



Curtin University

# Evaluation of the WA Regional Nurse-supported Hepatitis C Shared Care Program

*January 2014*

Western Australian Centre for Health Promotion Research





*This research was completed by the WA Centre for Health Promotion Research in conjunction with and funded by the WA Department of Health Sexual Health and Blood-borne Virus Program*

### Overview of the Western Australian Centre for Health Promotion Research

The WACHPR is a multi-disciplinary research centre within the School of Public Health and the Curtin Health Innovation Research Institute (CHIRI) at Curtin University. The WACHPR was established in 1986 and was the first research centre in health promotion to be established by an Australian university.

### Functions

The WACHPR views health promotion as a combination of educational, organisational, economic, social and political actions designed with meaningful participation, to enable individuals, groups and whole communities to increase control over, and to improve their health through attitudinal, behavioural, social and environmental changes. This comprehensive social justice perspective of health promotion is reflected in the WACHPR's research foci and programs. The WACHPR is committed to building evidence and capacity in health promotion theory, practice and evaluation through applied and participatory research. Grounded in an understanding of social determinants of health and a commitment to social justice and ethical practice, the WACHPR conducts research with vulnerable or most at risk communities and populations and works in partnership with relevant community, government, research and private organisations to improve the health of regional populations.

In addition to these core functions, the WACHPR conducts health promotion - continuing education and capacity building courses for the health promotion sector, as well as tailored courses for the HIV sector and allied health staff. Further activities include consultancy and evaluation services, training and development, workplace health, implementation and evaluation of community based interventions and assistance and advice with public health policy activities.

### Research Focus and Areas of Expertise

The WACHPR research team has expertise in the development, implementation and evaluation of formative and longitudinal intervention research in key areas such as: early childhood health and nutrition; physical activity and nutrition; alcohol and other drug use; seniors' health; mental health; and HIV and sexual health. The WACHPR is a unique research centre in that all core staff hold front-line research and teaching positions in the School of Public Health. The combined expertise of the WACHPR staff, together with the establishment of collaborative networks, aims to foster the practice of health promotion by encompassing the nexus between research and practice. The WACHPR has built and demonstrated high level expertise and research strength in:

- The design, planning, implementation, evaluation and dissemination of quality integrated health promotion programs
- Building sustained partnerships and collaborations with vulnerable and most at risk communities and relevant community, government and private sector organisations
- Health promotion approaches using community and settings-based interventions, peer and social influence, social marketing, advocacy, community mobilisation and sector capacity building
- Health promotion intervention research that improves outcomes in nutrition, physical activity, mental health, sexual health, drug use and injury prevention
- Promotion and dissemination of evidence-based practice and building practice-based evidence
- Provision of research training and capacity building techniques to undergraduate and postgraduate students, allied health promotion professionals and community workers

Enquiries and further information can be made by contacting:

Dr Roanna Lobo | **Research Fellow**  
WA Centre for Health Promotion Research  
School of Public Health | Faculty of Health Sciences | Curtin University  
PO Box U 1987 | Bentley | Western Australia | 6845  
+61 8 9266 1101 | [roanna.lobo@curtin.edu.au](mailto:roanna.lobo@curtin.edu.au)  
[www.wachpr.curtin.edu.au](http://www.wachpr.curtin.edu.au)

Suggested citation: WA Centre for Health Promotion Research. 2014. 'Evaluation of the WA Regional Nurse-supported Hepatitis C Shared Care Program' Perth: Curtin University.

ISBN: 978-0-9874704-8-5

## Table of Contents

Executive Summary .....	6
<b>1. Introduction and background .....</b>	<b>8</b>
1.1 Scope of evaluation.....	9
1.2 Utilisation of evaluation findings .....	10
<b>2. Methods and data analysis.....</b>	<b>11</b>
2.1 Desktop review .....	11
2.2 Interviews with key informants .....	11
2.3 Patients' survey.....	12
2.4 Ethics.....	12
<b>3. Results of desktop review and key informant interviews.....</b>	<b>13</b>
3.1 How does the regional nurse-supported hepatitis C shared care program currently operate in WA? .....	13
3.1.1 Role of hepatitis nurse .....	14
3.1.2 Role of GPs in shared care .....	15
3.1.3 Role of tertiary liver clinic .....	17
3.1.4 Role of allied health services .....	18
3.2 Are patients receiving care when they need it? .....	18
3.2.1 Patient profile and disease burden .....	18
3.2.2 Factors influencing regional treatment and care.....	19
3.3 What is the model of care in regions without a nurse-supported hepatitis C shared care program? .....	21
3.4 What are the perceived benefits of having a regional nurse-supported hepatitis C shared care program? .....	22
3.5 What challenges/enablers are associated with implementing the regional nurse-supported hepatitis C shared care program? .....	23
3.6 What are the consequences and implications for regions without a nurse-supported hepatitis C shared care program? .....	24
3.6.1 Telehealth .....	25
3.7 What are the critical features of the WA Regional nurse-supported hepatitis C shared care program compared with other best practice models of shared care? .....	26
3.7.1 Comparison with other best practice models of shared care .....	26
3.8 What elements are crucial to the success of a regional nurse-supported hepatitis C shared care program in WA?.....	26
<b>4. Results of patients' survey .....</b>	<b>28</b>
4.1 Demographics .....	28
4.2 Referral and treatment .....	28
4.3 Satisfaction levels.....	31
4.4 Access to treatment .....	32
4.5 Patient recommendations for hepatitis C services .....	32
<b>5. Overall summary and conclusions .....</b>	<b>33</b>
5.1 How does the regional nurse-supported hepatitis C shared care program currently operate in WA? .....	33
Western Australian Centre for Health Promotion Research.....	3

5.2 Are patients receiving care when they need it? .....	34
5.3 What is the model of care in regions without a nurse-supported hepatitis C shared care program? .....	34
5.4 What are the perceived benefits of having a regional nurse-supported hepatitis C shared care program? .....	35
5.5 What challenges/enablers are associated with implementing the regional nurse-supported hepatitis C shared care program? .....	35
5.6 What are the consequences and implications for regions without a nurse-supported hepatitis C shared care program? .....	35
5.7 What are the critical features of the WA regional nurse-supported hepatitis C shared care program compared with other best practice models of shared care? .....	36
5.8 What elements are crucial to the success of a regional nurse-supported hepatitis C shared care program in WA?.....	36
5.9 Study limitations .....	37
5.10 Conclusions .....	38
6. Key recommendations.....	39
Appendix 1: Desktop review .....	41
Appendix 2: Examples of interview schedules .....	43
Appendix 3: List of key informants .....	45
Appendix 4: Patients' survey .....	46
References.....	57

## List of Figures

Figure 1: Model of care for patients with hepatitis C (HCV) .....	8
Figure 2: Care pathway for nurse-supported hepatitis C shared care program .....	14
Figure 3: Care pathway for regions without a nurse-supported hepatitis C shared care program .....	22
Figure 4: Interval between referral & treatment (N=20) .....	28
Figure 5: Main person contacted when patient had problems relating to hepatitis C (N=20) .....	29
Figure 6: Main person involved in explaining details of hepatitis C treatment (N=20) .....	29
Figure 7: Main person involved in scheduling patient appointments (N=19) .....	30
Figure 8: Main person involved in giving blood test results while on hepatitis C treatment (N=20) .....	31
Figure 9: Participants favoured option if hepatitis C treatment was not available in their region (N=20).....	32

## List of Tables

<b>Table 1: Hepatitis C notification, Great Southern, Kimberley &amp; South West regions of WA 1/1/2012 - 31/12/2012.....</b>	<b>19</b>
<b>Table 2: Numbers of patients receiving hepatitis C treatment in the regional nurse-supported hepatitis C shared care program .....</b>	<b>19</b>
<b>Table 3: Patient satisfaction levels with differing aspects of care .....</b>	<b>31</b>

## Executive Summary

Hepatitis C is a viral infection of the liver with significant morbidity and mortality. It is a major public health issue in Western Australia (WA). In 2012 there were 1,078 hepatitis C notifications in WA (44.1 per 100,000). Notification rates have remained steady over the past 5 years (1). Current treatments offer a cure rate of around 60% (2) and this rate is likely to increase as new treatments are becoming available. Unfortunately, the number of individuals commencing treatment is low (3).

Managing chronic hepatitis C requires multi-disciplinary teams. The current model of care (4) aims to provide increased accessibility and equity of care across all health sectors for people with chronic hepatitis C and in particular, those living in rural and remote areas.

Nurse-supported hepatitis C shared care programs have evolved over the past 10 years and are now established in WA in the Kimberley, the Great Southern and the South West regions. While an implementation evaluation of the roll-out of the program in the Great Southern and South West regions was conducted in 2007, the WA regional nurse-supported hepatitis C shared care program has not been evaluated across the three regions before.

