Bloodborne viruses and sexually transmissible infections in Aboriginal and Torres Strait Islander people: Annual surveillance report 2017. Sydney; 2018.
12. Kirby Institute. Monitoring hepatitis C treatment uptake in Australia (Issue 8) December 2017. Sydney: UNSW Sydney; 2017.
13. Galindo L, Maginnis T, Wallace G, Hansen A, Sylvestre D. Education by peers is the key to success. *International Journal of Drug Policy*. 2007;18(5):411-6.
14. ACT Government. Hepatitis B, Hepatitis C, HIV and Sexually Transmissible Infections: ACT statement of priorities 2016-2020. Canberra. 2016.
15. Critical Appraisal Skills Programme. CASP Qualitative Checklist. 2016.
16. World Medical Association. WMA Declaration of Helsinki - Ethical principles for medical research involving human subjects. 2013.
17. Mack H, Paylor I. Hepatitis C and Social Work. *British Journal of Social Work*. 2016;46(4):1115-11130.
18. Duterte S, McNally S. Improving and Increasing Access to Hepatitis C Treatment: A research project exploring barriers to treatment for people of Vietnamese and Cambodian backgrounds. ARCSHS Monograph Series: La Trobe University, Australian Research Centre in Sex Health and Society; May 2008.
19. Mouton M. 'More Than a Liver': Social Work's Contribution to the Well-Being of People Undergoing Treatment for Hepatitis C. *Journal of Social Work Practice in the Addictions*. 2011;11(1):40-59.
20. Sweeney L, Owiti JA, Beharry A, Bhui K, Gomes J, Foster GR, et al. Informing the design of a national screening and treatment programme for chronic viral hepatitis in primary care: qualitative study of at-risk immigrant communities and healthcare professionals. *BMC Health Services Research*. 2015;15:97.

21. Treloar C, Jackson C, Gray R, Newland J, Wilson H, Saunders V, et al. Care and treatment of hepatitis C among Aboriginal people in New South Wales, Australia: implications for the implementation of new treatments. *Ethnicity & Health*. 2016;21(1):39-57.
22. Davies J, Bukulatjpi S, Sharma S, Davis J, Johnston V. "Only your blood can tell the story" - a qualitative research study using semi-structured interviews to explore the hepatitis B related knowledge, perceptions and experiences of remote dwelling Indigenous Australians and their health care providers in northern Australia. *BMC public health*. 2014;14:14.
23. Davis M, Rhodes T. Beyond prevention? Injecting drug user narratives about hepatitis C. *International Journal of Drug Policy*. 2004;15(2):123-31.
24. Wallace J, McNally S, Richmond J, Hajarizadeh B, Pitts M. Challenges to the effective delivery of health care to people with chronic hepatitis B in Australia. *Sex Health*. 2012;9(2):131-7.
25. Mehta SH, Genberg BL, Astemborski J, Kavasery R, Kirk GD, Vlahov D, et al. Limited Uptake of Hepatitis C Treatment Among Injection Drug Users. *Journal of Community Health*. 2007;33(3):126.
26. Wallace J, McNally S, Richmond J. *National Hepatitis B Needs Assessment 2007*. La Trobe University. 2007.
27. Blanas DA, Nichols K, Bekele M, Shankar H, Bekele S, Jandorf L, et al. Adapting the Andersen model to a francophone West African immigrant population: hepatitis B screening and linkage to care in New York City. *Journal of Community Health*. 2015;40(1):175-84.
28. Carabez RM, Swanner JA, Yoo GJ, Ho M. Knowledge and fears among Asian Americans chronically infected with hepatitis B. *Journal of cancer education : the official journal of the American Association for Cancer Education*. 2014;29(3):522-8.
29. Hajarizadeh B, Wallace J, Ngo N, Richmond J. *Hepatitis B Patient and Clinical Practice Survey*. Melbourne, Victoria: La Trove University, Australian Research Centre in Sex Health and Society; 2014.
30. Lee H, Yang JH, Cho MO, Fawcett J. Complexity and Uncertainty of Living with an Invisible Virus of Hepatitis B in Korea. *Journal of Cancer Education*. 2010;25(3):337-42.
31. Wallace J. Engaging communities affected by hepatitis B. *Cancer Forum*. 2007;33(2).
32. Crockett B, Gifford SM. 'Eyes wide shut': narratives of women living with hepatitis C in Australia. *Women & Health*. 2004;39(4):117-37.
33. Strauss SM, Astone-Twerell J, Munoz-Plaza CE, Des Jarlais DC, Gwadz M, Hagan H, et al. Drug treatment program patients' hepatitis C virus (HCV) education needs and their use of available HCV education services. *BMC Health Services Research*. 2007;7:39.
34. *Scottish Needs Assessment Program. Hepatitis C*. Glasgow, Scotland: Office for Public Health in Scotland, August 2000.
35. Conrad S, Garrett LE, Cooksley WG, Dunne MP, MacDonald GA. Living with chronic hepatitis C means 'you just haven't got a normal life any more'. *Chronic illness*. 2006;2(2):121-31.
36. Gifford SM, O'Brien ML, Bammer G, Banwell C, Stoové M. Australian women's experiences of living with hepatitis C virus: Results from a cross-sectional survey. *Journal of Gastroenterology and Hepatology (Australia)*. 2003;18(7):841-50.
37. Banwell C, Bammer G, Gifford SM, O'Brien ML. Australian lesbian and bisexual women's health and social experiences of living with hepatitis C. *Health Care for Women International*. 2005;26(4):340-54.
38. Adams J, Nowels C, Corsi K, Long J, Steiner JF, Binswanger IA. HIV risk after release from prison: A qualitative study of former inmates. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2011;57(5):429-34.

