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Findings of the Charting Health Impacts (CHI) Study

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Executive Summary

Hepatitis C virus infection is one of the most commonly notified communicable diseases in Australia. It has been estimated that more than 220,000 people live in Australia with chronic hepatitis C, including around 50,000 people experiencing moderate to severe liver disease as a result of the infection.

A hepatitis C diagnosis affects a wide range of physical, emotional and social aspects of life. The Charting Health Impacts (CHI) study was initiated by the Australian Research Centre in Sex, Health and Society (ARCSHS) in 2010 and aimed to document how people with hepatitis C respond to changes in health and social well-being over time, and to determine patterns of health and support service utilisation. While the study was initiated as a longitudinal cohort using an anonymous online survey, challenges with recruitment and resourcing meant that only one data set was produced. This report presents the initial findings of CHI including baseline data of the participants in this survey. Only limited analysis of the data has been conducted, and this data has been collated and presented given the need for social research investigating the experiences of people with hepatitis C.

Data was collected from 170 people with hepatitis C. Unlike estimates of the gender breakdown of people with hepatitis C in Australia, most people participating in the survey were women (62%). The median age of participants was 50 years, and ranged from 11 to 65 years with most born in Australia and living in Victoria, New South Wales or Queensland. Four participants (2%) reported being Aboriginal or Torres Strait Islanders. More than half the participants worked more than part-time while 20% were unable to work due to illness. Income for half of the participants was reported to be less than $600 per week.

In terms of general health and wellbeing, most men and women described their health as good (32%), very good (18%) or excellent (3%) with just over half (51%) reporting that their health did not limit moderate activities in a typical day. A greater proportion of older (>40 years; 51%) than younger people (≤40 years; 16%) described their general health as being fair or poor. Just over half (56%), with more women than men, reported accomplishing less than they would like over the previous four weeks due to their physical and/or mental health, with a comparable proportion reporting similar issues affecting their social life.

Just under half of the participants (49%), with a greater proportion of people older than 40 years of age (56%) reported other health conditions affecting their quality of life, with most conditions related to mental health issues including depression or anxiety (36%). A significantly higher proportion of younger (20%) than older (7%) participants believed their physical health was not worse as a result of hepatitis C infection. However, comparable proportions in two age groups (17% vs. 14%, respectively) believed that their mental health was not affected by hepatitis C. Less than one quarter (22%) of participants had stopped working or studying as a result of hepatitis C infection, while 31% felt that hepatitis C had no impact on their ability to work/study by hepatitis C. A significantly higher proportion of older (73%) than younger (48%) people reported that hepatitis C limited their ability to work/study.

The gap between hepatitis C infection and diagnosis ranged from 0 to 38 years with a median (IQR) of 12 (2-19) years. Most people (59%) believed that they had been infected with hepatitis C prior to 1990 while the greatest proportion (52%) was diagnosed between 1990 and 2000. Most participants (59%) reported the sharing or reusing injecting equipment as the probable route of their hepatitis C infection, with 8% of participants were unsure of how they were infected.

The majority of participants (57%) were initially diagnosed by a general practitioner and had not received any or only limited information about the infection when they were first diagnosed (61%). Pre-test and post-test discussion was reported to have occurred by 14% and 58% of participants, respectively, while 17% reported no discussion with their medical practitioner at the time of diagnosis. The proportion of people provided with information at diagnosis was greater when they were diagnosed after being tested by the Australian Red Cross Blood Service or at a sexual health service.

Just over one third of participants (38%) had been referred to a gastroenterologist or infectious diseases physician after their diagnosis, with 20% referred to a hepatitis organisation. Most participants (range: 62-91%) accessed services they had been referred too, within one year. Co-infection with HIV and hepatitis B were reported in 4.1% and 2.4% of participants, respectively.

Just over half of the participants (51%) were currently or had previously been treated for their hepatitis C. Of participants who had previously received medical treatment, 65% completed treatment among whom 55% had cleared the virus. For people not completing treatment, the most frequently reported reason was treatment failure (61%) and unmanageable treatment side effects (43%). Of the participants who had current or past experiences of hepatitis C treatment, 64% experienced treatment side effect with fatigue (89%) and sleep disturbance (84%) being the most common.

The most frequently reported barrier to treatment for people who had not been treated was of fear of side effects (59%). Complementary medicine was used by 40% of participants to treat or manage their hepatitis C. Most participants (89%) used some medical treatments to alleviate their treatment side effects while 65% used complementary or alternative therapies to do so. Non-prescription pain killers (73%) was the most commonly used medical treatments. Supplements (29%) and low impact exercises (27%) were the most commonly used complementary treatments. About 36% of participants using medical treatment versus 64% of participants using complementary treatment stated being very satisfied or somewhat satisfied with the treatments they used.

Background

The global hepatitis C prevalence has been estimated at 2–3%, which equates to 130–170 million people living with the infection.[1] Hepatitis C is one of the most commonly notified communicable diseases in Australia with an estimated prevalence approaching 1.4%,[2] and a diagnosis rate of 45.7 per 100 000 population in 2011. From 2002 to 2011, hepatitis C notifications declined by 72%, 60% and 45% in the 15-19 year, 20–29 year, and 30-39 year age groups, respectively.[2] In spite of this decline, the high chronicity rate of the virus contributes to an increasing population prevalence with about 75% of people initially infected experiencing a chronic or lifelong infection without treatment.[3, 4] Approximately 15-20% of people with a chronic infection will progress to liver cirrhosis within 20 years of exposure with up to 10% of these people developing hepatocellular carcinoma.[1]

The experience of living with hepatitis C is largely determined by different life circumstances over a life time. For example, some people may have become infected decades prior to their diagnosis and may no longer identify with the particular risk factors that may have been associated with their initial exposure. This may present a barrier to accessing ongoing support if and when required and ultimately affect quality of life. The social and personal impacts for someone more recently diagnosed with hepatitis C is likely to be greater than for someone accommodated to having received a diagnosis some time ago.

The consequences of hepatitis C infection for individuals can be severe. The impact on health and wellbeing and the effective management of infection can require people with hepatitis C to make significant changes their lifestyle, such as reducing hours of work and modifying behaviours to lower the risk of infecting others particularly through the sharing of injecting equipment.[5] The social implications of infection with hepatitis C often result from disclosure of infection, with widespread reports of discrimination resulting from the relationship between hepatitis C and injecting, and the stigmatisation and marginalisation of people who inject drugs.[6, 7] Disclosure of hepatitis C status can result in alienation from family and friends as well as discrimination in health services and workplaces.[8]

Treatments are available for hepatitis C, but uptake remains low across the country with only 1.4% of people with hepatitis C receiving treatment by the end of 2006.[9] This low uptake is thought to be related to the sometimes debilitating side effects associated with interferon-based therapies, long duration of treatment (six to 12 months) and uncertainty about treatment outcome.[10, 11] An overall increasing trend in treatment uptake was reported for patients who were dispensed anti-viral treatment since 2003 with a further sharp increase following the removal of the requirement for biopsy-proven liver damage in April 2006.[9] However, the proportion of people with hepatitis C on treatment is still low with the estimated number of people on treatment slightly increasing from about 3500 in 2007 to 3800 in 2010,[12] indicating that liver biopsy was not the only barrier for receiving treatment. The rapid development of new antiviral therapies for hepatitis C infection has resulted in considerable optimism, with the realistic hope that therapeutic interventions will soon be more effective, better tolerated and shorter in duration than current therapies.[13]

There are several ‘extrahepatic’ manifestations (causing such symptoms as painful joints and muscles, skin disorders and kidney disease) noted in chronic infection [5, 14, 15] and significantly reduced health status has been found in chronically infected populations irrespective of clinical signs and stage of disease progression.[16-19]

The vast majority of people with hepatitis C will grow old with the infection. The CHI (Charting Health Impacts) study describes the impact of hepatitis C on everyday lives of people living with hepatitis C including their health, work and family situations. In addition it investigates how people living with hepatitis make decisions about their health including decisions about treatment; management of treatment side effects; and the use of complementary therapies.

Study design

The CHI study was led by Investigators from the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University and included:

- Dr Stephen McNally
- Prof Marian Pitts
- Dr Emma Miller
- Jack Wallace
- Prof Anthony Smith
- Jen Johnson

Community and stakeholder consultation

A study reference group was established to oversee the study with its membership from ARCSHS and representatives of peak organisations and others with community, clinical and research expertise in hepatitis C. A complete list of the reference group is attached as Appendix A.

The survey instrument and recruitment strategies were developed in consultation with government and community stakeholders around Australia. Organisations involved in the consultation included the national, state and territory Hepatitis Councils, peer-based injecting drug user groups, as well as agencies providing health and support services to the affected community in each jurisdiction. State and Territory Government health sectors provided comments on the study development, as did peak national bodies such as the Australasian Society for HIV Medicine (ASHM), the Australian National Council on Drugs (ANCD), Hepatitis Australia and the Australian Injecting and Illicit Drug Users League (AIVL).

Promotional material for the study was developed in consultation with stakeholders and reference group, and disseminated through:

1. Community based organisations including Hepatitis Councils and peer based injecting drug user organisations in each state and territory
2. Clinical and other health services, including sexual health services, drug and alcohol services, needle and syringe programs, refugee health services and liver clinics

3. General practitioners with a high hepatitis C case load
4. Indigenous health organisations including Aboriginal and Torres Strait community controlled health organisations throughout Australia
5. Community based organisations representing people from culturally and linguistically diverse backgrounds

The questionnaire was available to be completed by anyone 18 years or over, with a hepatitis C diagnosis and access to the internet to complete the online survey. Promotional material was disseminated through organisational mail-outs; web-site advertisements, and through email lists with participants directed to the "CHI Study" web address. The first page of the on-line survey website provided detailed information about the study including the voluntary nature of participation, confidentiality and a tick box confirming the consent of the participant to participate in the study.

Instrument Design

The survey was presented in four parts.

The first part of the survey included questions seeking information about the demographic and background characteristics of study participants including gender, age, place of birth, education, accommodation, employment and income.

The second part sought information on participants' views of their general health using the Australian adapted version of the SF-12v2™.[20] This is a shorter alternative to the SF-36® Health Survey form, a validated form measuring eight domains of health including general health perceptions, physical functioning, role limitations due to physical health, role limitations due to emotional problems, bodily pain, vitality, mental health, and social functioning.[21]

The third and the fourth parts of the instrument asked for participants perspectives on diagnosis and treatment, including the year of initial diagnosis, pre- and post-test discussion at the time of diagnosis, probable hepatitis C transmission route, experiences of any medical and/or complementary treatments for hepatitis C, treatment outcomes and side effects.

Ethics

Ethics approval was sought and obtained from the following Ethics Committees:

- La Trobe, FHEC10/19
- Tasmania Health and Medical Research, HREC: EC00337
- St Vincent’s Hospital, Victoria, HREC A EC00344
- Monash Medical Centre, Southern Health HREC EC00382
- Queensland Health, HREC/10/QGC/95
- Mater Medical Research Institute, HREC protocol Ref No: 1817QA
- Cairns Base Hospital, HREC/10/QGC/95
- Toowoomba Hospital, HREC:EC00182
- Rockhampton Base Hospital, EC00173
- Townsville Hospital, Townsville Health Service District, HREC EC00183
- Mackay Base Hospital, HREC/10/QGC/95
- Concord Repatriation Hospital, Ec00118
- Royal Prince Alfred Hospital, EC00113
- John Hunter Hospital, New England Area Health Service EC00403
- Coffs Harbour (Mid) North Coast Area Health Service, HREC EC00415
- Royal Adelaide Hospital, RAH protocol No 110510
- Flinders Medical Centre Number, 372.11
- Queen Elizabeth Hospital, Government of South Australia, HREC (TQEH/LMH/MH)

Analysis

Data were collected in an electronic database with collected data cleaned, removing records with all blank cells and also duplicated records. Statistical comparisons between various groups were conducted using chi-square for categorical variables and student T test for continuous variables. All significant differences reported had a probability of $\alpha<0.05$. All analyses were conducted using IBM® SPSS® Statistics version 20.