In 2013, the WA Department of Health Sexual Health and Blood-Borne Virus Program (SHBBVP) approached the Western Australian Centre for Health Promotion Research (WACHPR) at Curtin University to evaluate the regional nurse-supported hepatitis C shared care program in WA. The evaluation was commissioned in response to a recommendation from the WA Committee for Sexually Transmitted Infections and Blood-borne Viruses (WACBBVS).

The focus of the evaluation by WACHPR was to answer the following questions:

1. How does the regional nurse-supported hepatitis C shared care program currently operate in WA?
2. Are patients receiving care when they need it?
3. What is the model of care in regions without a nurse-supported hepatitis C shared care program?
4. What are the perceived benefits of having a regional nurse-supported hepatitis C shared care program?
5. What challenges/enablers are associated with implementing the regional nurse-supported hepatitis C shared care program?
6. What are the consequences and implications for regions which do not have a nurse-supported hepatitis C shared care program?
7. What are the critical features of the WA regional nurse-supported hepatitis C shared care program compared with other best practice models of shared care?
8. What elements are crucial to the success of a regional nurse-supported shared care hepatitis C program in WA?

A mixed methods design was used for the evaluation comprising three components. These were: a desktop review, key informant interviews and a patients' survey.

The findings of the evaluation suggested that the waiting time to start treatment and support services available to patients undergoing hepatitis C treatment in regions with a nurse-supported shared care hepatitis C program, seemed to be as good, if not better, than in Perth. The majority of patients expressed high levels of satisfaction with the services available and patients preferred to access treatment locally. However, there were no Aboriginal patients currently enrolled in the shared care programs although Aboriginal people comprised approximately 21% of hepatitis C notifications in these regions in 2012.

There was a limit to the number of patients that a hepatitis nurse and physician could support (about 5-6 patients per day that the nurse is employed). Nurse resource allocations should therefore be considered based on patient caseload. The participation of general practitioners in shared care services was considered to improve regional capacity to offer treatment to patients. However, there were very few incentives for regional general practitioners to get involved and regional general practitioners were in short supply.

For regions that did not have a hepatitis nurse, the barriers to a patient starting treatment were significant and the likelihood was that patients would be unable to start treatment unless they had a long-term general practitioner and/or were able to travel back and forth to Perth. A scarcity of general practitioners in regional areas, the perceived characteristics of hepatitis C patients and the complexity of psychosocial issues often experienced by hepatitis C patients presented challenges to starting treatment.

The following recommendations are based on the findings of the evaluation of the WA nurse-supported hepatitis C shared care program:

- **Recommendation 1**  
*Maintain existing regional nurse-supported hepatitis C shared care programs.*
- **Recommendation 2**  
*Investigate requirements and feasibility of nurse-supported hepatitis C shared care services in other regions.*
- **Recommendation 3**  
*Investigate barriers to accessing treatment for Aboriginal people.*
- **Recommendation 4**  
*Increase participation of general practitioners in regional hepatitis C shared care services.*
- **Recommendation 5**  
*Investigate options for expanding telehealth services to enable local hepatitis C treatment and care and to reduce waiting times for tertiary clinic appointments.*

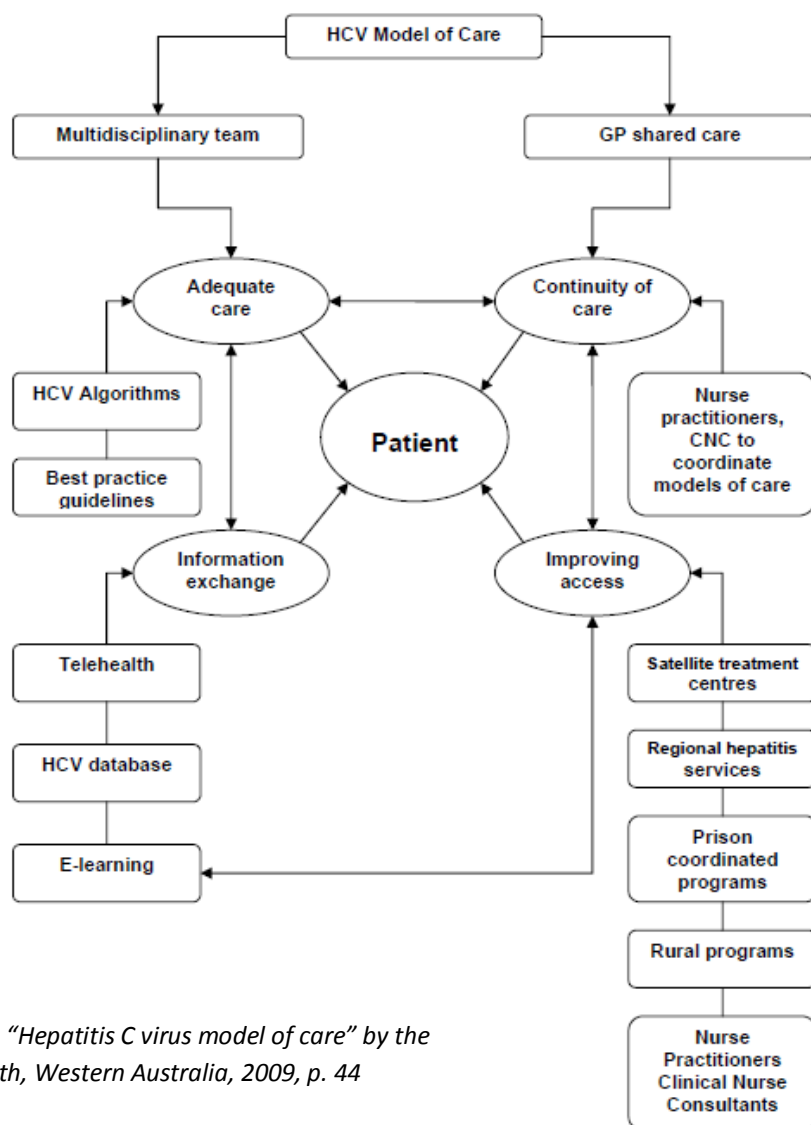
Recommendations 2 and 3 may be partially addressed by the *Evaluation of Nursing Structure and Resources in the Management of Chronic Hepatitis C (2013-2014) project* at Edith Cowan University Systems and Intervention Research Centre for Health in conjunction with the Royal Perth Hospital Liver Service and the Infections and Immunology Network.

## 1. Introduction and background

Hepatitis C is a viral infection of the liver with significant morbidity and mortality. It is a major public health issue in Western Australia (WA). In 2012 there were 1,078 new notifications in WA (44.1 per 100,000). The majority of notifications were in people aged 20 to 34 years. Injecting drug use is the most commonly reported risk factor. Notification rates have remained steady over the past 5 years (1).

Most of those infected go on to develop chronic hepatitis C of which 10-15% will develop cirrhosis of the liver; 5% of those with cirrhosis will develop hepatocellular carcinoma. Current treatments offer a cure rate of around 60% (2) and this rate is likely to increase as new treatments are becoming available. Unfortunately, the number of individuals commencing treatment is low (3). Managing chronic hepatitis C requires multi-disciplinary teams. The model of care shown in Figure 1 aimed to provide increased accessibility and equity of care across all health sectors for people with chronic hepatitis C and in particular, those living in rural and remote areas (4).

**Figure 1: Model of care for patients with hepatitis C (HCV)**



*Note: Adapted from "Hepatitis C virus model of care" by the Department of Health, Western Australia, 2009, p. 44*



One of the proposed strategies to increase treatment uptake by patients with hepatitis C was the WA regional nurse-supported hepatitis C shared care program. The program provides dedicated hepatitis nurses to improve access to and uptake of treatment and to provide holistic care for regional patients by assisting with and coordinating patient care. These dedicated nurse positions assist liaison between a patient and their general practitioner (GP), physician, and/or tertiary services and facilitate patient access to allied services including mental health services and drug and alcohol services.

Nurse-supported hepatitis C shared care programs have evolved over the past 10 years and are now established in WA in the Kimberley (0.4FTE), the Great Southern (0.6FTE) and the South West (1.0FTE) regions. The four regions (Goldfields, Midwest, Pilbara and Wheatbelt) without a regional hepatitis nurse use a GP-driven coordination model of care.

The regional nurse-supported hepatitis C shared care program was initially established in 2003 in the Great Southern and South West regions. A Clinical Nurse Consultant (CNC) from Fremantle Hospital was employed to implement and develop a hepatitis C treatment access and support program in these regions. The program was initially supported by limited funding through the Commonwealth Hepatitis C Education and Prevention Program. In 2007, the shared care program was transitioned from being managed through Fremantle Hospital to being managed locally through the relevant WA Country Health Service region.

The Kimberley program was established in 2004 and was also initially funded through a Commonwealth funding stream that was available at that time. The SHBBVP now provides funding support to the three regions for the program; however, funding limitations have restricted expansion of the program to other regions.