39. Woolhouse S, Cooper E, Pickard A. 'It gives me a sense of belonging': Providing integrated health care and treatment to people with HCV engaged in a psycho-educational support group. *International Journal of Drug Policy*. 2013;24(6):550-7.
40. Brousselle A, Petit G, Giraud M-J, Rietmann M, Boisvert K, Foley V. Using the evaluation process as a lever for improving health and healthcare accessibility: The case of HCV services organization in Quebec. *Evaluation and Program Planning*. 2016;55:134-43.
41. Hopwood M, Lea T, Aggleton P. Multiple strategies are required to address the information and support needs of gay and bisexual men with hepatitis C in Australia. *Journal of Public Health*. 2016;38(1):156-62.
42. Owen G. An 'elephant in the room'? Stigma and hepatitis C transmission among HIV-positive 'serosorting' gay men. *Culture, Health & Sexuality*. 2008;10(6):601-10.
43. Hepatitis Australia. Do You C What I C? National Hepatitis C Needs Assessment 2008. Report on the information and support needs of people living with hepatitis C in Australia. Hepatitis Australia; 2008.
44. Temple-Smith M, Stoové M, Smith A, O'Brien M, Mitchell D, Banwell C, et al. Gender differences in seeking care for hepatitis C in Australia. *Journal of Substance Use*. 2007;12(1):59-70.
45. Lee H, Hann H-w, Yang JH, Fawcett J. Recognition and Management of HBV Infection in a Social Context. *Journal of Cancer Education*. 2011;26(3):516-21.
46. Guirgis M, Nusair F, Bu YM, Yan K, Zekry AT. Barriers faced by migrants in accessing healthcare for viral hepatitis infection. *Internal Medicine Journal*. 2012;42(5):491-6.
47. Lee J, Lok AS, Chen J. Hepatitis B prevalence among Asian Americans in Michigan: an assessment to guide future education and intervention strategies. *J Community Health*. 2010;35(5):534-42.
48. McNally S, Latham R. Recognising and Responding to Hepatitis C in Indigenous Communities in Victoria: A research project exploring barriers to hepatitis C treatment. Melbourne, Victoria: La Trobe University, The Australian Research Centre in Sex Health and Society; 2009.
49. Treloar C, Newland J, Harris M, Deacon R, Maher L. A diagnosis of hepatitis C - insights from a study on patients' experiences. *Australian Family Physician*. 2010;39(8):589-92.
50. Jessop AB, Cohen C, Burke MM, Conti M, Black M. Hepatitis support groups: meeting the information and support needs of hepatitis patients. *Gastroenterology nursing : the official journal of the Society of Gastroenterology Nurses and Associates*. 2004;27(4):163-9.
51. Farrell G, Comiskey C. Dualities of living with HIV/HCV co-infection: patients' perspectives from those who are ineligible for or nonresponsive to treatment. *Journal of the Association of Nurses in AIDS Care*. 2014;25(1):9-22.
52. Sgorbini M, O'Brien L, Jackson D. Living with hepatitis C and treatment: the personal experiences of patients. *Journal of Clinical Nursing*. 2009;18(16):2282-91.
53. Gifford SM, O'Brien ML, Smith A, Temple-Smith M, Stoove M, Mitchell D, et al. Australian men's experiences of living with hepatitis C virus: results from a cross-sectional survey. *Journal of Gastroenterology & Hepatology*. 2005;20(1):79-86.
54. Grundy G, Beeching N. Understanding social stigma in women with hepatitis C. *Nursing Standard*. 2004;19(4):35-9.
55. North CS, Devereaux R, Pollio DE, Hong BA, Jain MK. Patient perspectives on hepatitis C and its treatment. *European Journal of Gastroenterology & Hepatology*. 2014;26(1):74-81.
56. Evon DM, Simpson KM, Esserman D, Verma A, Smith S, Fried MW. Barriers to accessing care in patients with chronic hepatitis C: the impact of depression. *Aliment Pharmacol Ther*. 2010;32(9):1163-73.