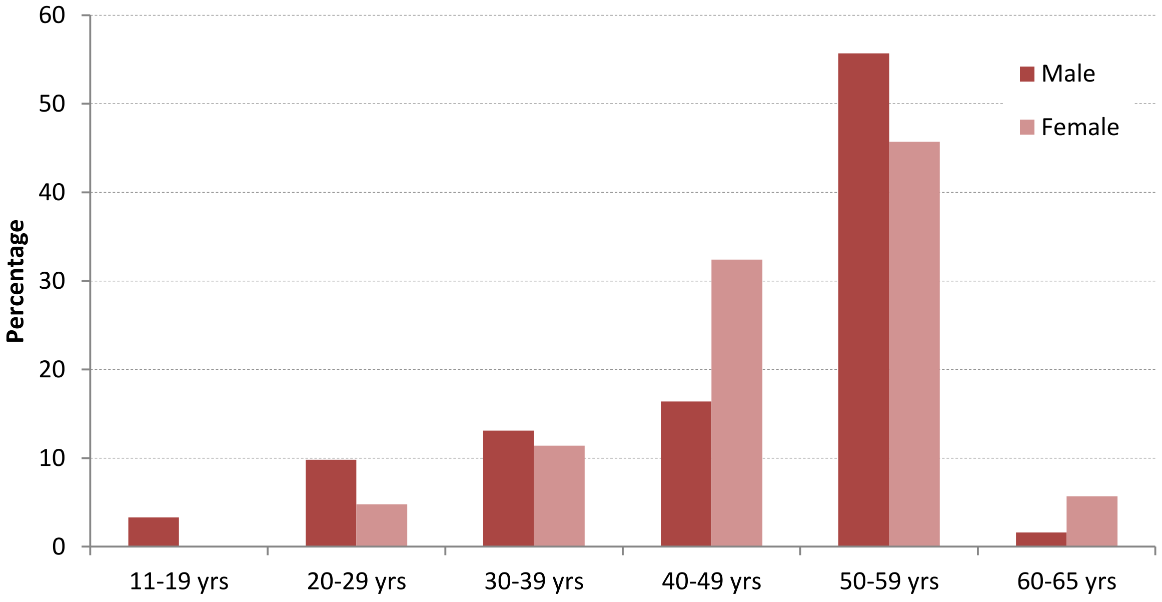
Findings

Section 1: Who participated?

Two hundred and three individuals completed the online survey. After removing records with all blank cells and duplicates, the data of 170 participants was available for analysis.

The participant population consisted of 106 (62.4%) women, 61 (35.9%) men and 3 (1.8%) transgender or transsexual. Participants' age ranged from 11 to 65 years with a mean (SD) of 47.6 (10.1) years and a median (IQR) of 50.0 (41.5-55.0) years. Mean (SD) age among men and women was 46.0 (11.7) years and 48.4 (9.2) years, respectively. The mean age difference between men and women was not statistically significant (*P*=0.170). More information about age distribution is shown in Figure 1.

Figure 1: Age distribution among men and women

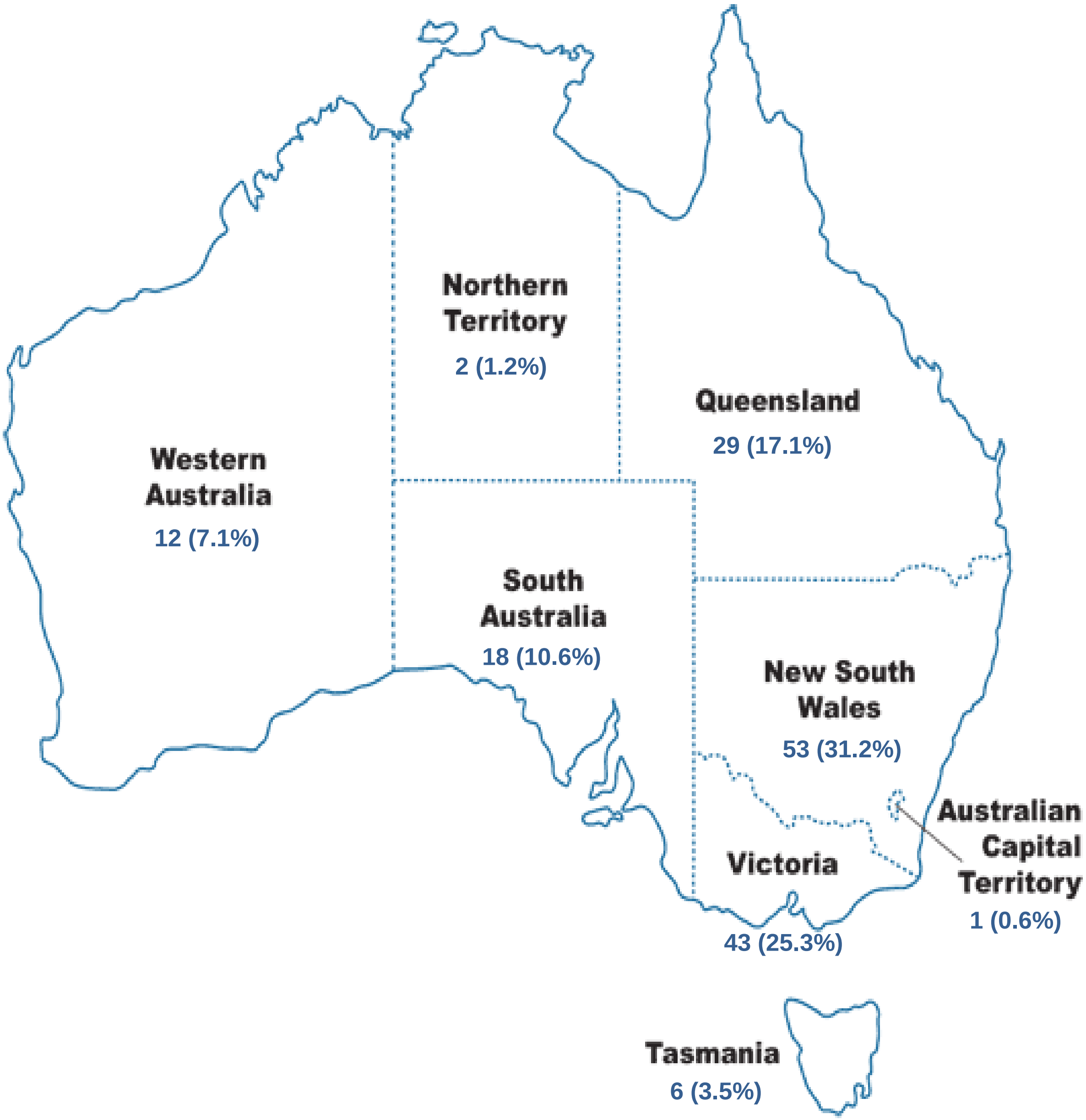


Most participants (n=131; 77.1%) were born in Australia and a higher proportion of participants (n=166; 97.6%) spoke mainly English at home. Among 38 people born outside Australia, most (n=20; 52.6%) were born in Europe with others born in New

Zealand (n=7; 18.4%), North America (n=6; 15.8%), and South-East Asia (n=4; 10.5%). Four participants (2.4%) indicated they were Aboriginal or Torres Strait Islanders.

The majority of participants (n=125; 73.5%) lived in NSW, Victoria or Queensland (Figure 2). Six participants (3.5%) did not specify their state of residence.

Figure 2: State or Territory distribution of participants' residence



The education levels of the participants are summarized in Table 1 with over 38% of participants reporting having a university degree.

Table 1: Participants' highest educational levels

Educational level	**Frequency** *total n = 170*	**Percent**
Primary school	2	1.2
Middle high school (Year 10)	22	12.9
High school	25	14.7
Diploma or Certificate	55	32.4
Undergraduate Degree	29	17.1
Post-graduate Degree	35	20.6
Not specified	2	1.2

Forty one participants (24.1%) lived alone, while others lived with partner/spouse, dependent children, other family members, or flatmate/friend. Most participants (n=131; 77.0%) were paying rent or board, or paying off their own flat/house. The other participants owned their home outright (16.5%), were living rent/board free (4.1%), or had no fixed address (1.2%).

The employment and study situations of participants are summarized in Table 2. Participants were allowed to choose more than one response if applicable.

Table 2: Distribution of participants' employment or study status

Employment/study status	**Frequency** *total n = 170*	**Percent**
Employed full time	54	31.8
Employed part time	44	25.9
Studying full time	10	5.9
Studying part time	18	10.6
Home duties	22	12.9
Volunteer work	17	10.0
Retired	6	3.5
Unemployed	9	5.3
Unable to work due to illness	34	20.0
Actively looking for work	10	5.9
Not currently looking for work	3	1.8
Not specified	4	2.4

Participants were asked to indicate their weekly after-tax ('in hand') income, adding up their income from all sources, i.e., wages, pensions/benefits, shares and/or pocket money. The results are summarized in Table 3. Weekly income of 85 participants (50.0%) was less than $600.

Table 3: Distribution of participants' weekly income

Weekly income	**Frequency** *total n=170*	**Percent**
Less than $300	26	15.3
$300 to $399	26	15.3
$400 to $599	33	19.4
$600 to $799	26	15.3
$800 to $1099	26	15.3
$1100 or more	21	12.4
Not specified	12	7.1

Section 2: General health & Wellbeing

The first 12 questions within this section were based on the SF-12v2 Health Survey.

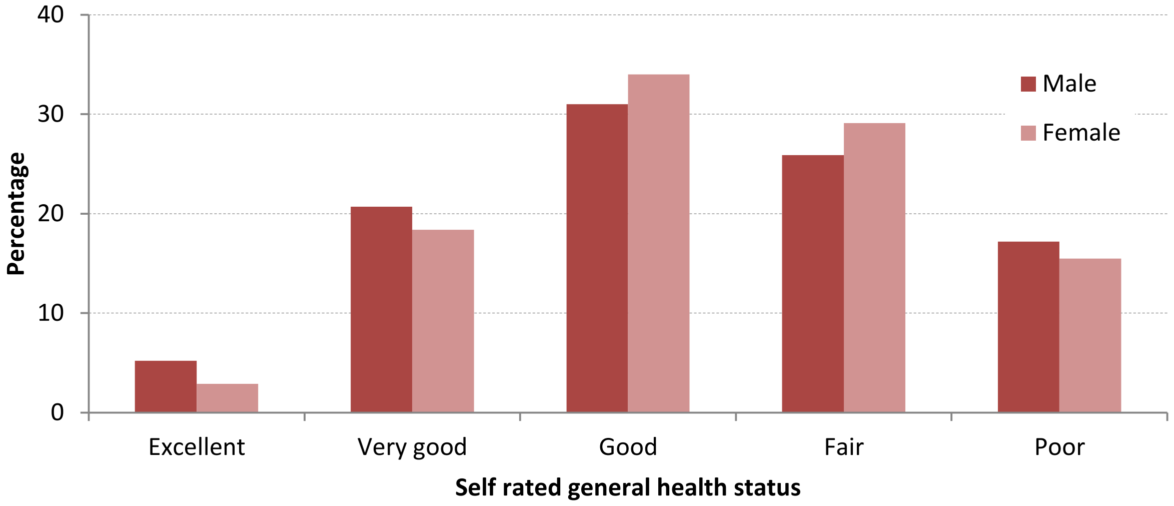
Ninety one participants (53.5%) described their general health as excellent, very good or good while 73 participants (42.0%) rated their health as fair or poor (Table 4).

Table 4: Participants' rating of general health status

General health status	**Frequency** *total n=170*	**Percent**
Excellent	6	3.5
Very good	31	18.2
Good	54	31.8
Fair	47	26.7
Poor	26	15.3
Not specified	6	3.5

Analysis among men and women who responded this question (Figure 3) indicated that 56.9% of men (n=33) and 55.3% of women (n=57) described their general health as excellent, very good or good while 43.1% of men (n=25) and 44.7% of women (n=46) described their general health as fair or poor. The difference between two gender groups was not statistically significant (*P*=0.849).

Figure 3: Respondents' rating of general health status, by gender



Age specific analysis among respondents equal or younger than 40 compared to those older than 40 (Figure 4) indicated that a higher proportion in the younger (84.4%; n=27) compared to the older group (48.5%; n=64) described their general health as excellent, very good or good. However, 15.6% of the younger group (n=5) compared to 51.5% of older group (n=68) described their general health as fair or poor. The difference between two age groups was highly significant (*P*<0.001).

Figure 4: Respondents' self rating of general health status, by age

About half of participants reported that their health did not limit moderate activities in a typical day, while 30% noticed slight limits and 14% noticed their health limited their activity a lot (Table 5).

Table 5: Participants' self rating of limitations in a typical day

	n (%) *total n = 170*			
	Yes, limited a lot	Yes, limited a little	No, not limited at all	No response
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	24 (14.1)	52 (30.6)	87 (51.2)	7 (4.1)
Climbing several flights of stairs	37 (21.8)	56 (32.9)	70 (41.2)	7 (4.1)

Ninety five participants (55.9%) reported accomplishing their work or daily activities less than they would like due to their physical health at least some of the time during the four weeks prior to completing the survey (Table 6).