In metropolitan Perth, a tertiary liver clinic-driven coordination model of care operates and the functions of the regional hepatitis nurse are carried out by a CNC or a nurse-practitioner (NP) employed by liver clinics in the tertiary hospitals. Nurse practitioner models of care for hepatitis C in Perth have been shown to increase access to quality care for people with hepatitis C (5).

## 1.1 Scope of evaluation

The WA regional nurse-supported hepatitis C shared care program has not been evaluated before across the three regions. In 2013, the WA Department of Health Sexual Health and Blood-borne Virus Program (SHBBVP) contracted the Western Australian Centre for Health Promotion Research (WACHPR) at Curtin University to evaluate the regional nurse-supported hepatitis C shared care program in WA. The evaluation was commissioned in response to a recommendation from the WA Committee for Sexually Transmitted Infections and Blood-borne Viruses (WACBBVS).

The focus of the evaluation by WACHPR was to answer the following questions:

1. How does the regional nurse-supported hepatitis C shared care program currently operate in WA?
2. Are patients receiving care when they need it?

3. What is the model of care in regions without a nurse-supported hepatitis C shared care program?
4. What are the perceived benefits of having a regional nurse-supported hepatitis C shared care program?
5. What challenges/enablers are associated with implementing the regional nurse-supported hepatitis C shared care program?
6. What are the consequences and implications for regions which do not have a nurse-supported hepatitis C shared care program?
7. What are the critical features of the WA regional nurse-supported hepatitis C shared care program compared with other best practice models of shared care?
8. What elements are crucial to the success of a regional nurse-supported shared care hepatitis C program in WA?

## 1.2 Utilisation of evaluation findings

It is expected that if funding can be identified to address the recommendations, access to and uptake of treatment will be improved for patients with chronic hepatitis C living in regional, rural and remote areas.

The evaluation findings presented in this report will also be made available to the *Evaluation of Nursing Structure and Resources in the Management of Chronic Hepatitis C (2013-2014)* project team. This project is currently being implemented by the Systems and Intervention Research Centre for Health (SIRCH) at Edith Cowan University in conjunction with the Royal Perth Hospital Liver Service and the Infections and Immunology Network. The SIRCH evaluation project is focused on hepatitis C workforce assessment and aims to answer the following questions:

1. Where are the areas of identified need for hepatitis C treatment and management?
2. Which areas have the best potential for developing a shared care team for treatment and management of hepatitis C?
3. What is needed to establish shared care teams in areas of identified need (e.g. training, telehealth, and other services)?

## 2. Methods and data analysis

A mixed methods evaluation design was used to answer the evaluation questions incorporating three components:

1. Desktop review
2. Key informant interviews
3. Patients' survey.

These methods and the associated data analysis processes are described below.

### 2.1 Desktop review

A desktop review of documents, epidemiological data and reports considered relevant to the evaluation of the WA regional nurse-supported hepatitis C shared care program was conducted in June 2013 (see Appendix 1). The purpose of the desktop review was to understand the rationale and the current operation of the regional nurse-supported hepatitis C shared care program in WA and to identify similarities and differences between the WA regional nurse-supported hepatitis C shared care program and other models of hepatitis C shared care in Australia.

### 2.2 Interviews with key informants

The interview schedules for key informants (see Appendix 2) were based on the questionnaires developed for the evaluation of the Queensland hepatitis C shared care program (6).

Sixteen (16) potential key informants were identified by the SHBBVP and sent an email by the evaluation team informing them of the evaluation project and its aims and requesting their involvement. Two key informants declined to participate, two did not respond to the invitation and one key informant was interested but unable to find time to participate. Overall, 11 participants were interviewed (see Appendix 3).

Key informants were interviewed via telephone using the web-cam based software Scopio™ where possible. All interviews were audio-recorded and handwritten notes were also taken by the interviewer during the interviews.

In June and July 2013, semi-structured interviews were conducted with the three regional hepatitis nurses, one regional general practitioner (GP), two regional physicians and a tertiary liver clinic specialist to collect qualitative data about the current operation of the WA regional nurse-supported hepatitis C shared care program. In particular, what aspects of the program worked well and areas noted for improvement.

Four key informant interviews were also held with physicians and public health nurses in regions which currently do not operate a nurse-supported hepatitis C shared care program. The purpose of these interviews was to understand any regional differences in services and patient needs and to assess the consequences and implications of the absence of a nurse-supported shared care

program, including influences on service delivery, health service resources, and patients' access to and uptake of treatment.

The interview data were transcribed verbatim and thematic analysis was used to establish an understanding of their meaning and identify emerging themes. The analysis process involved breaking down of transcribed data into smaller units or 'codes' to create common categories or themes.

## 2.3 Patients' survey

A short questionnaire was developed to collect data about patients' experiences of the WA regional nurse-supported hepatitis C shared care program (Appendix 4). The questionnaire was based on the patient survey used in the evaluation of the Queensland hepatitis C shared care program (6).

In August 2013, paper questionnaires, accompanied by a reply-paid envelope, were posted by the regional hepatitis nurses to all 47 patients enrolled in the WA regional nurse-supported hepatitis C shared care program at that time.

The questionnaire was anonymous and sought information on a range of areas including patient demographics; patterns of accessing health services; reasons for commencing treatment; the types of professionals primarily responsible for treatment management and support; perceptions of the quality of care, including access to medication, support and information; and overall impressions of and attitudes towards the shared care initiative. The questionnaire was designed to be completed within 5-10 minutes.

The results of the patients' survey were used to assess overall levels of patient satisfaction with the WA regional nurse-supported hepatitis C shared care program and to compare the data collected about patients' experiences of treatment and care with data collected from health professionals about the WA regional nurse-supported hepatitis C shared care program.

## 2.4 Ethics

Ethics approval for this study was obtained from the WA Country Health Service Human Research Ethics Committee (Ref: 2013:09). A reciprocal ethics agreement was also obtained from the Curtin University Human Research Ethics Committee (Approval number: HR 11/2014).

### 3. Results of desktop review and key informant interviews

This section presents the results of the desktop review and key informant interviews using the eight evaluation questions for this study as a framework. Quotes from key informant interviews are shown indented in *italics* and have been grouped and coded as follows:

- A. Regional hepatitis nurses (Great Southern, Kimberley, and South West)
- B. Specialist physicians and GPs (Great Southern, Goldfields, Kimberley, Midwest and Perth metropolitan)
- C. Public Health Unit nurses (Pilbara and Wheatbelt).

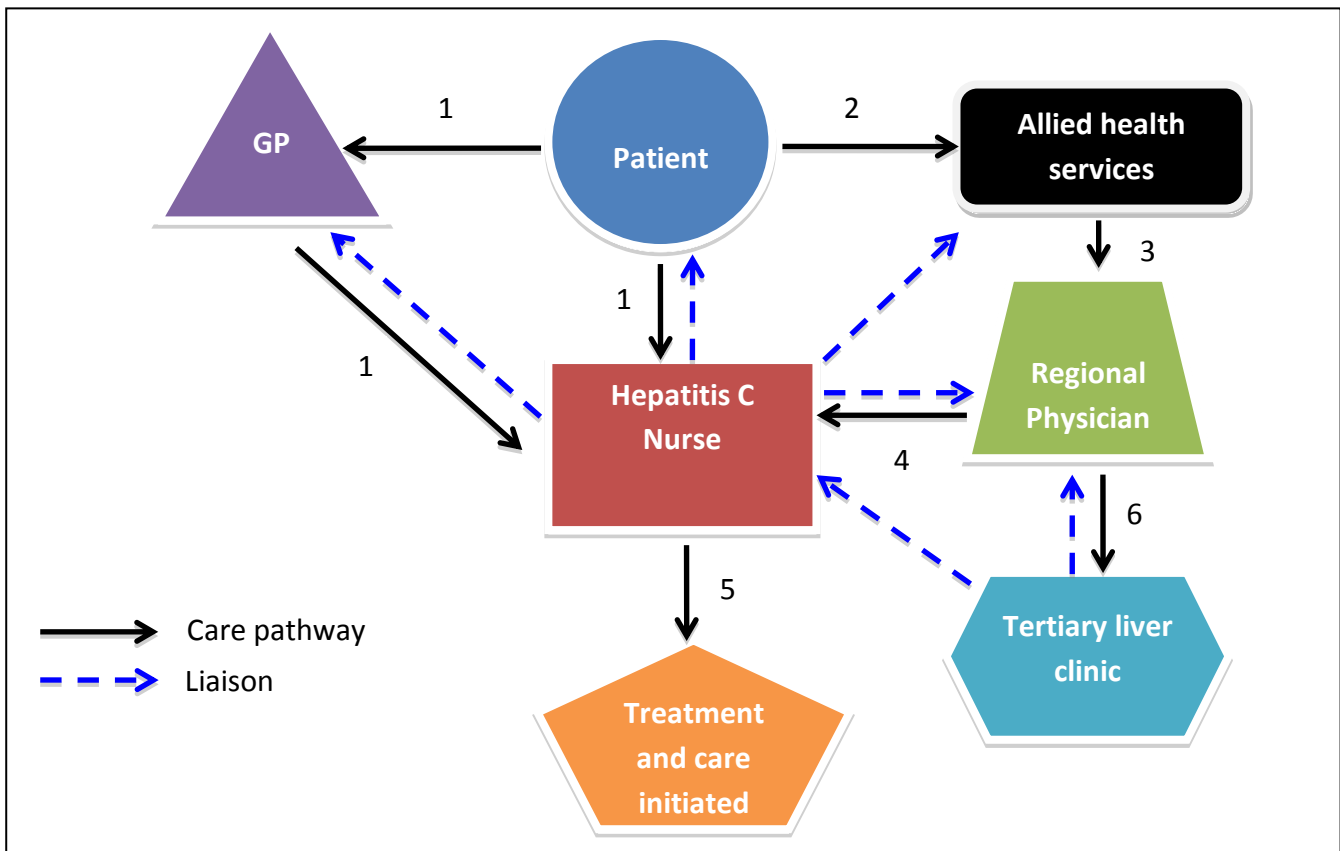
#### 3.1 How does the regional nurse-supported hepatitis C shared care program currently operate in WA?