57. Newland J, Treloar C. Peer education for people who inject drugs in New South Wales: Advantages, unanticipated benefits and challenges. *Drugs: Education, Prevention & Policy*. 2013;20(4):304-11.
58. Sylvestre DL, Zweben JE. Integrating HCV services for drug users: A model to improve engagement and outcomes. *International Journal of Drug Policy*. 2007;18(5):406-10.
59. Treloar C, Rance J, Bath N, Everingham H, Micallef M, Day C, et al. Evaluation of two community-controlled peer support services for assessment and treatment of hepatitis C virus infection in opioid substitution treatment clinics: The ETHOS study, Australia. *International Journal of Drug Policy*. 2015;26(10):992-8.

Appendix 1: Participant information and consent form and Interview guide

PARTICIPANT INFORMATION	
A Comprehensive Needs Assessment – Evaluating Contemporary Needs for Community Hepatitis Services in the ACT	

RESEARCH TEAM CONTACTS

Researcher:	Dr Jane Koerner	Public Health Researcher
Organisation:	Mr John Didlick	Executive Officer, Hepatitis ACT
	Ms Melanie Walker	President, Hepatitis ACT

DESCRIPTION

Hepatitis ACT is Canberra’s community hepatitis organisation, funded by ACT Health to deliver a comprehensive range of programs and services that help prevent viral hepatitis transmission, reduce morbidity and mortality, and minimise the personal and social impacts of the virus.

This study is funded by ACT Health and its aim is to assist Hepatitis ACT and funding partners to better understand and respond to the contemporary information and support needs of people with and affected by hepatitis B and hepatitis C in the ACT.

Interviews will be conducted with priority populations and people working in key organisations to investigate the gaps in provision of information and support for people with and affected by hepatitis B and hepatitis C in the ACT.

The research team invites you to participate in this research because you have been identified as a person from a priority population or who works in an organisation with clients affected by hepatitis.

PARTICIPATION

Your participation will involve a member of the research team, who is an experienced health researcher, interviewing you. The interviewer will ask you for your opinion on the provision of information and support for people affected by hepatitis B and hepatitis C in the ACT, and directions for possible future programs.