Table 6: Participants' self rating of limitations in daily activities as a result of physical health during previous four weeks

	n (%) *total n = 170*					
	All of the time	Most of the time	Some of the time	A little of the time	None of the time	No response
Accomplished less than you would like	13 (7.6)	29 (17.1)	53 (31.2)	32 (18.8)	35 (20.6)	8 (4.7)
Were limited in the kind of work or other activities	15 (8.8)	25 (14.7)	45 (26.5)	33 (19.4)	44 (25.9)	8 (4.7)

Similar to that reported for limits to activity due to physical health, 54.8% of participants (n=93) reported that they accomplished less due to emotional problems at least some of the time during the last four weeks before completing the survey (Table 7).

Table 7: Participants' self rating of limitations in daily activities as a result of emotional challenges during previous four weeks

	n (%) *total n = 170*					
	All of the time	Most of the time	Some of the time	A little of the time	None of the time	No response
Accomplished less than you would like	4 (2.4)	35 (20.6)	54 (31.8)	37 (21.8)	31 (18.2)	9 (5.3)
Did work or other activities less carefully than usual	4 (2.4)	23 (13.5)	50 (29.4)	43 (25.3)	39 (22.9)	11 (6.5)

Normal work was not interfered with by pain for 32.9% of participants (n=56). However, in 24.7% (n=42) pain interfered normal work a little bit, while for 18.8% (n=32), 13.5% (n=23), and 4.7% (n=8) pain interfered their normal work moderately, quite a bit, and extremely.

Among participants, 62.9% (n=107) felt calm and peaceful and 46.5% (n=79) had a lot of energy at least some of the time during the four weeks prior to completing the survey. In contrast, 54.7% (n=93) felt downhearted and depressed at least some of the time during the same period (Table 8).

Table 8: Participants' rating of feelings during previous four weeks

	n (%) *total n = 170*					
	All of the time	Most of the time	Some of the time	A little of the time	None of the time	No response
Have you felt calm and peaceful?	5 (2.9)	43 (25.3)	59 (34.7)	48 (28.2)	7 (4.1)	8 (4.7)
Did you have a lot of energy?	3 (1.8)	28 (16.5)	48 (28.2)	48 (28.2)	7 (4.1)	9 (5.3)
Have you felt downhearted and depressed?	6 (3.5)	27 (15.9)	60 (35.3)	47 (27.6)	21 (12.4)	9 (5.3)

Just over one quarter (25.3%) of participants (n=43), reported that physical or emotional health problems had not interfered with their social life in the 4 weeks prior to completing the survey, while 28.8% (n=49) said that their health problems interfered their social life some of the time during this time period.

The descriptive score statistics for all the SF-12v2 components among all participants are summarized in Table 9. The mean row scores are also shown disaggregated by gender and age groups in Table 10 and Table 11, respectively.

Table 9: Item description and mean score for the SF-12v2 items (total participants)

SF-12v2 item	Mean row scores (SD)
Health rating in general (General Health)*	3.3 (1.1)
Limitations in moderate physical activities (Physical Functioning)**	2.4 (0.7)
Limitations in climbing several flights of stairs (Physical Functioning)**	2.2 (0.8)
Accomplished less due to physical health (Role-Physical)**	3.3 (1.2)
Limited in kind of work or activities due to physical health (Role-Physical)**	3.4 (1.3)
Accomplished less due to emotional problems (Role-Emotional)**	3.3 (1.1)
Less careful in work or activities due to emotional problems (Role-Emotional)**	3.6 (1.1)
Pain interference with work inside or outside home (Body Pain)*	2.3 (1.2)
Feel calm and peaceful (Mental Health)*	3.1 (0.9)
Having a lot of energy (Vitality)*	3.5 (1.1)
Feel downhearted and blue (Mental Health)**	3.3 (1.0)
Interference of physical health or emotional problems with social activities (Social Functioning)**	3.3 (1.3)

* Lower scores indicate better condition

** Higher scores indicate better condition

Mean scores of one item in the physical functioning domain were significantly lower in women compared to men showing women being less able to accomplish work or other activities due to physical health.

There was significant difference between men and women in mean scores of one item in the role-emotional domain which asked if participants were less careful in work/activities due to emotional problems. Mean scores of this item were significantly lower in women compared to men, indicating more self-perceived limitations among women. Marginal but non-significant differences were observed between men and women regarding one vitality item asking about having a lot of energy, and with one social functioning item asking if physical health or emotional problems interfered with social activities. In both items, women showed more self-perceived limitations compared to men (Table 10).

Table 10: Mean scores for the SF-12v2 items among men and women

SF-12v2 item	Mean row scores (SD)		*P* value
	Men	Women	
Health rating in general (General Health)*	3.3 (1.1)	3.4 (1.0)	0.710
Limitations in moderate physical activities (Physical Functioning)**	2.5 (0.7)	2.3 (0.7)	0.161
Limitations in climbing several flights of stairs (Physical Functioning)**	2.3 (0.8)	2.2 (0.8)	0.219
Accomplished less due to physical health (Role-Physical)**	3.6 (1.1)	3.1 (1.2)	0.009
Limited in kind of work or activities due to physical health (Role-Physical)**	3.6 (1.3)	3.3 (1.3)	0.178
Accomplished less due to emotional problems (Role-Emotional)**	3.5 (1.1)	3.2 (1.1)	0.118
Less careful in work or activities due to emotional problems (Role-Emotional)**	3.8 (1.0)	3.4 (1.1)	0.028
Pain interference with work inside or outside home (Body Pain)*	2.1 (1.2)	2.3 (1.2)	0.295
Feel calm and peaceful (Mental Health)*	2.9 (1.0)	3.1 (0.9)	0.339
Having a lot of energy (Vitality)*	3.3 (1.0)	3.6 (1.1)	0.072
Feel downhearted and blue (Mental Health)**	3.3 (1.1)	3.3 (1.0)	0.964
Interference of physical health or emotional problems with social activities (Social Functioning)**	3.6 (1.2)	3.2 (1.3)	0.075

* Lower scores indicate better condition

** Higher scores indicate better condition

The mean score in the general health item was significantly lower in participants 40 years and younger, compared to the people older than 40. This indicates that younger participants had a better opinion of their general health compared to older participants. Significant differences between two age groups were observed in mean score of all items in physical functioning and role-physical domain indicating more self-perceived limitations due to physical health in older participants compared to younger participants.

No significant difference was found between the two age groups regarding mean scores in items of role-emotional, mental health and social functioning domains. There was however a significant difference between the two age groups in mean scores in body pain indicating more limitations due to pain perceived by older participants compared to younger ones (Table 11).

Table 11: Mean scores for SF-12v2 items among people younger and older than 40 years.

SF-12v2 item	Mean row scores (SD)		*P* value
	≤ 40 yrs	> 40 yrs	
Health rating in general (General Health)*	2.8 (0.8)	3.5 (1.1)	<0.001
Limitations in moderate physical activities (Physical Functioning)**	2.8 (0.5)	2.3 (0.7)	<0.001
Limitations in climbing several flights of stairs (Physical Functioning)**	2.6 (0.6)	2.1 (0.8)	0.001
Accomplished less due to physical health (Role-Physical)**	3.7 (1.0)	3.2 (1.2)	0.021
Limited in kind of work or activities due to physical health (Role-Physical)**	3.8 (1.0)	3.3 (1.3)	0.026
Accomplished less due to emotional problems (Role-Emotional)**	3.5 (1.0)	3.3 (1.1)	0.444
Less careful in work or activities due to emotional problems (Role-Emotional)**	3.7 (1.1)	3.5 (1.1)	0.575
Pain interference with work inside or outside home (Body Pain)*	1.7 (0.9)	2.4 (1.2)	>0.001
Feel calm and peaceful (Mental Health)*	2.8 (0.9)	3.1 (0.9)	0.148
Having a lot of energy (Vitality)*	3.1 (1.0)	3.6 (1.0)	0.016
Feel downhearted and blue (Mental Health)**	3.4 (1.0)	3.3 (1.0)	0.964
Interference of physical health or emotional problems with social activities (Social Functioning)**	3.6 (1.1)	3.3 (1.3)	0.129

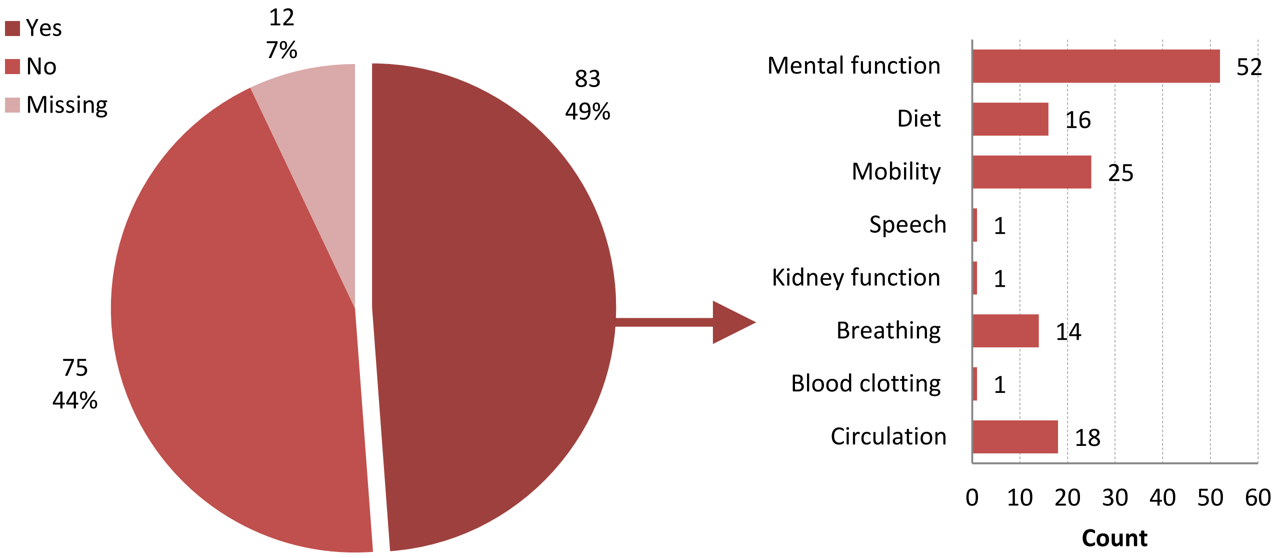
* Lower scores indicate better condition

** Higher scores indicate better condition

Eighty three participants (48.8%) reported health conditions apart from hepatitis C affecting their quality of life with the most common conditions related to mental functioning in 62.7%, mobility in 30.1%, and blood circulation in 21.7% (Figure 5).

No significant difference was found between men and women in their ongoing health conditions (53.6% vs. 51.5%, respectively; *P*=0.806). However, a higher proportion of participants older than 40 (56.2%) compared to those equal/younger than 40 (43.8%) reported co-morbidities with marginally significant difference between two age groups (*P*=0.053).

Figure 5: Frequency of ongoing health conditions or disabilities other than hepatitis C, affecting quality of life (total participants)*



* Examples of health conditions included:

- *Mental function: (e.g. due to depression or anxiety)*
- *Diet (e.g. due to diabetes or other metabolic disease)*
- *Mobility (e.g. due to injury or difficulty apparent since birth)*
- *Speech (e.g. due to stroke or head injury)*
- *Kidney function (e.g. due to renal colic/stones, renal failure)*
- *Breathing (e.g. due to asthma or chronic obstructive airway disease)*
- *Blood clotting (e.g. due to haemophilia or von Willibrands disease)*
- *Circulation (e.g. due to high blood pressure, angina or other heart condition)*

Mental health issues were the most common condition reported in 36.5% (Table 12). Co-infection with HIV and hepatitis B were reported in 4.1% and 2.4% of participants, respectively.