The WA regional nurse-supported hepatitis C shared care program is coordinated in each region offering this service by a hepatitis nurse based in that region. Management of hepatitis C treatment and care is provided by regionally-based multi-disciplinary teams which may consist of GPs, physicians, private physicians and specialists, and the hepatitis nurses. Support may also be provided from tertiary liver units at Royal Perth Hospital and Fremantle General Hospital.

The steps in the care pathway for a patient enrolled in the WA regional nurse-supported hepatitis C shared care program are summarised below and in Figure 2:

1. Self-referral by patient (or patient is referred by a GP) to the hepatitis nurse. Patient is briefed by the hepatitis nurse about risks, benefits and precautions of treatment. The hepatitis nurse has several consultations with the patient, performing a good assessment and completing pathology workup before treatment can commence.
2. The hepatitis nurse refers the patient to allied health services for psychological review or drug and alcohol assessment and support if needed. After tests are complete, the hepatitis nurse contacts the referring GP and makes recommendations to them about the patient's condition and treatment.
3. When the patient consents to treatment the hepatitis nurse schedules an appointment for the patient to see the regional physician.
4. The regional physician liaises with the hepatitis nurse and the patient visits the nurse to receive their scripts, receive counselling and begin treatment.
5. The hepatitis nurse coordinates all patient treatment and care in consultation with the regional physician. The tertiary liver clinics provide advice and support to the regional physician and the hepatitis nurse on request.
6. Complex cases are referred to the tertiary liver clinics by the regional physician.

**Figure 2: Care pathway for nurse-supported hepatitis C shared care program**



### 3.1.1 Role of hepatitis nurse

Key informants were asked about the role of the hepatitis nurses. The main responsibilities identified were: a point of contact for patients; initial assessment of patients and pathology workup; coordination of treatment plans; and follow up and monitoring of patients.

*The nurse does the monitoring. We'll [physician] see them in the clinic and we'll start them on treatment. The nurse will give the patients their 1, 2 and 4 week blood test forms and then chase up those results each week and call the patient if needed to see them in person if they're struggling. If the results are within parameters that's fine if they're not she'll email me or ring me before she talks to the patients. (B)*

*The physician is extremely busy, and does expect and rely on our service to do all the educating, workup and to basically assess the suitability of a client holistically for treatment, whether it is medical, psych, socially, before patients get referred. (A)*

Key informants from regions with a nurse-supported hepatitis C shared care program identified the following key benefits of having a regional hepatitis nurse: increased likelihood of patients completing treatment; providing a constant point of contact in a context of changing locums; and nurses having capacity to provide a 'social work' role.

*Most of the patients value the support from the nurse, she's very conscientious and makes sure that they've had all their tests done and they're up to date and they know what's going on and she informs them what their test results are. (B)*

*I believe the support I've been able to give in the past by sometimes evening calls, weekend calls if they've rung with a problem I think it's enormously valuable to them [patients] to know that there is somebody at the other end of the phone. (A)*

*People with Hep C often have so many other social problems as well, so a full time nurse would be able to do a bit of a social work role as well the nursing role which I think these people often really need. (B)*

*With locums etc., the nurse is the constant. (B)*

Patient education was also noted as a key component of the hepatitis nurses' role.

*The nurse teaches the patients how to inject the medication and provides advice regarding taking oral medication and potential side effects. (B)*

*Being a general physician it's been just a lot easier for me. By the time I see them patients are usually pretty well up to date what to expect [with treatment] and what the eventual benefits, what the side effects are. (B)*

Key informants from regions without a nurse-supported hepatitis C shared care program were asked what benefits they believed having a dedicated hepatitis nurse in their region would bring. Perceived benefits included: improved access to treatment for patients; increased participation of GPs in hepatitis C shared care; increased data about patients to inform treatment plans; and increased likelihood patients would complete treatment.

Comments from regional physicians and public health nurses in regions without a nurse-supported hepatitis C shared care program included:

*If we had a Hep C nurse they could contact the GPs and say go ahead and refer them to the physician. The GPs might even take on the shared care a bit more proactively. (B)*

*Having a Hep C nurse would certainly make it more likely that we could treat more people. (B)*

*For every lab positive case notified to the Public Health physician, if I can chase all these patients, call them to the clinic, then see what sort of investigations they need, it may be very helpful data for us. (B)*

*Because we don't really engage with Hep C clients we don't really know what they're looking for or what they need. (C)*

### 3.1.2 Role of GPs in shared care

Few GPs were involved in the WA regional nurse-supported hepatitis C shared care program and only one GP was able to participate as a key informant in the evaluation. The main role of GPs in shared care was associated with assisting patients with medication to manage side effects.

*If the client presents with skin problems, sleep problems, any of the other side effects they might have I would recommend they return to their GP if there's a need for some prescribed medication. (A)*

However, for patients in more remote areas who were unable to meet with the hepatitis nurse, the GP was responsible for all the patient follow-up and monitoring.

*The nurse will send us an email saying this person needs bloods and so then we'll send out our drivers and use our connections to try and get the person in to have the bloods and then we'll send all the results back to the physician. So the physician does all the changing of doses and things but we [GP] mainly just do the chasing in between and monitoring for infections. (B)*

In rural and remote areas, effective communication between the physician, the hepatitis nurse and the GP was crucial.

*What works really well is the really good communication between the physicians and the nurse and the GP. Patients move around quite a lot as well, so they've got two locations where people are looking out for a patient and trying to chase someone up. So we're really quite proactive about chasing people and communicating with each other exactly what we're doing and what needs to be done. (B)*

The availability and capacity of GPs, high time investment required, and short appointment times allowing no opportunity to build rapport with patients were particular challenges noted by the key informants.

*It's harder for the patient to get a GP appointment than the hospital appointment so GPs do not play a role in follow up and patient monitoring. (B)*

*GPs can only give 10 minutes per patient. (B)*

*It's hard to get a GP here, they don't stay very long. (B)*

*GPs need to be very organised and structured because certain follow up tasks have to be done a particular day, it's not something you can do squeezing in between a couple of patients in clinic. You have to put dedicated time aside for it. (B)*

Other challenges included: keeping abreast with complex and changing treatments; and no incentives available e.g. CME points.

*There's a lot of GPs that could do it for one or two patients but there's a big reluctance to become known as the regional GP that helps with Hep C because they don't feel they have the time to dedicate 2 hours a week to it even. (B)*

*The GPs don't provide support, because it's just not one of their priorities. (B)*

The lack of bulk billing in some regional areas also presented a barrier for GPs to participate in shared care given the unpredictability of many clients:

*Hep C patients can be a nightmare to look after. It's just really hard in the private system that GPs have, they don't have bulk billing, and people might not turn up or don't have \$80 to pay for a consultation. We don't have a public system here. (B)*

*In our region it's a bulk billing system so there's a bit more chance GPs will follow up patients. (B)*

High caseloads, with only a small percentage of this caseload dedicated to hepatitis C, and competing priorities discouraged GPs from prescribing despite having completed the training to gain prescriber status. Others were discouraged from gaining prescriber status.

*A lot of GPs have done the e-learning course and are prescribers but have not come forward as wanting to prescribe. (B)*



*GPs are very interested and delighted to refer to physicians but don't want to get the S100 prescribing qualifications because they're probably not going to use them anywhere else. (B)*

The general feeling amongst key informants was that GPs should be more involved but achieving higher rates of GP participation in hepatitis C shared care was considered problematic for a variety of reasons.