The interview will be conducted in a location that is comfortable for you. If you agree, the interview will be recorded on a recorder to allow data analysis. If you prefer that the interview is not recorded, interview notes will be taken. Please note that we do not require any personal details. Details that can possibly identify you, such as your name, will be removed from interview recording or notes. There will be up to 5 people participating in interviews in the ACT.

Your participation in this project is entirely voluntary. If you agree to participate, you can withdraw from the project at any time without comment or penalty. Your decision to participate or not

participate will in not impact upon your current or future relationship with Hepatitis ACT or ACT Health.

EXPECTED BENEFITS

There will be no benefit to you from participation in this project. The findings from this research will be provided to the Board of Hepatitis ACT and to ACT Health to give evidence on the information and support needs of people with hepatitis B and hepatitis C in the ACT.

RISKS

There are no expected risks associated with your participation in this project.

If you experience emotional discomfort in the interview due to recalling and reporting your experiences relating to hepatitis B and hepatitis C, please:

- discuss this with the researcher
- contact Hepatitis ACT on (02) 6230 6344 (9am to 5pm - Monday to Friday)
- contact Lifeline on 13 11 14 (24 hours a day – 7 days a week)

PRIVACY AND CONFIDENTIALITY

All comments and responses will be treated confidentially unless required by law.

What you discuss in the interview will remain confidential except if you discuss something that puts you or others at risk. Researchers will let you know if they need to follow up on this and how they will do this.

Information obtained from this study will eventuate in a research report and publications. Your identity and any other identifying details will not be disclosed in any documents, reports or publications during and after completion of this research.

The project is funded by ACT Health however they will not have access to the data obtained from the project.

CONSENT TO PARTICIPATE

If you agree to participate, we request you to sign the enclosed written consent form and return it to us in the enclosed return envelope. If you require verbal information or have questions that are not addressed in this document, please contact Dr Jane Koerner by email or telephone to organise a convenient time to talk. This information sheet is for you to keep.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If have any questions or require further information, please contact one of the research team members.

Study team:	Dr Jane Koerner	[redacted]	janekoerner@gmail.com
	Mr John Didlick	(02) 6230 6344	executive@hepatitisACT.com.au

CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

Hepatitis ACT is committed to the research integrity and ethical conduct of this project. If you do have any concerns or complaints about the ethical conduct of the project, you may contact the Hepatitis ACT Board President on (02) 6230 6344 or email info@hepatitisACT.com.au. The ACT

Hepatitis Board President can facilitate a resolution to your concern in an impartial manner.

Thank you for helping with this research project. Please keep this sheet for your information.

CONSENT FORM	
A Comprehensive Needs Assessment – Evaluating Contemporary Needs for Community Hepatitis Services in the ACT	

RESEARCH TEAM CONTACTS

Study team:	Dr Jane Koerner	[redacted]
	Mr John Didlick	(02) 6230 6344
	Ms Melanie Walker	(02) 6230 6344

STATEMENT OF CONSENT

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the ACT Hepatitis Board President on (02) 6230 6344 or email info@hepatitisACT.com.au if you have concerns about the ethical conduct of the project.
- Agree to participate in the project.

Name

Signature

Date

**A Comprehensive Needs Assessment –
Evaluating Contemporary Needs for Community Hepatitis Services in the ACT**

INTRODUCTION, INFORMATION AND CONSENT

My name is Jane Koerner and I am a researcher working with Hepatitis ACT to conduct a needs assessment for community hepatitis services in the ACT.

Hepatitis ACT is Canberra’s community hepatitis organisation, funded by ACT Health to deliver a comprehensive range of programs and services. These aim to prevent viral hepatitis transmission, reduce death and complications associated with viral hepatitis, and minimise the personal and social impacts.

This study is funded by ACT Health and its aim is to assist Hepatitis ACT and funding partners to better understand and respond to the contemporary information and support needs of people affected by hepatitis B and hepatitis C in the ACT.