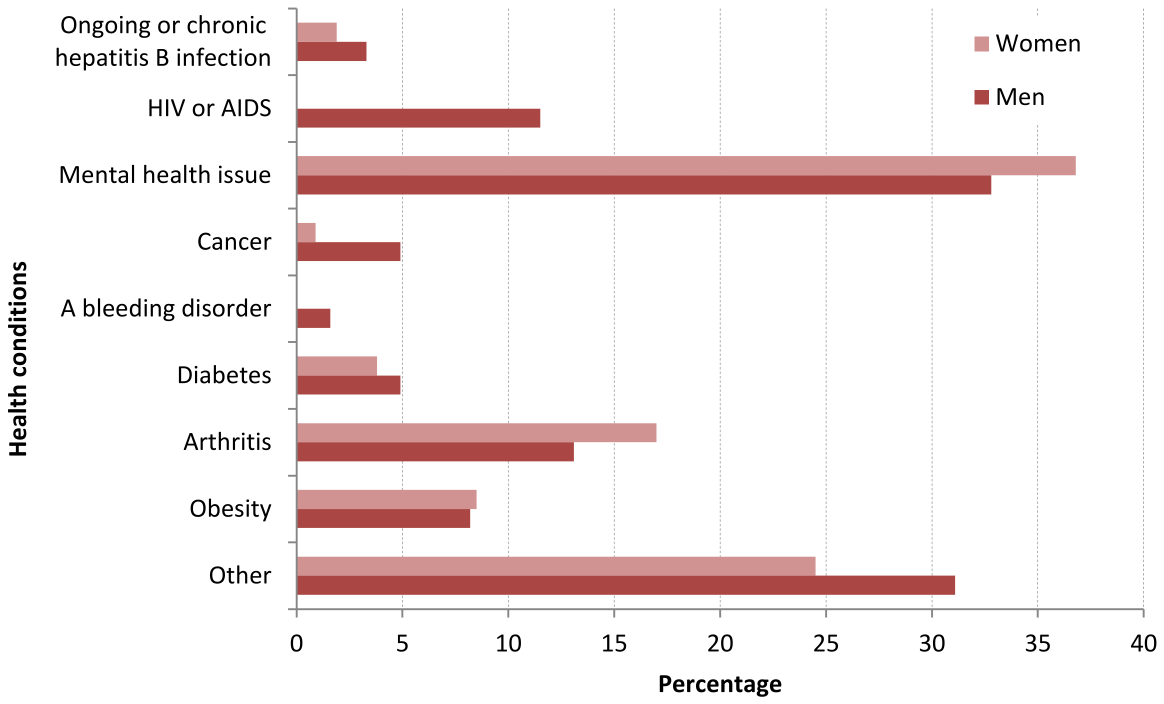
Table 12: Frequency of diagnosed health conditions other than hepatitis C

Health condition	**Frequency** *total n=170*	**Percent**
Ongoing or chronic hepatitis B infection	4	2.4
HIV or AIDS	7	4.1
Mental health issue	62	36.5
Cancer	4	2.4
A bleeding disorder	1	0.6
Diabetes	8	4.7
Arthritis	26	15.3
Obesity	15	8.8
Other	45	26.5

Findings disaggregated by gender and age are summarised in Figure 6 and 7, respectively.

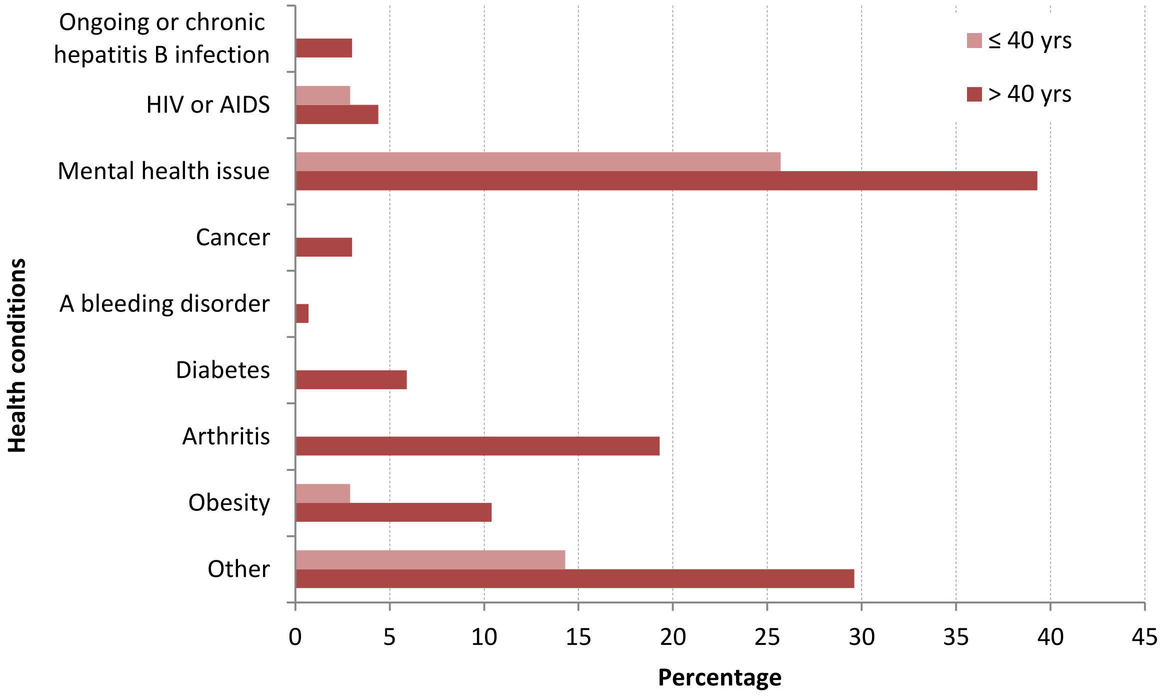
In gender specific analysis (Figure 6) comparing men (n=61) and women (n=106), co-infection with HIV was the only health condition significantly more prevalent among men (11.5%) compared to women (0%; *P*=0.001). The differences between two genders were not statistically significant in the other conditions.

Figure 6: Frequency of diagnosed health conditions other than hepatitis C, by gender



Age specific analysis (Figure 7) among participants 40 years old or younger (n=35) compared to participants older than 40 (n=135) indicated that all co-morbidities were observed more frequently among older group compared to the younger group. However, arthritis was the only health condition significantly more prevalent among older group (19.3%) compared to the younger group (0%; *P*=0.005). The differences between two age groups were not statistically significant in most conditions, most probably due to the limited sample size and consequent low power.

Figure 7: Frequency of diagnosed health conditions other than hepatitis C, by age



While 10% and 15% of participants respectively believed that their physical and mental health was not affected by hepatitis C, 50% noticed a negative impact on their general health as a result of their hepatitis C infection (Table 13). It should be noted that there was a relatively high proportion of missing data for this question (13.5%).

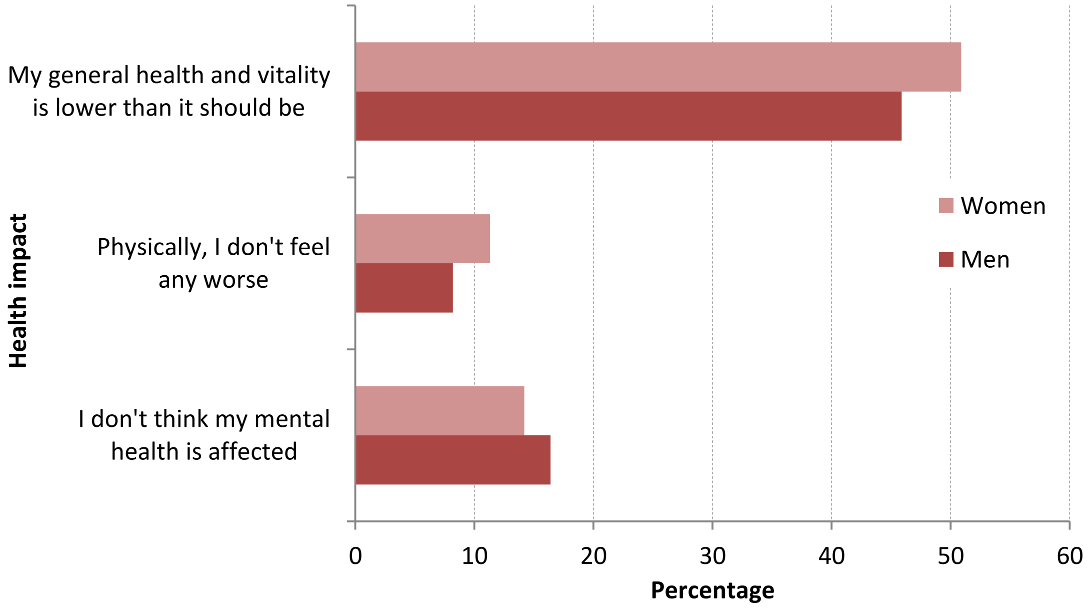
Table 13: Impact of hepatitis C on participants' health*

	Frequency *total n=170*	**Percent**
My general health and vitality is lower than it should be	85	50.0
Physically, I don't feel any worse	17	10.0
I don't think my mental health is affected	25	14.7

* Twenty-three participants (13.5%) did not answer the question

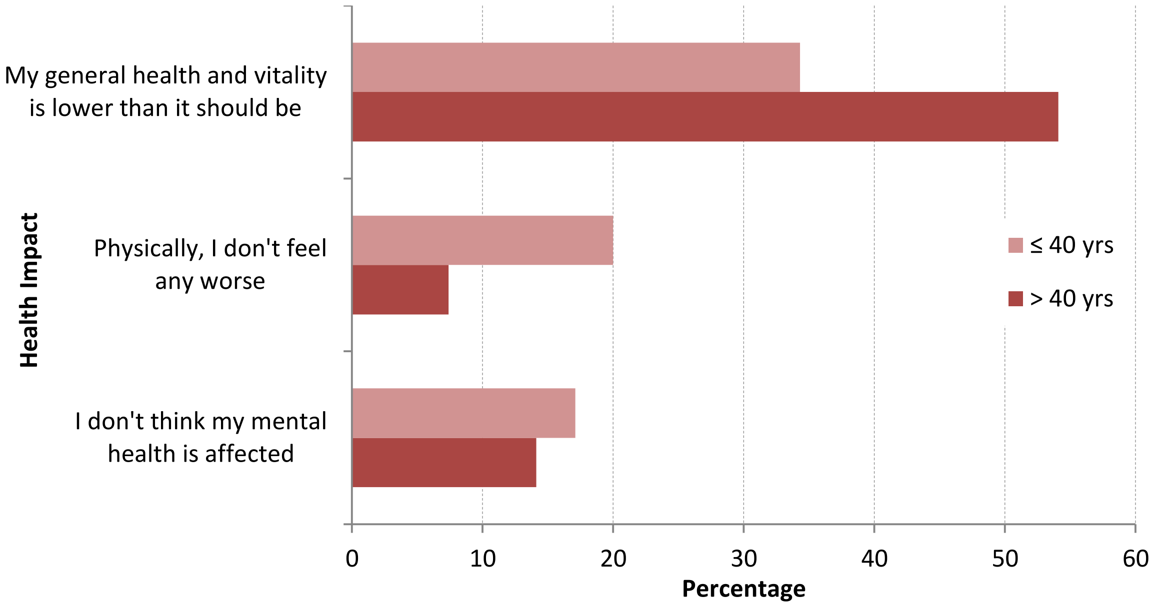
In a gender specific analysis, there were no significant differences between men and women in any items (Figure 8).

Figure 8: Impact of hepatitis C on participants' health, by gender



In age-specific analysis (Figure 9), 34.3% of participants in the younger group versus 54.1% in older group believed that their general health and vitality were lower than it should have been. This difference was marginal (*P*=0.074). Significantly, a higher proportion of participants in the younger group (20.0%) compared to those in the older group (7.4%) believed that their physical health was not worse (*P*=0.013) as a result of their hepatitis C infection. In contrast, comparable proportions in the two age groups (17.1% vs. 14.1%, respectively) believed that their mental health was not affected by hepatitis C (*P*=0.489).

Figure 9: Impact of hepatitis C on participants' health, by age



Around 22% of participants had stopped working/studying while about 31% felt no impact on their ability to work/study as a result of hepatitis C (Table 14). A high proportion of missing data (28.8%) should be considered in interpreting the results of this question.