*GPs arrange for patients to come back and have their vaccinations and they refer them to the physician and they've done the work up. So it's not that they'd reject getting involved it's just that they haven't got time to contact patients if they don't turn up for the next appointment. (B)*

*Would shared care services improve if we had more GP involvement? Yes it probably would if it was a GP who was committed, could give you half a day a week to come to clinic and was going to stick around in the region long term. (B)*

*I wouldn't say it is lack of skills but some GPs are completely unaware that there is this option of treatment. In the old days you didn't treat hep C (B).*

### 3.1.3 Role of tertiary liver clinic

Key informants highlighted that the nurse practitioner role at the Royal Perth Hospital liver clinic is unique in Australia and had similar functions to the regional hepatitis nurses' role.

*Once we know the patient is for shared care we send the GP the protocol that we use here and when the blood tests need to be done. The GP says yes or no whether they want to be involved. We start the patient on treatment and tell them when the next blood test is. We do major things like dose reduction. For the straightforward ones we don't see the patients again until the end of treatment. (B)*

Within the WA regional nurse-supported hepatitis C shared care program, the tertiary liver clinic had several functions including: advising on complex cases; as a referral point for patients with cirrhosis or those requiring a liver transplant; telehealth; and providing education for GPs, nurses and physicians.

However, the protocols used by regional shared care teams for referring patients to the tertiary liver clinics were not always clear.

*At the moment we don't know what criteria regional areas use before referring patients to RPH [Royal Perth Hospital]. There have been no problems so far. (B)*

Better communication systems where patient data could be shared and information about new treatments could be sent to regional physicians who were unable to attend education sessions in Perth were considered desirable.

*Some GPs refer to RPH for management of side effects. But we [RPH] don't have details about the patient's treatment, what he's already had, what is his genotype, what is the viral load. (B)*

*Communication has got to be better. We need one coordinating body to ensure services are not being duplicated. We do not know which patients have been treated by rural physicians. (B)*

*Maybe every six months Perth could send us some sort of bulletin of what is the most up to date changes and what they feel may be changing in the next 6 months. It would be nice to see what*

*might change so I can communicate that to patients or if there's likely to be new trials in treatment. I'm not always aware of the current trials in Perth. (B)*

However, overall, communications between the tertiary liver clinics and regional areas were considered to be very effective and timely.

*Any time I can contact RPH, they are happy to give support. Generally communications are smooth. (B)*

*We're happy for the regions to use RPH as a contact for advice. If there's a problem we will see the patient by telehealth. (B)*

*Communications from the region to Perth we don't have any issues at all. We can usually get someone on the phone without any problems. (B)*

The waiting time to see a tertiary liver clinic specialist was up to 18 months. Key informants noted that patient needs were still not being met despite the existence of regional nurse-supported hepatitis C shared care teams.

*The waiting list for us is something like 18 months. We can only see so many patients, our system is efficient but we need more manpower. (B)*

### 3.1.4 Role of allied health services

Regional mental health and alcohol and drug services were generally available and considered very good. Key informants reported that it was easy to refer patients and waiting times ranged from same day to 1-2 months. However, it was not always certain if patients then accessed the services they were referred to and some psychological reports could take time to receive.

*Access to drug and alcohol services does not seem to be an issue (A)*

*We've got a good relationship with drug and alcohol services in the region. (B)*

## 3.2 Are patients receiving care when they need it?

Key informants were asked to describe the typical patient profile and burden of hepatitis C in their region and the factors influencing treatment and care.

### 3.2.1 Patient profile and disease burden

The term 'Aboriginal' is used in preference to 'Aboriginal and Torres Strait Islander', in recognition that Aboriginal people are the original inhabitants of WA. No disrespect is intended to our Torres Strait Islander colleagues and community.

The majority of hepatitis C patients in each region were Caucasian with increasing numbers of Aboriginal and Asian patients.

*Most of the hepatitis C patients are Caucasian although we have increasing numbers of Aboriginal, and we are seeing an increasing number now of referrals for Asian. (B)*

Table 1 shows hepatitis C notifications for Western Australia for 2012; and the percentage of notifications that were identified as Aboriginal people in the three nurse-supported shared care regions (1).

**Table 1: Hepatitis C notification, Great Southern, Kimberley & South West regions of WA 1/1/2012 - 31/12/2012**

Region	Aboriginal	Non-Aboriginal	Not Stated	Total	Percentage Aboriginal
Great Southern	17	27	2	46	36.9%
Kimberley	3	16	2	21	14.3%
South West	12	46	27	85	14.1%
<b>Totals</b>	<b>32</b>	<b>89</b>	<b>31</b>	<b>152 (3 regions)</b>	<b>21.0%</b>

There were 152 hepatitis C notifications across the three regions in 2012 including 32 (21%) notifications for Aboriginal people. During this period, for these regions, the highest numbers of hepatitis C notifications were in the Great Southern and South West regions, with 46 and 85 notifications respectively. The highest number of hepatitis C notifications for Aboriginal people in these regions was also in the Great Southern and South West regions, with 17 and 12 notifications respectively.

### 3.2.2 Factors influencing regional treatment and care

There were 48 patients accessing hepatitis C treatment across the three nurse-supported regions between 1/1/12-31/12/12.

Table 2 shows the total number of patients receiving hepatitis C treatment through the regional nurse-supported hepatitis C shared care program in the Great Southern, Kimberley and South West regions.

**Table 2: Numbers of patients receiving hepatitis C treatment in the regional nurse-supported hepatitis C shared care program**

Region	Number of patients accessing treatment through nurse-supported hepatitis C shared care program	Period
Great Southern	14	July 2012 - Dec 2012
Kimberley	4	July 2012 - Dec 2012
South West	30	June 2011 - July 2012
<b>Totals</b>	<b>48</b>	

The key informant interviews discussed a range of factors that influenced whether regional patients received treatment and care when they needed it. Some factors were associated with the patient and included: patient's medical condition (e.g. existence of any co-morbidities); hepatitis C genotype (since some genotypes required more complex treatments than other genotypes);

circumstances of patient (e.g. lifestyle, age and work commitments); patient's choice given possible side effects; and patient's willingness and commitment to attend initial appointments and complete the treatment schedule.

Other factors influencing whether patients received treatment were associated with the capacity of regions to treat and care for patients and included: delays in getting results from psychological and drug and alcohol investigations; capacity to follow up patients by specialist physicians; and the experience and capacity of the hepatitis nurse.

Comments received included:

*Patients who are stable with no co-morbidities I will start the treatment. (2)*

*I think shared care is alright for genotype 2 and 3 but the direct antivirals have more side effects and are more difficult. (B)*

*If I start treatment I have to follow up. That is a limitation for me ... if it's more than two, four, five, ten patients, I cannot follow up. (B)*

*We do have a threshold for how many patients we can treat - a maximum of 12 at any one time. We've got 6 patients waiting who we would be treating now if we had the nurse more days per week. (B)*

*There may be a 6 month wait for treatment even though the patients are perfectly ready to start now. (A)*

Physician and nurse capacity and waiting for results of tests were also key factors influencing whether patients received treatment and care when they needed it.

*Waiting time to see the physician is usually 6 months. We used to have two physicians and the waiting time was 3 months. (A)*

*To actually get psych reports back on our patients who have had some sort of mental illness. That can delay things. (A)*

*Usually there's more investigations required, more blood tests, more information from ultrasound. Maybe there needs to be some time for them to stop drinking alcohol. (A)*

*The nurse is not full time and that's a tricky thing if you have a question or trying to chase something up on a day that she's not working. (B)*

Time to accessing treatment varied and was influenced by patient choice and lifestyle.

*Some patients are older and have lived with hepatitis C for a long time before they access treatment. (A)*

*It seems that a lot of people go to their GP and get tested but don't tell their GP that they already knew they had Hep C. (C)*

*We've got about 40 who are not suitable for treatment because they're still drinking or they want monitoring but they don't want treatment yet. We could probably be treating 15-20 patients and we get 2-3 new referrals per month. (B)*

At 31/12/12, there were **no** Aboriginal people accessing hepatitis C treatment in the WA regional nurse-supported hepatitis C shared care program. The key informant interviews provided some

insights concerning why Aboriginal people were not accessing treatment. These included lack of referrals, patient stability and compliance with the treatment regime.

*Sadly a lot of them are just not suitable for treatment because they're still drinking or they're not compliant with medications. (B)*

Overall, very few Aboriginal people had accessed treatment through the WA regional nurse-supported hepatitis C shared care program, outside of the correctional facilities.