The research team invites you to participate in confidential interviews as you have been identified as one of the following groups:

- People affected by hepatitis B and hepatitis C
- People working in key community organisations

THE INTERVIEW

The researcher will ask your personal and professional perspectives (not your organisation’s perspectives) about information and support for people with hepatitis B and hepatitis C in the ACT.

The participant information and consent form outlines the study, what is involved in participating, expected benefits and risks, how your privacy will be protected, and asks you for your consent to participate.

If you agree, the interview will be recorded for the purposes of analysis. If you prefer that the interview is not recorded, interview notes will be taken. Please note that we do not require any personal details. Details that can possibly identify you, such as your name, will be removed from interview transcription or notes, and will not be appear in any reports or papers about the study. You are free to pause the interview at any time by raising your hand.

Your participation in this project is entirely voluntary. If you agree to participate, you can withdraw from the project at any time without comment or penalty. Your decision to participate or not participate will in not impact upon your current or future relationship with Hepatitis ACT or ACT Health.

Do you have any questions about the format, informed consent, or any other question?

People affected by hepatitis B and hepatitis C:

- people living with hepatitis B and/or C
- people at risk of hepatitis B and/or C
- people from culturally and linguistically diverse backgrounds, particularly those from high prevalence countries and regions
- people with a history of injecting drug use
- Aboriginal and/or Torres Strait Islander people
- people with a history of detention in corrections settings
- families and friends of these groups, and
- workers in organisations whose clients include people living with or at risk of hepatitis B and/or C.

Where do people affected by hepatitis B and hepatitis C currently access information and support regarding hepatitis B and hepatitis C in the ACT?

What kind of information and support do they need?

What are the particular information and support needs for people accessing Direct Acting Antiviral treatments for hepatitis C?

- for priority populations
- for organisations working with priority populations

Are you satisfied with the information and support available for individuals and communities affected? How could these be improved?

What information and support gaps are there for people with hepatitis B and hepatitis C in the ACT?

Prompts:

- Do you think people know about services providing information and support?
- Why do you think people who need services don't use them?

Why do these gaps exist?

Do you have any ideas on how to improve information and support for people with and affected by hepatitis B and hepatitis C?

If a dedicated hepatitis community based service did not exist, could people with hepatitis B and hepatitis C adequately obtain information and support elsewhere?

Is there anything else that you like to say about information and support for people with hepatitis B and hepatitis C?

Prompts for areas of information/support – drawn from literature:

- Adequacy of community awareness resources
- Information on transmission – especially in regards to family and friends
- How to live with liver disease
- Treatment – how it will affect lifestyle and ability to work
- Testing

- Vaccination for hepatitis B
- Diagnosis
- Liver health
- Support for person with hepatitis B or hepatitis C, support for partner/family
- Stigma
- Disparity in services for people with hepatitis B and hepatitis C?
- Information and support for overseas born migrants
- Adequate information on the benefits of testing for migrants and people who have a history of IDU
- Culturally appropriate information and support, in particular peer support, for Aboriginal and Torres Strait Islander people
- How well is hepatitis B and hepatitis C information and support integrated into alcohol and other drug services
- Adequacy of specific information and support for people who have a history of IDU
- Healthy diet info
- Contact with others on treatment
- Phone contact during treatment
- Privacy during consultations
- Counselling during treatment
- More support post treatment
- Need for a variety of LGBTI specific services
- Need for online and group support groups

Thanks for your time.

Note:

Check with participant to see if they are distressed or in need of further support after the interview - provide them with the number for Lifeline or Hepatitis ACT and researcher and Hepatitis ACT email details.

Lifeline 13 11 14

Hepatitis ACT 6230 6344

Appendix 2: Table of findings of systematic review of literature on the information and support needs of people with hepatitis B and hepatitis C

Please see separate attachment, available at www.hepatitisACT.org.au.