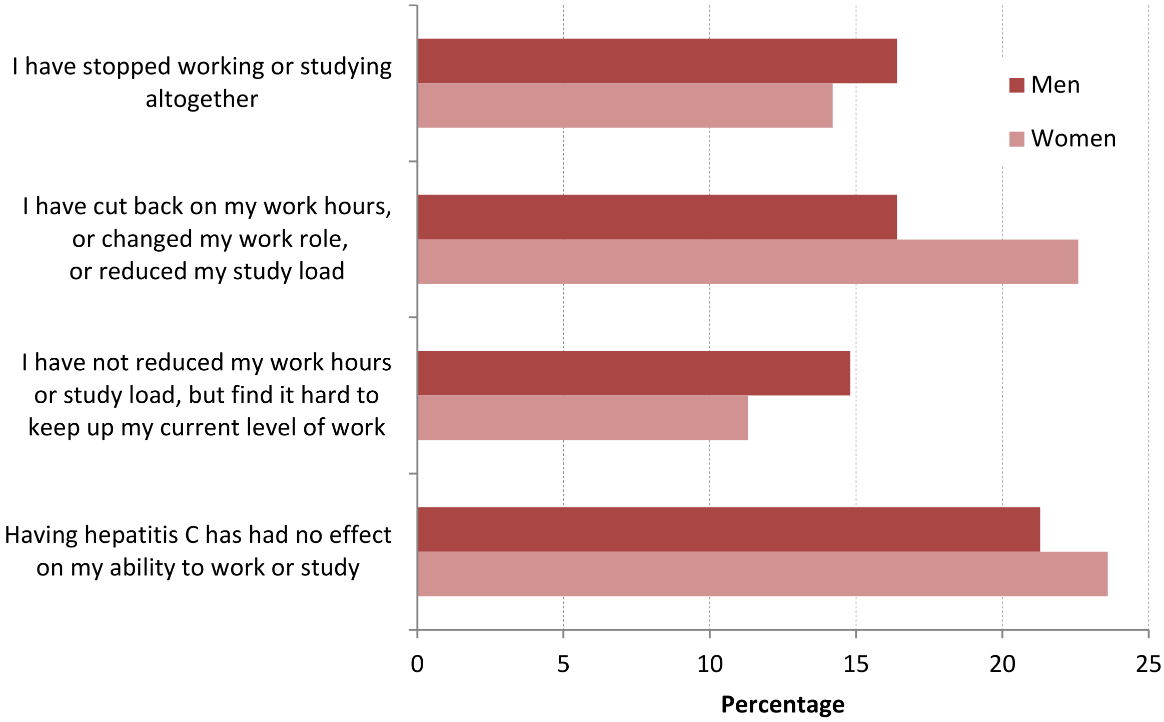
Table 14: The impact of hepatitis C on participants ability to work or study*

	Frequency *total n=170*	**Percent**
I have stopped working or studying altogether	27	22.3
I have cut back on my work hours, or changed my work role, or reduced my study load	35	28.9
I have not reduced my work hours or study load, but find it hard to keep up my current level of work	21	17.4
Having hepatitis C has had no effect on my ability to work or study	38	31.4

* Forty nine participants (28.8%) did not answer the question

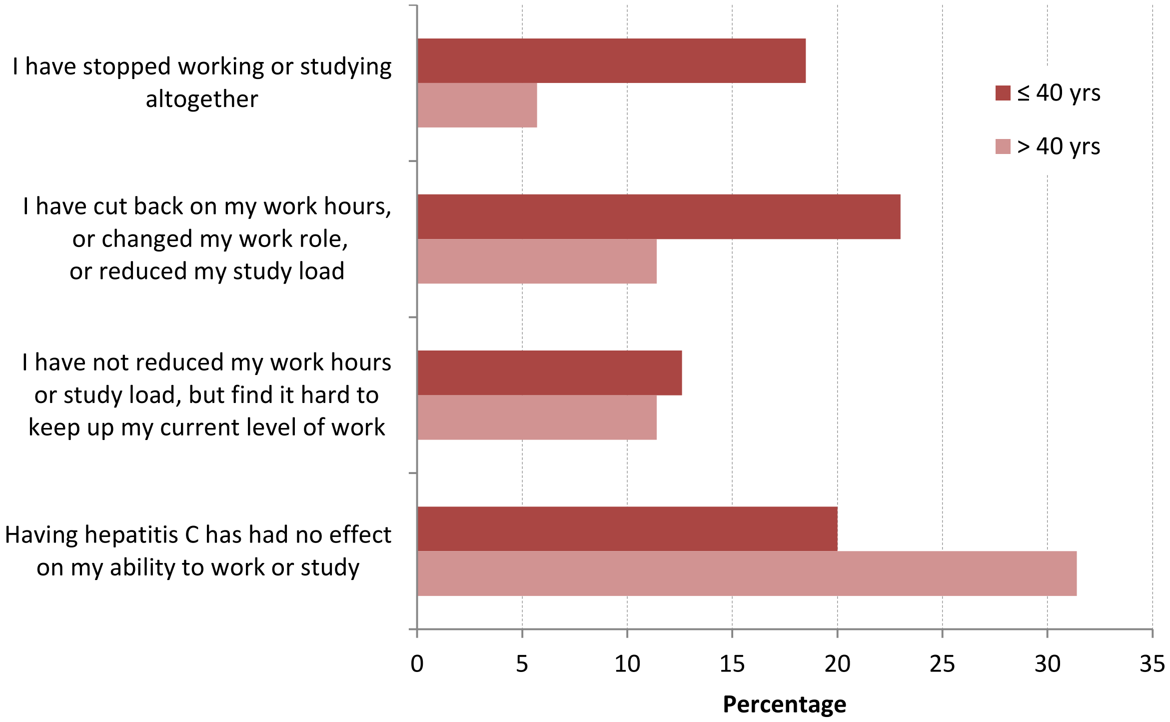
Findings disaggregated by gender are summarised in Figure 10. In general, 69.0% of men compared to 67.1% of women reported a negative impact of hepatitis C on their ability to work/study to some extent, but the difference was not statistically significant (*P*=0.829).

Figure 10: The impact of hepatitis C on participants' ability to work or study, by gender



In age specific analysis (Figure 11), a significantly higher proportion of respondents in the older group compared to those in the younger group reported that hepatitis C to some extent limited their ability to work or study (73.0%vs. 47.6%, respectively; *P*=0.023).

Figure 11: The impact of hepatitis C on participants' ability to work or study, by age



Section 3: Hepatitis C diagnosis

While most participants (58.8%) believed that they had been infected with hepatitis C prior to 1990, the majority were diagnosed with hepatitis C after 1990 with the highest proportion (51.7%) diagnosed between 1990 and 2000 (Table 15). Participants were able to nominate receiving a non-A non-B hepatitis diagnosis if tested before the availability of hepatitis C diagnostic testing.

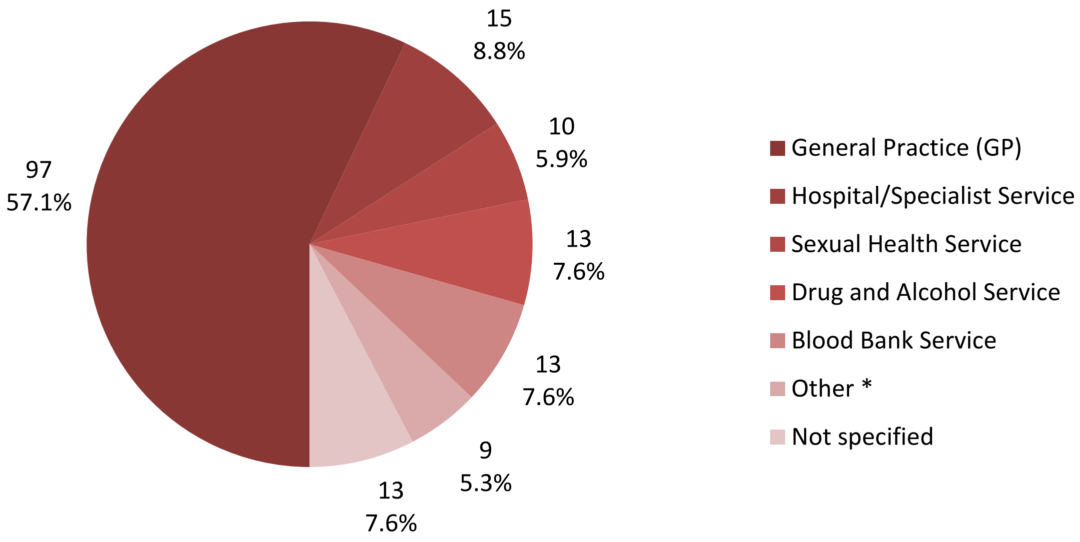
The gap between hepatitis C infection and diagnosis ranged from 0 to 38 years with a mean (SD) of 12.6 (10.3) years and a median (IQR) of 12.0 (2.0-19.0) years. There was a longer than two-year gap between hepatitis C infection and diagnosis among most participants (n=107; 62.5%). Twenty-one participants (12.4%) were diagnosed in the same year of infection, and 39 (23.0%) diagnosed within two years since infection acquisition (missing data in 24 participants (14.1%)).

Table 15: Self report of when diagnosed, and when infected with hepatitis C.

Year	**Date infected (est) n (%)** *total n=170*	**Diagnosed n (%)** *total n=170*
Before 1990	100 (58.8)	9 (5.3)
1990-1995	12 (7.1)	56 (32.9)
1996-2000	18 (10.6)	32 (18.8)
2001-2005	8 (4.7)	19 (11.2)
After 2005	9 (5.3)	41 (24.1)
Not specified	23 (13.5)	13 (7.6)

Most participants (57.1%) were first diagnosed with hepatitis C by a General Practitioner (GP) (Figure 12).

Figure 12: Location of hepatitis C diagnosis



* 'Other' included 'Indigenous Health Service', 'Prison', 'Women's Health Centre', 'Community Health Services', 'Rehab facilities', and 'Insurance policy blood test'.

More than half of participants (61.2%) reported receiving hardly any or no information at the time of being diagnosed (Table 16).

Table 16: Level of information received by participants when diagnosed with hepatitis C

	Frequency *total n=170*	**Percent**
I received a lot of information	10	5.9
I received some information	38	22.4
I received hardly any information	52	30.6
I did not receive any information	52	30.6
I don't remember	6	3.5
Not specified	12	7.1

The level of information received by participants at the time of hepatitis C diagnosis varied with the service making the diagnosis. The proportion of participants receiving 'a lot of information' or 'some information' was 90.0% (n=9) in participants diagnosed in Sexual Health services, 53.8% (n=7) in participants diagnosed in Blood Bank services, 25.0% (n=3) in participants diagnosed in Drug and Alcohol services, 23.7% (n=22) in participants diagnosed by GP, and 21.4% (n=3) in participants diagnosed in hospitals or specialist clinics.

Among 48 participants receiving 'a lot of information' or 'some information' at the time of hepatitis C diagnosis, 56.3% were very satisfied or somewhat satisfied with the level of information they were provided (Table 17).

Table 17: Participants' satisfaction of information received when diagnosed - among participants receiving 'a lot of' or 'some' information

	Frequency *total n=48*	**Percent**
Very satisfied	14	29.2
Somewhat satisfied	13	27.1
Neither satisfied nor dissatisfied	13	27.1
Somewhat dissatisfied	6	12.5
Very dissatisfied	2	4.2

Ninety nine participants (58.3%) reported post-test discussion with a health professional while pre-test discussion was reported by 24 participants (14.2%). About 32% of participants reported not having or not remembering receiving any pre- or post-test discussion at the time of hepatitis C diagnosis (Table 18).

Table 18: Frequency of discussion with a health professional before and after being tested for hepatitis C

	Frequency *total n=170*	**Percent**
We talked about hepatitis C before the test and after I received the result	21	12.4
We discussed hepatitis C only after I received the result of the test	78	45.9
We talked about hepatitis C only before having the test, but not after I received the result	3	1.8
We didn't talk about hepatitis C before the test or after I received the result	29	17.1
I don't remember if we had any discussion	25	14.7
Not specified	14	8.3

Of the 102 participants reporting pre-test and/or post-test discussion at the time of their hepatitis C diagnosis, only 31 (30.4%) were very satisfied or somewhat satisfied with the level of discussion (Table 19).

Table 19: Participants' satisfaction of pre-test and/or post-test discussion at the time of hepatitis C diagnosis among people reporting any of these discussions

	Frequency *total n=102*	**Percent**
Very satisfied	16	15.7
Somewhat satisfied	15	14.7
Neither satisfied nor dissatisfied	29	28.4
Somewhat dissatisfied	23	22.5
Very dissatisfied	19	18.6

About 38% of participants were referred to specialist services (gastroenterologists or ID physicians) with 20% referred to hepatitis organisations. Seventy five people chose neither a service listed in the question or ‘other,’ indicating that they had not been referred to any service after diagnosis. Most participants (range: 62-91%) accessed the services they were referred to within one year (Table 20).