*From April 2008 to 2013 we have received 18 referrals for indigenous clients in those 5 years. I've followed up every one either by letter or phone call. A good percentage has not responded by phone call. We've had 4 treatments in the region of Aboriginal people in the 5 years. (A)*

The barriers to accessing treatment for Aboriginal patients were not known but may have been related to issues of cultural security according to one key informant:

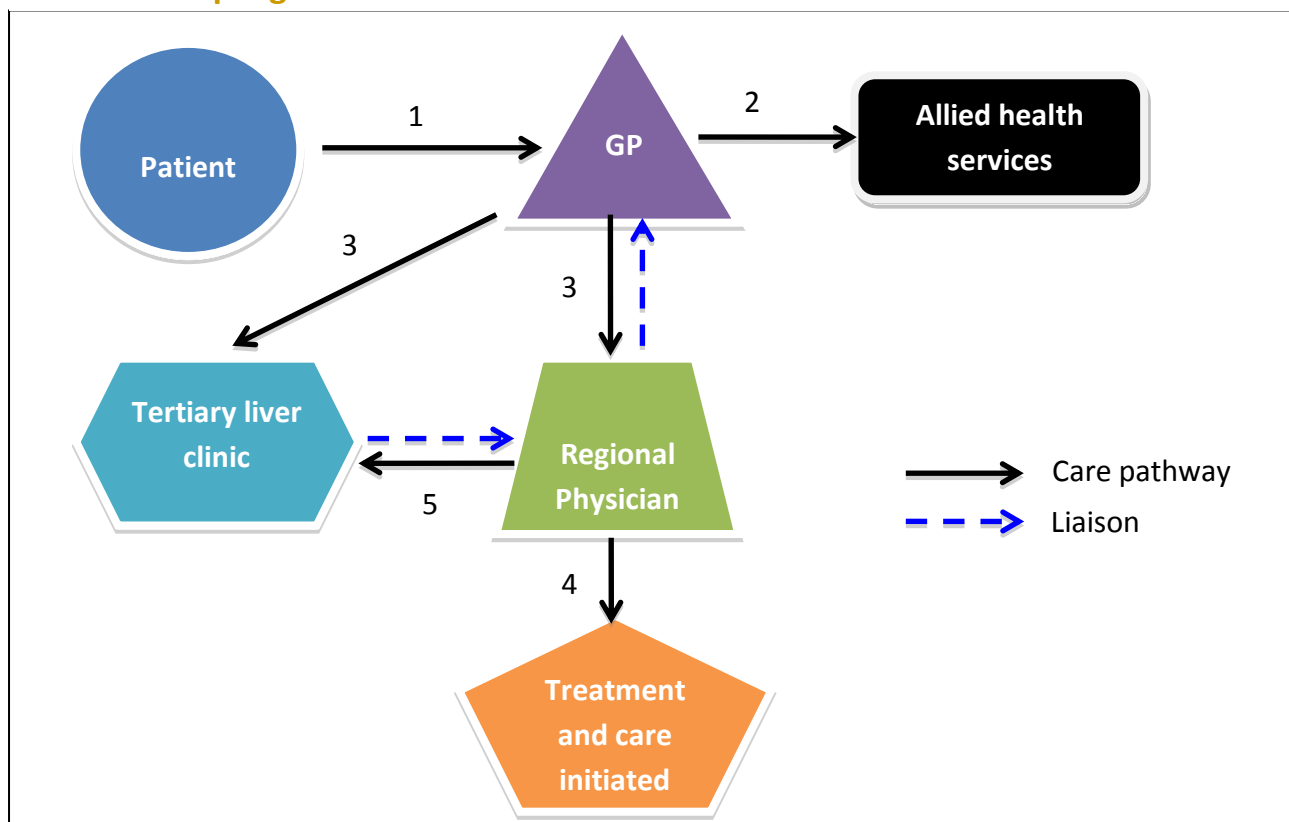
*Aboriginal patients are under-represented in the treatment program. Not sure why. An Aboriginal Health Worker may encourage more clients to access the services. (A)*

### 3.3 What is the model of care in regions without a nurse-supported hepatitis C shared care program?

The steps in the care pathway for a patient in a region without a nurse-supported hepatitis C shared care program are summarised below and in Figure 3:

1. Patient visits a GP for hepatitis C screening.
2. GP assesses patient condition and initiates pathology workup, also pre-treatment investigations with allied health services for psychological review and drug and alcohol assessment and care if needed.
3. GP refers patient to regional physician (or directly to a tertiary liver clinic if there is no regional physician or no capacity to treat patients in the region). Regional physician or tertiary liver clinic completes pathology workup and pre-treatment investigations for patient if required.
4. Regional physician initiates treatment and coordinates patient care, sometimes in a shared care arrangement with local GP clinics. The tertiary liver clinic provides advice and support to regional physician on request.
5. Regional physician refers complex cases to tertiary liver clinic for treatment and care.

**Figure 3: Care pathway for regions without a nurse-supported hepatitis C shared care program**



### 3.4 What are the perceived benefits of having a regional nurse-supported hepatitis C shared care program?

The perceived benefits associated with the regional nurse-supported hepatitis C shared care program were: shorter waiting times for appointments; longer appointment times; ability to be more responsive to patient needs; treatment closer to home and therefore reduced patient transport costs to tertiary clinics; increased patient compliance; and continuity of care.

Comments from the hepatitis nurses and regional physicians included:

*The GP appointments are only 15 odd minutes. Most of the time when we see clients it's 30 minutes. So we have time, we try to engage them quite holistically reviewing where they're at with not just their physical health but other issues in their life. (A)*

*Probably about 6 or 8 weeks to see a physician and then starting treatment within a week or two if they want to. Compared to Perth it's pretty good. (B)*

*We do establish a very good rapport with patients and maintain that contact which I know they appreciate. (A)*

*Patients say it's much, much better having a person that we can actually come and talk to in person. A lot of people do say it makes a difference between whether they choose to have treatment or not, being able to do it locally. (B)*

*If we can see the patient here it's better for the patient and they're more compliant and then they can use the local services properly. If we have to refer the patient to a tertiary centre we have to pay for the patient assisted travelling service from the hospital to the tertiary centre. (B)*

The data collected from the key informant interviews reported 98% - 100% patient compliance with medication and completion of the treatment regime in all three WA regions with a nurse-supported hepatitis C shared care program. The reasons given by key informants for patients not completing treatment were: no response to treatment; reaction to treatment; and difficulties coping with treatment. Comments included:

*It's mainly null responders by week 12. (B)*

*One had a major adverse reaction. He had a retinal haemorrhage at week 28, so we had to stop. (B)*

*We had a guy who got severe depression, suicidal, so he was not going to get through treatment. (B)*

*One just couldn't cope with the dysgeusia [loss of taste] with boceprevir and he was trying to work full time. Unfortunately he didn't contact the nurse to say he was having problems and just stopped his treatment. (B)*

### 3.5 What challenges/enablers are associated with implementing the regional nurse-supported hepatitis C shared care program?

Challenges and enablers associated with implementing a regional nurse-supported hepatitis C shared care program included patient characteristics; GP turnover and medical registrars on locum in regional areas; and capacity of nurses and physicians to meet the needs and expectations of patients.

Comments from health professionals included:

*Some of the Hep C patients are quite high demand patients and a lot have mental health issues. (B)*

*We have 4 registrars rostered for on call, night duty, night off, and clinic. No permanent registrar, so for treatment they cannot follow up and the follow up plan might be difficult with different registrars (B)*

*There was an attempt to get the GPs interested and involved in shared care but it didn't work. It's partly because a lot of GPs don't stay all that long in the region. (B)*

*With locums you don't get that rapport happening, the locum doctor doesn't really know the patient and patients don't want to be seeing somebody different every time. (A)*

*We have had a few comments, usually from people who have been treated previously in a great big teaching hospital centre in Brisbane, Melbourne, Perth, who are used to having a nurse available 24/7. (B)*

It was the responsibility of the hepatitis nurse to decide when to consult a physician and it was noted that this judgment was based on the nurse's experience and education.

*It needs to be a fairly experienced nurse. You don't just delegate it to someone without that clinical skill. (B)*

There was no regular dedicated time available for the nurse and physician to meet in some regions and this was highlighted by one hepatitis nurse as a challenge:

*I would like to think that I could have a regular meeting with our physician to discuss the clients, particularly the ones on triple therapy. Sometimes the physician doesn't even get to see them from pre-treatment until the end of treatment and I know he's acknowledged the work that I do in this role and obviously trusts me to consult with him if there's a real concern which I certainly do. But it would be nice to have a little bit more time face to face with him. (A)*

### 3.6 What are the consequences and implications for regions without a nurse-supported hepatitis C shared care program?

In regions without a nurse-supported hepatitis C shared care program, treatment was offered to patients if regional physicians were available.

*I don't think the physician's ever refused anyone. Occasionally he says he doesn't think it's a good idea because it looks like they're not going to give up their using [drugs] and they've got alcohol problems and they've got nowhere to live but most of the time he will take them on so that is a service that's here which is much better than not having a service here. (B)*

However, there appeared to be little awareness of what happened to patients after they were referred to a GP or tertiary clinic, for example how much support they were getting, patients' awareness of support organisations, and patients' access to specialist care.

*Our role [nurses] ends with the notification and information to the doctors. I'd certainly like more involvement. I hate just knowing that patients are out there and you really don't know how much support they're getting, whether they know about the Hep C Council [HepatitisWA], all that type of thing. (C)*

A lack of GPs was also noted and options were identified for supporting GPs who were interest in participating in a shared care model. Comments from key informants included:

*Some GPs would like to get involved [in shared care] and some don't. I think you've got to nurture those that do. I think Medicare Locals may be a way of supporting the GPs. (C)*

Some key informants indicated that stigma associated with hepatitis C treatment still existed in their region. As a result, the absence of shared care was not considered significant for those patients who preferred to access treatment in Perth to avoid discrimination.

*From a patient's perspective it depends how far they have to travel. I would say it also depends on what support they have in the community. A lot of the patients don't want other people to know that they're having treatment in the community. (C)*

*It's not in my town. We don't do sex, we don't do drugs. Unfortunately that attitude is amongst health professionals delivering services like needle and syringe programs. It's also coming from the Aboriginal people - drug taking is very, very shameful. (C)*



The implications for regions without a regional hepatitis nurse included increased presentations at emergency departments and lack of treatment or follow up for patients.

*If we have a hepatology nurse, patients would contact the hepatology nurse if they have a problem. As we don't have a nurse, if they are too ill or have a high temperature we have an emergency department and if they need admission then the on call physician has to look after them (B)*

*There may be no follow up or they get lost in the system. (B)*

*The proportion of people that travel out of the region for treatment is zero. People are either treated within the region or they're not treated because there's no capacity (B)*

### 3.6.1 Telehealth

The majority of key informants who had used telehealth spoke positively about telehealth as an enabler to providing patient care and treatment, although one key informant noted mobile coverage could present an issue.

*We've got problems with mobile coverage as well so even if a person's got a phone doesn't necessarily means it works. (A)*

*The liver clinic offers regions without a hepatitis C nurse surrogate nurse support by telehealth. It's not ideal. But we did a survey on telehealth and the patients were happy, although they worry about confidentiality. I think we're doing well with telehealth. (B)*

Telehealth was considered to be an enabler particularly for patients in rural and remote areas:.

*In the rural areas, telehealth works really well and is cheaper. (B)*

*We use telehealth a lot for patients in remote areas because it's a long way for patients to travel. (B)*

There was general interest expressed by both physicians and the liver clinic that the telehealth service could be expanded and enhanced further:

*Telehealth works well we just need more support – nurses, trained nurses in the region. The physicians need to be linked. A database we can both access would be ideal. (B)*

*I think telehealth has got a role and I think it would be good to expand, at least be discussed with GPs. (B)*

While local care was considered more practical, the use of other regional service providers and telehealth were mentioned as options worth exploring:

*It's too expensive, difficult and impossible, Hep C patients are quite disorganised, to get them going back and forth to Perth it's just a ridiculous concept. (B)*

*You can do a lot with telehealth. So initially they might go down to Perth and be screened and then they could be supported by telehealth. I think you've got to look at those other options too. (C)*

### 3.7 What are the critical features of the WA Regional nurse-supported hepatitis C shared care program compared with other best practice models of shared care?

The critical features of the WA regional nurse-supported hepatitis C shared care program identified by key informants were:

- **Patient-centred care** enabling patients to choose when to start treatment depending on health status and personal or work commitments
- **Dedicated hepatitis nurse located regionally** who is responsible for patient education and coordinating all patient treatment and care including follow up and monitoring of patients and patient referrals to allied health services
- **Specialist physicians with S100 prescriber qualifications** responsible for assessing patient's health status, initiating treatment, and refining treatment schedule as required
- **Collaboration with GPs** where possible to help patients manage side effects of treatment once initiated
- **Telehealth links** between regional areas and tertiary liver clinics in Perth for ongoing support and for referral of complex cases according to agreed protocols
- **Excellent communications** between nurse, GP, physician, and tertiary centres
- **Stability of key roles** involved to provide continuity of care.

#### 3.7.1 Comparison with other best practice models of shared care

Nurse-supported models of hepatitis C shared care are not unique to WA. Hepatitis C shared care programs also exist in South Australia, Queensland, New South Wales, Victoria and New Zealand. The desktop review identified the key features and principles of shared care programs in other states and New Zealand (Appendix 5).

In summary, the common goal across all of the hepatitis C shared care models reviewed, including the WA model, was to improve patients' access to holistic treatment and care for hepatitis C through multi-sectoral participation and partnerships between primary care providers and tertiary specialists. Additional benefits of the hepatitis C shared care programs were increased patient compliance, increased likelihood of patients completing treatment, reduced travel costs for patients able to access treatment locally and reduced demand on tertiary clinics for appointments.

### 3.8 What elements are crucial to the success of a regional nurse-supported hepatitis C shared care program in WA?

In WA, the focus of the regional nurse-supported hepatitis C shared care program was on effectively coordinating and providing treatment to regional patients, particularly those in rural and remote areas.

The key informant interviews identified five critical success factors for the WA regional nurse-supported hepatitis C shared care program. These factors have been highlighted in the quotes from key informants in the previous sections and are summarised below:

1. **Appropriate funding** so that patients can be started on treatment and workload associated with following up and monitoring patients will be manageable.
2. **Ongoing education and training for GPs and physicians** about new research, status of new treatments and side effects.
3. **Standard protocols for shared care health professionals and guidelines for patients.**
4. **Support for regional GPs** who wish to participate in shared care for hepatitis C treatment and care.
5. **Support for hepatitis nurses** including training and education; access to regional physicians; and telehealth backup from tertiary centres.

## 4. Results of patients' survey

Twenty-two (22) completed surveys were returned by patients enrolled in regional nurse-supported hepatitis C shared care programs in Western Australia. Two (2) surveys were not eligible for analysis; one individual was receiving treatment within a correctional facility (treatment site outside the scope of the study) and one survey did not have a signed participant declaration sheet (consent requirement not met).

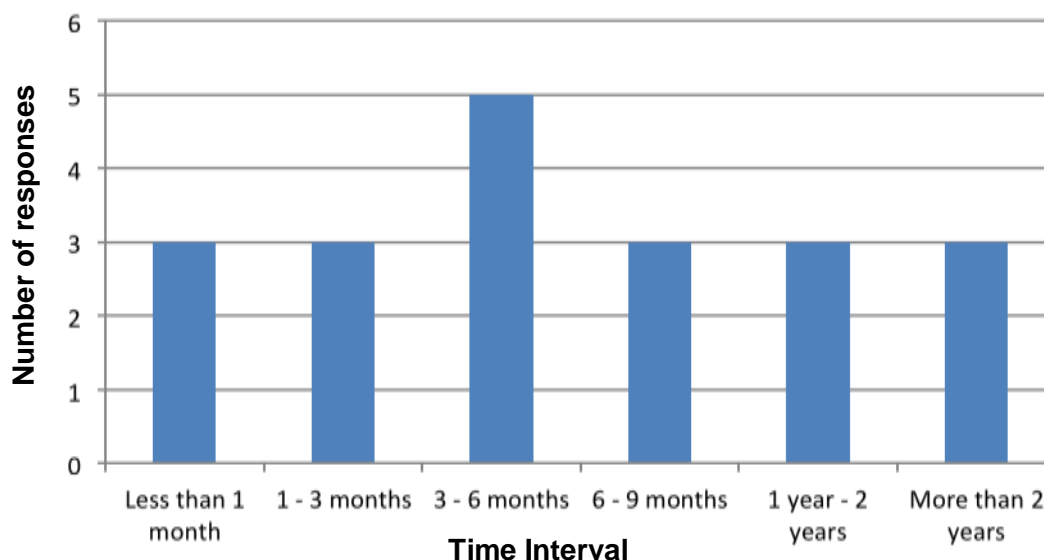
### 4.1 Demographics

Of the questionnaires analysed, 13 were from males and seven (7) from females; all reported being 'non-indigenous'. Eight patients (40%) were aged 56-65 years; seven (35%) aged 46-55 years and five (25%) aged 36-45 years. The majority (80%) were born in Australia. Fourteen (70%) were currently residing in the South West region of Western Australia, four (20%) in the Great Southern and two (10%) in the Kimberley.

### 4.2 Referral and treatment

Year of diagnosis for hepatitis C ranged from '1980s' to 2013, with ten (50%) patients reporting having been diagnosed within the past six years (2007-2013). The duration between referral to treatment commencement varied from within one month of referral to more than two years after referral (see Figure 4).