Table 20: Services the participants were referred to after diagnosis of hepatitis C and frequency of access

	Referred after diagnosis n (% out of total) *total n=170*	**Accessed within one year n (% of referred people)***
Gastroenterologist	51 (30.0)	40 (78.4)
Hepatitis organisations	34 (20.0)	24 (70.6)
Infectious Diseases specialist	14 (8.2)	12 (85.7)
Drug and Alcohol services	11 (6.5)	10 (90.9)
Internet resources	11 (6.5)	10 (90.9)
A GP with a special interest in hepatitis C	9 (5.3)	7 (77.8)
Sexual Health services	8 (4.7)	5 (62.5)
Drug user organisations	4 (2.4)	-
Needle and Syringe Programs (NSPs)	3 (1.8)	-
Indigenous Health services	1 (0.6)	-
Multicultural services	1 (0.6)	-
Refugee services	1 (0.6)	
Haemophilia support services	0 (0)	-
Offender or prisoner support services	0 (0)	-
Other	17 (10.0)	11 (64.7)

* Reported for referred n>5

Participants were asked “how do you think you may have become infected with hepatitis C?” with more than one response allowed, and were then asked of the most likely way they were infected (Table 12). Most participants (59.4%) reported ‘Sharing or reusing injecting equipment’ as the *probable route* of their hepatitis C infection with a slightly lower proportion (55.3%) reported sharing injecting equipment as their *most likely* transmission route. Most participants reporting ‘Sharing or reusing injecting equipment’ as the probable route of hepatitis C infection (n=101) stated that they were in Australia (n=90; 89.1%) and at home, at a friend’s house or in the street (n=97; 96.0%) when they injected. Of the 26 reported having been to prison or spent time in a youth detention centre, only one reported that they may have been infected with hepatitis C while they were incarcerated.

Among 14 participants reporting receiving a tattoo as their probable transmission route, most stated being tattooed at a tattoo parlour or salon (n=7; 50.0%) or at home/friend's house (n=8; 57.1%). One person stated that they were tattooed in prison.

Of the 19 participants reporting medical or dental procedure as their probable route of infection, most stated that the procedure was done by a health professional (n=16; 84.2%) while three people (15.8%) stated that the procedure was done by an alternative or complementary medical practitioner. Most procedures by health professionals were done in Australia (n=14; 73.7%).

About 8% of participants were unsure how they were infected with hepatitis C.

Table 21: Distribution of all probable route(s), and the most probable route of hepatitis C infection acquisition

	Probable route(s) **n (%)** *total n=170*	**Most probable route** **n (%)** *total n=170*
Sharing or reusing injecting equipment	101 (59.4)	94 (55.3)
Getting a tattoo	14 (8.2)	7 (4.1)
Blood or blood product transfusion	24 (14.1)	14 (8.2)
Unprotected sex with someone you think had hepatitis C	19 (11.2)	12 (7.1)
Born to a mother who had hepatitis C	2 (1.2)	1 (0.6)
Sharing bathroom implements (e.g. razors, tooth brushes) with someone who had hepatitis C	13 (7.6)	1 (0.6)
A 'needle stick', or other 'sharps', injury while working in health care	5 (2.9)	1 (0.6)
Medical or dental procedure	19 (11.2)	6 (3.5)
Having a body or ear piercing	5 (2.9)	2 (1.2)
Others	19 (11.2)	3 (1.8)
I'm unsure how I got hepatitis C	-	14 (8.2)
Not specified	-	15 (8.8)

Among 146 participants who remembered having an alanine aminotransferase (ALT) test, 75 (51.0%) reported that their most recent ALT results were higher than normal. The most recent ALT test was done in 2011 for 59 participants (40.4%) and in 2010 for 59 participants (40.4%). For the other participants, the ALT test was done before 2010.

Among 122 participants who remembered having a HCV RNA PCR test, virus was detected in the most recent test in 84 (68.9%) people, while in 31 (25.4%) no virus was detected and 6 participants (4.9%) did not know what the result was. The most recent HCV RNA PCR test was done in 2011 in 33 participants (27.0%), in 2010 in 41 participants (33.6%), and in 2009 in 17 participants (13.9%). For the other respondents it was done before 2009. Most participants who remembered the results of their genotype test had genotype 1 (59.9%), genotype 2 (5.8%), genotype 3 (20.4%) and genotype 4 (0.7%).

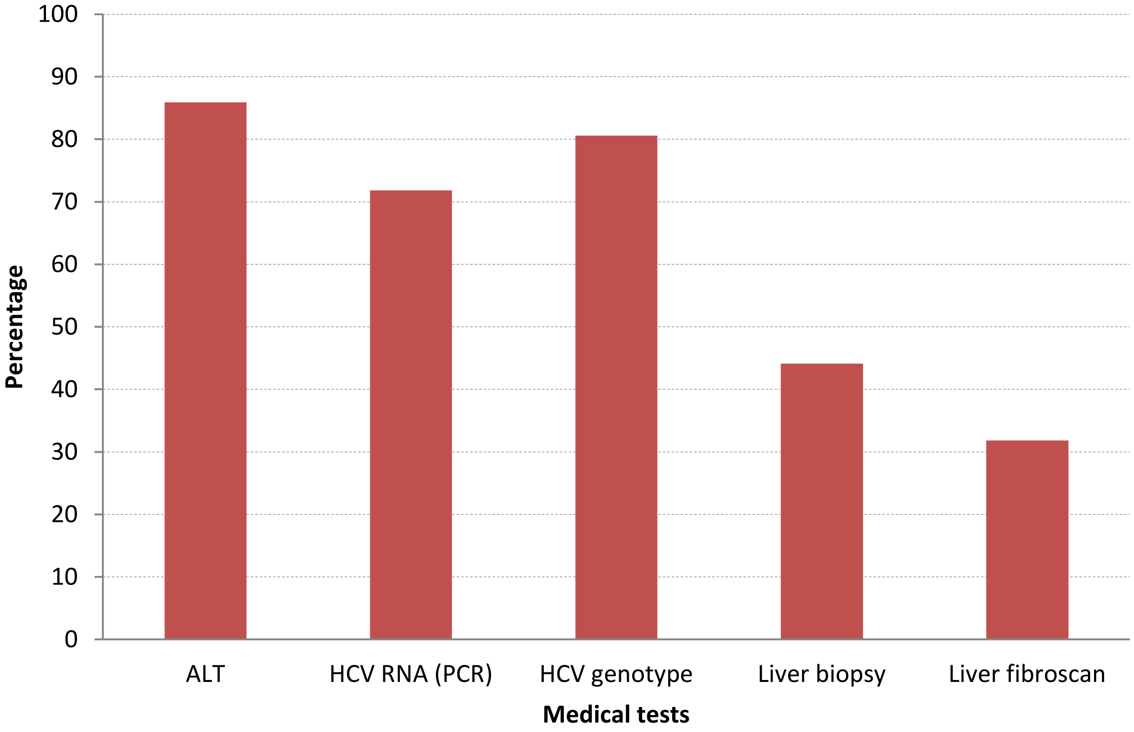
Liver biopsy was reported by 75 of the participants (44.1%) among whom the most recent results showed no fibrosis in 15 (20.0%), stage 1 fibrosis in 18 (24.0%), stage 2 fibrosis in 10 (13.3%), stage 3 fibrosis in 15 (20.0%), and stage 4 fibrosis in 6 (8.0%). Ten participants (13.3%) did not know about the results.

One participant reported having been diagnosed with hepatocellular carcinoma (liver cancer).

Table 22: Frequency of medical tests including ALT, HCV RNA PCR, hepatitis C genotype, liver biopsy and liver fibroscan for hepatitis C

	ALT n (%) *total n=170*	**Hepatitis C RNA (PCR) n (%)** *total n=170*	**Hepatitis C genotype n (%)** *total n=170*	**Liver biopsy n (%)** *total n=170*	**Liver fibroscan n (%)** *total n=170*
Yes	146 (85.9)	122 (71.8)	137 (80.6)	75 (44.1)	54 (31.8)
No	1 (0.6)	0 (0)	7 (4.1)	77 (45.3)	87 (51.2)
I don’t know	9 (5.3)	30 (17.6)	9 (5.3)	1 (0.6)	12 (7.1)
Not specified	14 (8.2)	18 (10.6)	17 (10.0)	17 (10.0)	17 (10.0)

Figure 13: Proportion of participants who had done medical tests including ALT, HCV RNA PCR, genotype, liver biopsy and liver fibroscan for hepatitis C



Section 4: Hepatitis C treatment

The overall participants flow for treatment uptake and response to treatment is summarised in Figure 14. Overall, treatment uptake was 50.6% among participants. Excluding participants currently on treatment, treatment was adhered to by 64.6%. This treatment adherence may be underestimated given an unknown proportion of participants who stopped treatment based on their doctor's decision (treatment failure). Missing data should also be considered in interpreting the results. More details about treatment uptake, adherence and outcome are noted in the following tables.

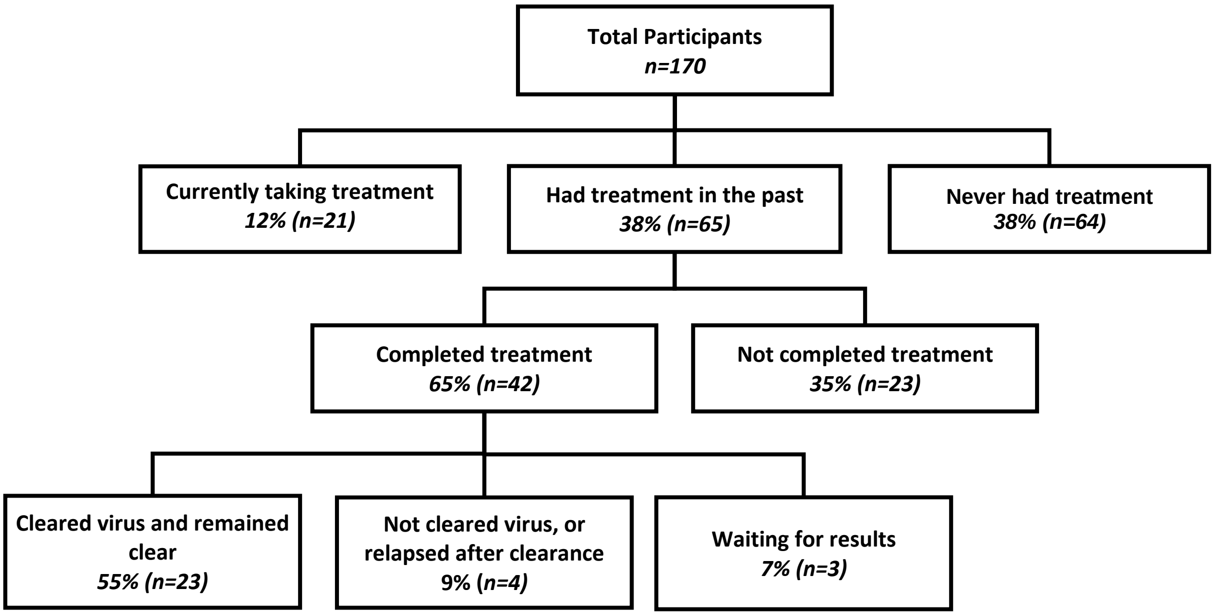
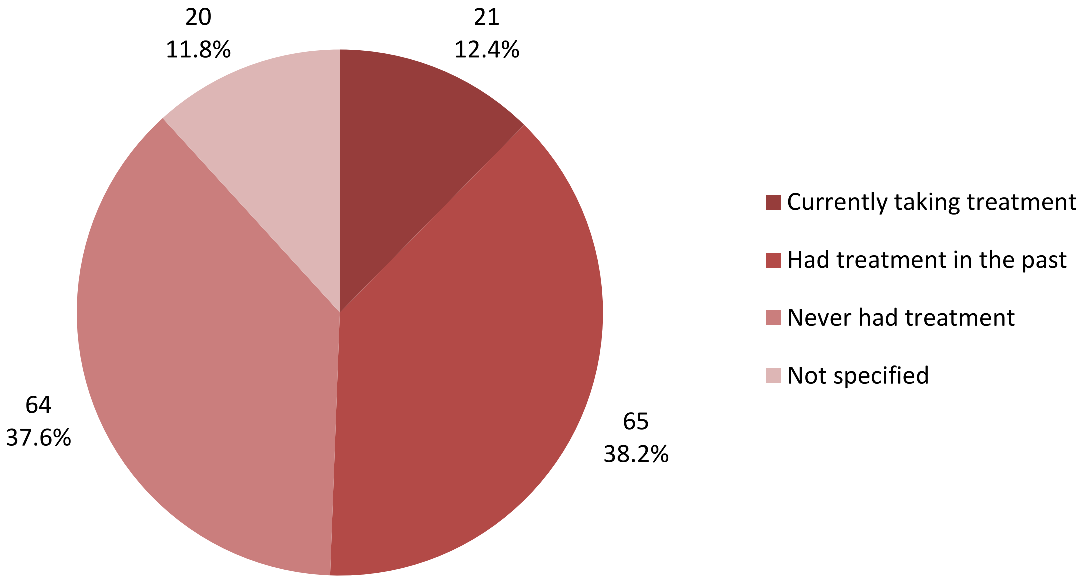


Figure 14: Participants flow for treatment uptake and response*

* Missing data has been considered for calculating percentages

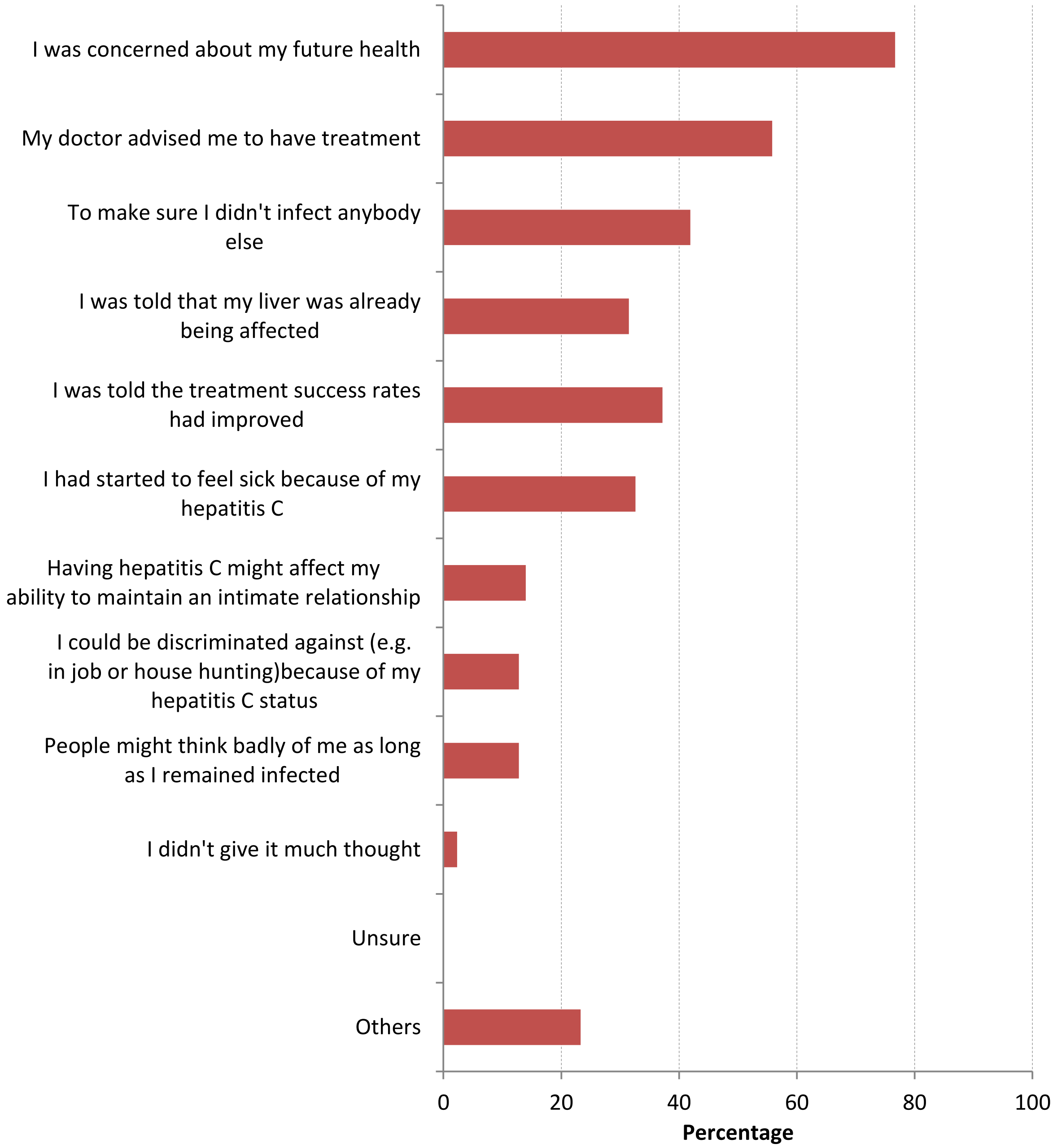
Eighty-six participants (50.6%) had current or past experiences of hepatitis C treatment. Data was not available in 11.8% for this item (Figure 15).

Figure 15: Distribution of hepatitis C treatment experience among participants



Of the 86 participants who had a current or past experience of hepatitis C treatment, the most frequently reported reason for being treated was concern about future health (76.7%), the second most common reason was following doctor's advice (55.8%) and the third was not to infect others with hepatitis C. About 23% of participants reported other reasons not specified in the questionnaire (Figure 16).

Figure 16: Reasons for being teated for hepatitis C



Among 64 participants who had never been treated for hepatitis C, the most frequently reported reason for not being treated was concern of side effects (59.4%). About 37% of participants reported other barriers not listed in the questionnaire (Table 23).

Forty-seven participants (73.5%) who had never undertaken treatment stated that they would consider treatment in the future.

Table 23: Reasons for not being treated for hepatitis C

	Frequency *total n=64*	**Percent**
I am concerned about side effects to treatment	38	59.4
I am waiting for new treatments to become available	24	37.5
I have been told the treatment success rate is still low	20	31.3
Hepatitis C is not currently making me feel sick	16	25.0
I am concerned about telling people about my hepatitis C	8	12.5
I was told my liver was not badly affected enough to warrant treatment	7	10.9
I had never been referred to a specialist or treatment centre	6	9.4
I do not want to have to inject my treatment	6	9.4
I do not want to have a biopsy	5	7.8
I was told I would have to reduce or stop drinking alcohol	5	7.8
I was told my virus levels were too low	5	7.8
I would have trouble travelling to a treatment centre	3	4.7
I was pregnant, or planning a pregnancy, at the time treatment was discussed	3	4.7
I do not believe that hepatitis C will make me sick in the future	3	4.7
I haven't given it much thought	3	4.7
I was told I would have to reduce or stop using drugs	2	3.1
I was told my liver was too badly affected for successful treatment	1	1.6
Unsure	3	4.7
Other	24	37.5

Of the 65 participants who had been treated previously, 42 (64.6%) completed the full treatment schedule. Among 42 participants who completed treatment, 23 (54.8%) cleared and had remained clear of the virus, while 12 (28.6%) had cleared but had a recurrence of hepatitis C (mainly due to recurrence or re-infection). Four participants (9.5%) did not clear the virus (Table 24).

Table 24: Treatment outcome for participants completing treatment

	Frequency *total n=42*	**Percent**
Completely cleared virus and remain clear since then	23	54.8
Cleared the virus at first, but the virus has been detected in blood since treatment	12	28.6
Did not clear virus at all	4	9.5
Still waiting to find out results	3	7.1
Not specified	0	0

Twenty-three people (35.4%) who had been treated in the past did not complete treatment. The most frequently reported reason for treatment withdrawal was failure in clearing the virus (60.9%) followed by unmanageable side effects (43.5%). About 30% of participants reported reasons not listed in the questionnaire (Table 25). While 14 participants stopped treatment due to not clearing the virus, it was unclear how many of them withdrew based on a doctor’s decision and how many made their own decision.

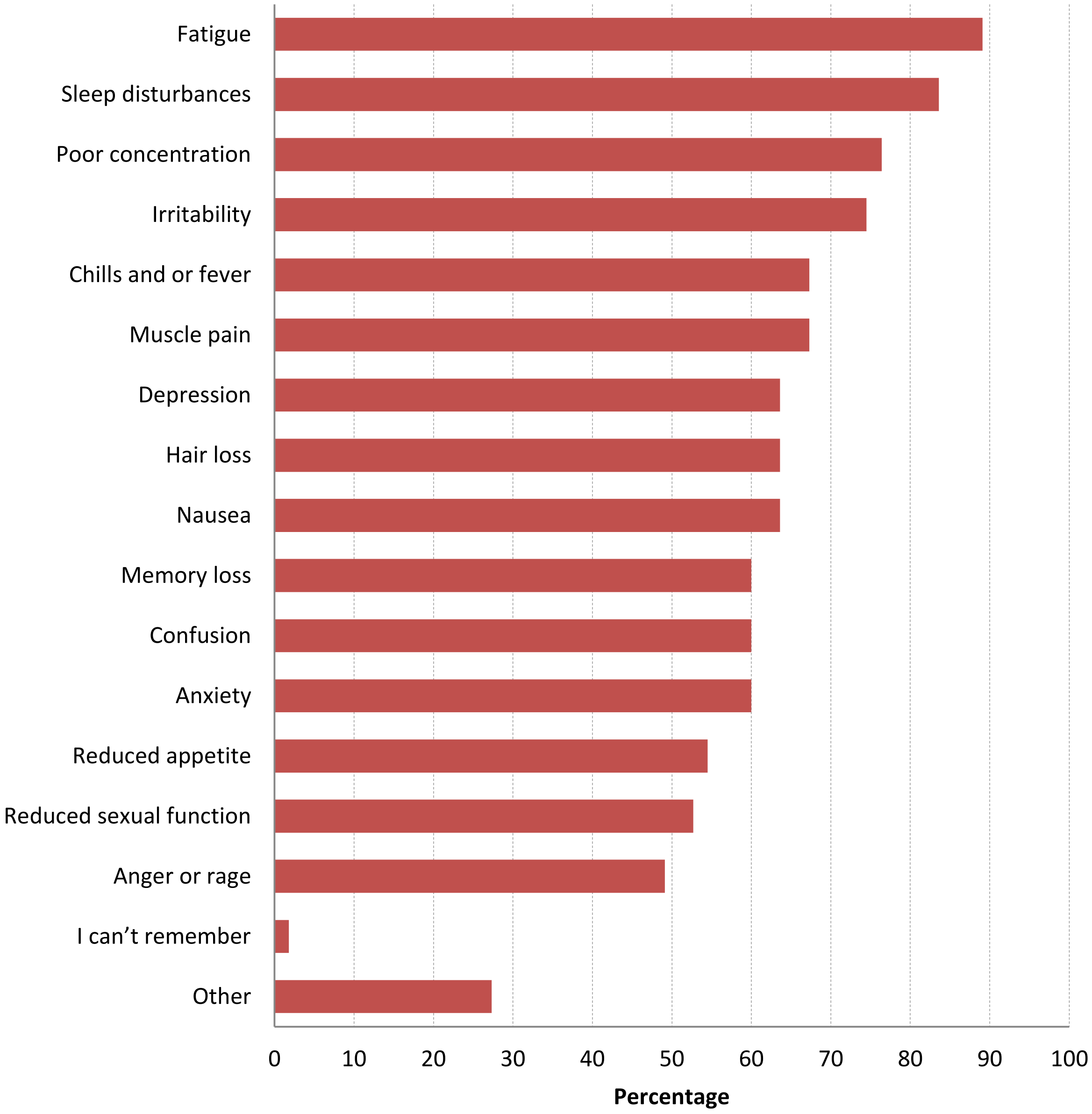
Table 25: Reasons for stopping treatment

	Frequency *total n=23*	**Percent**
The virus was not going away	14	60.9
The side effects were unmanageable	10	43.5
I did not have sufficient support from family and friends	3	13.0
I had difficulty organising transport from home at the time	1	4.3
The doctor could not see me when it was convenient	1	4.3
I don't know why my treatment was discontinued	0	0
Other	7	30.4

Of the 86 participants with current or past experience of hepatitis C treatment, 55 (64.0%) experienced treatment side effects. There was 27.9% missing data for this item.

Distribution of various side effects among the 55 participants who reported side effects during treatment is summarised in Figure 17. Fatigue (89.1%) and sleep disturbance (83.6%) were the most common side effects reported.

Figure 17: Side effects experienced by participants treated for hepatitis C



Among the 37 participants who were not on treatment at the time of completing the survey, and who experienced side effects during treatment, these side effects cleared up a short time after they stopped treatment in 20 participants (54.0%). However, 14 participants (37.8%) stated that side effects persisted and they were still experiencing them at the time of survey.

Among 55 respondents experiencing side effects as a result of anti-viral treatment, 49 (89.1%) used medical treatments to alleviate these side effects. Distribution of various medical treatments used by participants to alleviate treatment side effects is summarised in Table 26. Non-prescription pain killers (72.7%) were the most commonly used medical treatments.

Table 26: Medical treatments used by participants to relieve hepatitis C treatment side effects

	Frequency *total n=55*	**Percent**
Panadol, Aspirin or other non-prescription pain killers	40	72.7
Sleeping pills (eg 'benzos' such as Temazepam or Valium, or melatonin pills etc)	24	43.6
Anti-depressants	22	40.0
Anti-nausea medications	15	27.3
Psychiatric or psychological counselling	10	18.2
Anti-anxiety medications	3	5.5
Other	9	16.4

Of the 49 respondents using medical treatment for their side-effects, 17 (34.7%) stated being very satisfied or somewhat satisfied with the treatments they used (Table 27).

Table 27: Satisfaction of participants with medical treatment(s) used to relieve hepatitis C treatment side effects.

	Frequency *total n=47*	**Percent**
Very satisfied	4	8.2
Somewhat satisfied	13	26.5
Neither satisfied nor dissatisfied	10	20.4
Somewhat dissatisfied	13	26.5
Very dissatisfied	7	14.3
Not specified	2	4.1

Among 55 respondents experiencing treatment side effects, 36 participants (65.5%) used some form of complementary or alternative therapies to alleviate the side effects. Supplements (29.1%) and low impact exercises (27.3%) were the most commonly used complementary treatments (Table 28).

Table 28: Complementary therapies used to alleviate hepatitis C treatment side effects

	Frequency *total n = 55*	**Percent**
Supplements (e.g. vitamins, antioxidants, etc)	16	29.1
Low impact exercise (e.g. Yoga, Tai Chi, etc)	15	27.3
Massage	12	21.8
Herbal medicinal	11	20.0
Meditation	10	18.2
Acupuncture	4	7.3
Aromatherapy	2	3.6
Traditional Chinese medicine	2	3.6
Other	7	12.7

Among 36 respondents reporting using complementary therapies for their side-effects, 20 participants (55.5%) stated being very satisfied or somewhat satisfied with the treatments they used (Table 29).

Table 29: Satisfaction of participants with the complementary therapies used for hepatitis C treatment side effects.

	Frequency *total n=36*	**Percent**
Very satisfied	4	11.1
Somewhat satisfied	16	44.4
Neither satisfied nor dissatisfied	8	22.2
Somewhat dissatisfied	2	5.6
Very dissatisfied	1	2.8
Not specified	5	13.9

Among 55 respondents experiencing treatment side effects, 33 (60.0%) used both medical and complementary therapies to alleviate these side effects. Sixteen participants (29.1%) used only medical treatments, 3 participants (5.5%) used only complementary treatments, and 3 participants (5.5%) used none.

Sixty-eight participants (40.0%) reported using complementary or alternative therapies to treat their hepatitis C infection or manage hepatitis C symptoms. There was 24.2% missing data for this item.

Among 68 participants using complementary or alternative therapies to treat their hepatitis C infection, herbal medicines (e.g. milk thistle, gingko, old man's weed, etc) were the most commonly used treatments used by 79.4%. About 20% of participants used other complementary treatments not listed in the questionnaire (Table 30).

Table 30: Complementary therapies used by participants to treat hepatitis C infection or manage symptoms

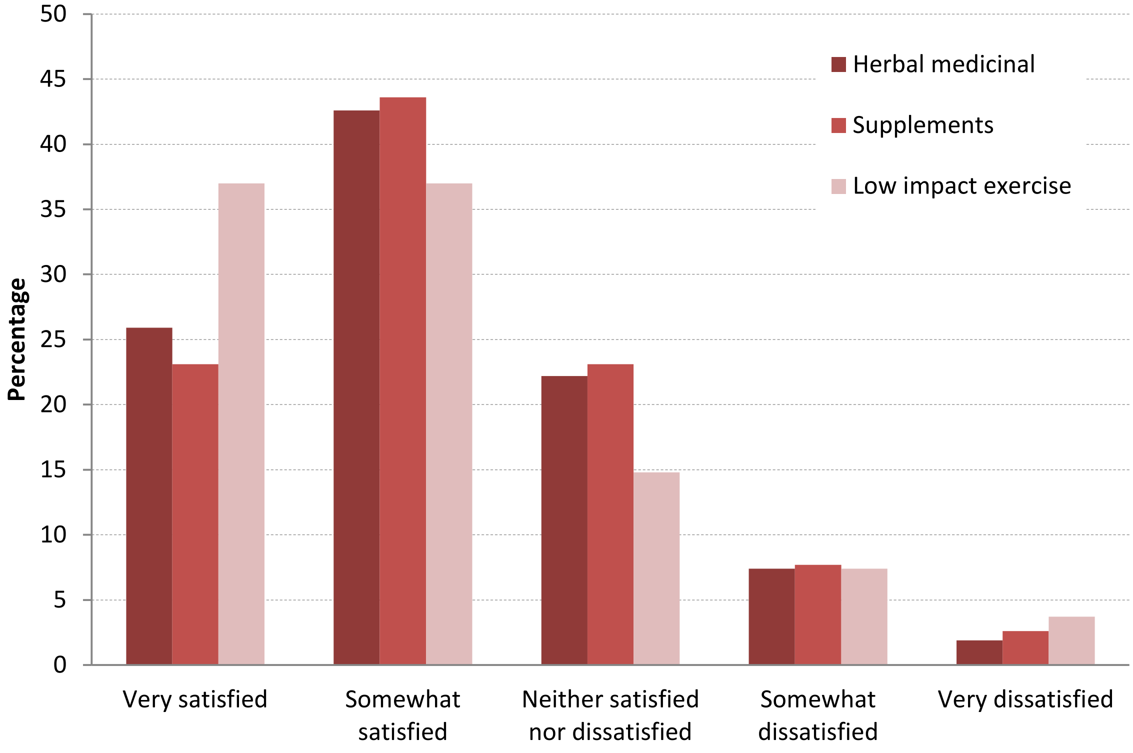
	Frequency *total n = 68*	**Percent**
Herbal medicinal	54	79.4
Supplements (e.g. vitamins, antioxidants, etc)	39	57.4
Low impact exercise (e.g. Yoga, Tai Chi, etc)	27	39.7
Traditional Chinese medicine	22	32.4
Massage	21	30.9
Meditation	17	25.0
Acupuncture	17	25.0
Aromatherapy	6	8.8
Not sure what I used	0	0
Other	14	20.6

The overall results and specific results for three most commonly used treatments (i.e. herbal medicines, supplements, and low impact exercise) are summarised in Table 31 and Figure 18, respectively. Overall, 42 participants (64.7%) stated being very satisfied or somewhat satisfied with the treatments they used.

Table 31: Satisfaction with complementary therapies to treat hepatitis C infection or manage symptoms

	Frequency *total n=68*	**Percent**
Very satisfied	17	25.0
Somewhat satisfied	27	39.7
Neither satisfied nor dissatisfied	16	23.5
Somewhat dissatisfied	5	7.4
Very dissatisfied	2	2.9
Not specified	1	1.5

Figure 18: Participant satisfaction with three most commonly used complementary therapies to treat hepatitis C infection or manage symptoms



Apart from previous personal knowledge, internet was the most common source of information about complementary medicine (30.9%). Health professionals such as GPs, specialists and nurses were the least common sources for information about complementary therapies.

Table 20: How participants first found out about complementary or alternative therapies for hepatitis C

	Frequency *total n = 68*	**Percent**
I have known about complementary or alternative therapies for a long time	42	61.8
The internet	21	30.9
Hepatitis organisations (formerly Councils)	18	26.5
Friends (with and without hepatitis C)	16	23.5
People I know with hepatitis C	15	22.1
Family members	7	10.3
GP	5	7.4
Specialist	4	5.9
Other community support organisations	4	5.9
Clinical Nurse (or CNC)	3	4.4
I can’t remember	2	2.9
Other places	6	8.8

Summary

Data from a total of 170 participants were included in these results. The age and gender distribution of participants in the current study were inconsistent with those described in Australian annual surveillance reports. Most participants in CHI were women (62%) and older than 49 years (54%). Based on the most recent Australian annual surveillance report, 35% of hepatitis C notifications in 2012 were among women with 24% being older than 49 years.[22]

While over one in five participants (22%) reported their general health status as excellent or very good, most (58%) reported fair to good health. About one in six participants (15%) described their general health as poor. Participants' self rating of their general health was comparable between men and women but significantly different between the two age groups. The proportion of participants describing their general health as fair or poor was three times greater among participants older than 40 years compared to participants aged 40 years or younger.

Analysis of SF-12v2 items indicated more self-perceived limits in physical functioning domain and role-emotional domain among women compared with men. More self-perceived limitations were also observed among participants older than 40 compared to participants aged 40 years or younger with respect to general health, physical functioning, role-physical and body pain.

About half of the participants (49%) reported health conditions apart from hepatitis C affecting their quality of life. The most common co-morbidity related to mental health issues (including depression or anxiety), which were reported by 36% of participants. Only a small proportion of participants reported infection with HIV (4.1%) or hepatitis B (2.4%). This reflects findings of other Australian research where in one study of 550 people with chronic hepatitis C, 3.1% of participants were infected with HIV and 2.4% with hepatitis B.[23]

While most participants (59%) believed that they had been infected with hepatitis C prior to 1990, the majority were diagnosed after 1990, with the highest proportion (52%) diagnosed between 1990 and 2000. There was a longer than two-year gap between hepatitis C infection and diagnosis among most participants (62%).

Only about one in seven participants (14%) reported receiving a pre-test discussion with a health professional when they were first told that they had hepatitis C. More than half of participants (58%) reported a post-test discussion while 17% did not report any pre- or post-test discussion at the time of hepatitis C diagnosis. Among participants reported pre-test and/or post-test discussion, only 30% were very satisfied or somewhat satisfied of the level of discussion they had.

Most participants (55%) reported 'Sharing or reusing injecting equipment' as the most likely transmission route of hepatitis C infection.

Overall, treatment uptake was about 50% among participants, a very high proportion considering other data showing very poor treatment access.[9] Treatment completion was 65%. Fourteen participants stopped treatment due to not clearing the virus, but the data is unclear of how many stopped treatment based on doctor's decision or a personal decision.

About a quarter (29%) of participants who had taken treatment in the past had not completed their treatment with the most frequently reported reason being treatment failure (61%) followed by unmanageable treatment side effects (43%). Just over one-third of participants (38%) had not received any medical treatment for hepatitis C with the most frequently reported barrier for treatment among these participants being concern of treatment side effects (59%).

About two-thirds (64%) of participants with current or past experiences of hepatitis C treatment, experienced treatment side effects. Fatigue (89%) and sleep disturbance (84%) was the most common side effects reported.

Among participants experiencing treatment side effects, 89% used some medical treatments to alleviate their treatment side effects with non-prescription pain killers (73%) being the most commonly used medical treatment. Only one-third of participants (35%) were satisfied with the medical treatments they used for side effects.

Complementary or alternative therapies to alleviate treatment side effects were less common compared to medical treatment, and were reported by 65% of participants. However, a higher proportion of participants (55%) were satisfied with the complementary therapies they used, compared to participants using medical treatment. Supplements (29%) and low impact exercises (27%) were the most commonly used complementary treatments to alleviate hepatitis C treatment side effects. Most participants (60%) used both medical and complementary treatments to alleviate their treatment side effects.

Complementary or alternative therapies to treat hepatitis C was reported by 40% of participants. Herbal medicinal was the most commonly used complementary treatment used by 79%. About two third of participants used complementary therapies to treat hepatitis C (65%) were satisfied with the treatments they used.

The CHI study was initiated as a longitudinal cohort using an anonymous online survey and significant challenges with recruitment and resourcing has resulted in only one data set. This report presents the baseline data gathered by the study. There are several limitations to the data presented. The age and gender distribution of participants significantly differ from that reported in Australian annual surveillance reports. This limits the external validity of the findings given the probable selection bias in participant enrolment. The high proportion of missing data in some questions should be considered in interpreting the findings.

Appendix A

Charting Health Impacts (CHI) Reference Committee Members:

- Emma Miller, Australian Research Centre in Sex, Health and Society
- Stephen McNally, Australian Research Centre in Sex, Health and Society
- Marian Pitts, Australian Research Centre in Sex, Health and Society
- Dr Benjamin Cowie, Victorian Infectious Diseases Reference Laboratory and the Victorian Infectious Diseases Service at Royal Melbourne Hospital
- Levinia Crooks, Australasian Society for HIV Medicine
- Helen McNeill, Hepatitis Victoria
- Dayle Stubbs, Australian Injecting and Illicit Drug Users League
- Peter Waples-Crowe, Victorian Aboriginal Community Controlled Health Organisation
- Jack Wallace, Australian Research Centre in Sex, Health and Society
- Jen Johnson, Australian Research Centre in Sex, Health and Society
- Anthony Smith, Australian Research Centre in Sex, Health and Society

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