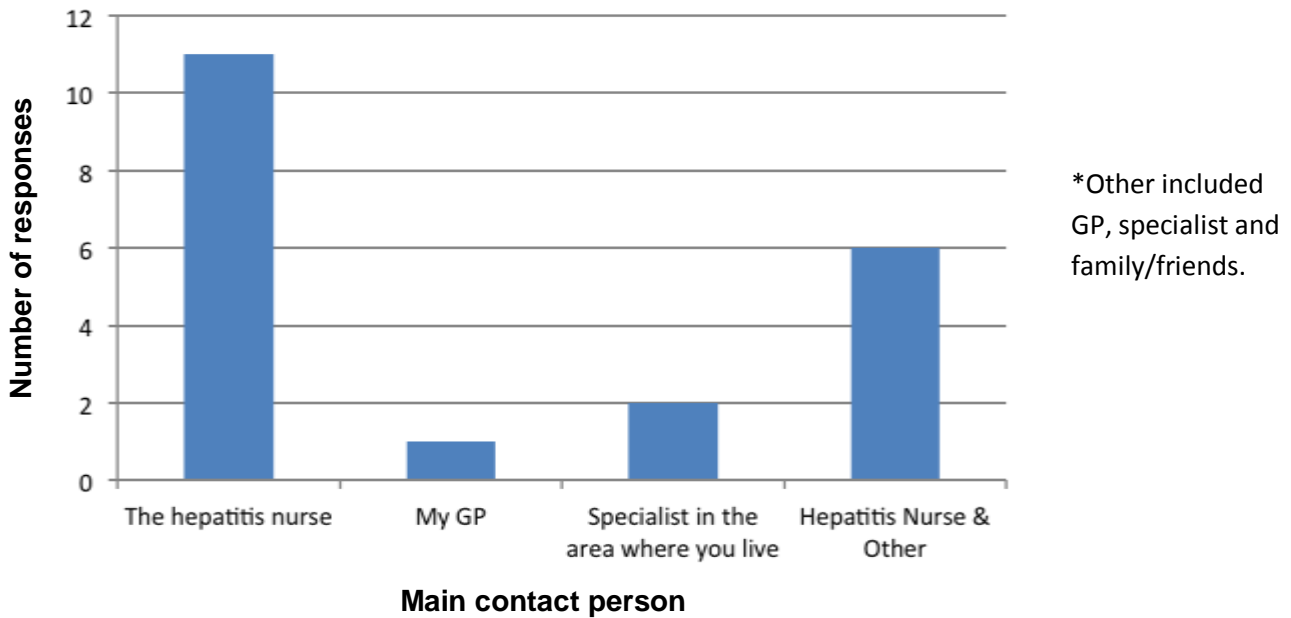
**Figure 4: Interval between referral & treatment (N=20)**



The majority of patients (55%) reported their hepatitis nurse being the main point of contact for hepatitis C-related problems (Figure 5). 'Hepatitis nurse and other' was also reported by six respondents, with 'other' referring to one of the other categories or family/friends. Twelve patients (60%) indicated that it was 'easy' to contact this person, 6 (30%) that it was 'very easy' to

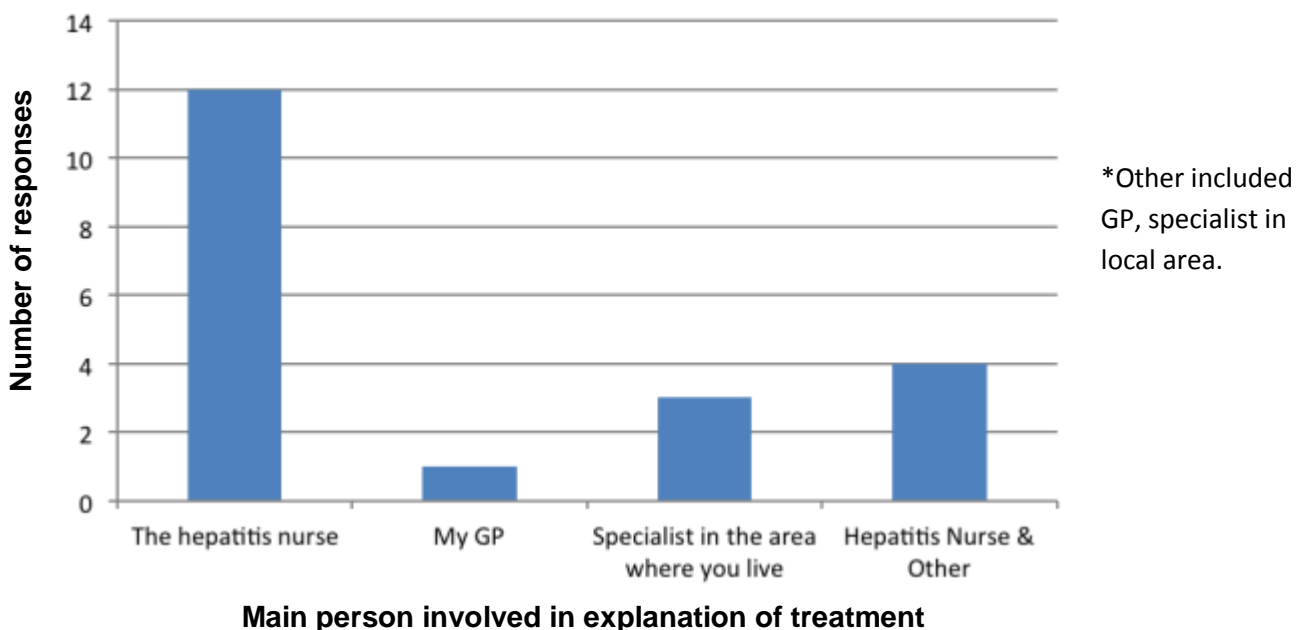
contact this person. One patient believed it was 'difficult' to contact this person, and one patient did not answer this question.

**Figure 5: Main person contacted when patient had problems relating to hepatitis C (N=20)**



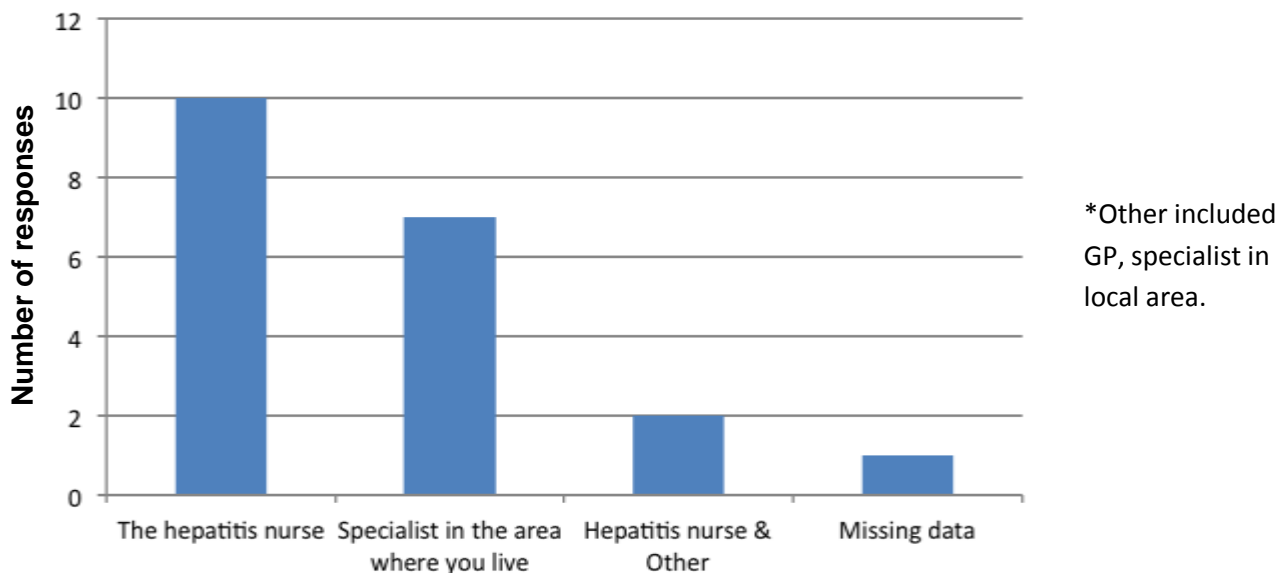
As identified in Figure 6, twelve patients (60%) named their hepatitis nurse as the main person involved in explaining hepatitis C treatment to them, with 'hepatitis nurse and other' identified as the second most popular response (four patients – 20%).

**Figure 6: Main person involved in explaining details of hepatitis C treatment (N=20)**



The patient's hepatitis nurse was also identified as the most reported contact person involved in scheduling appointments for patients (10 patients - 50%), as represented in Figure 7, with the second highest recorded response being the specialist in their local area (seven patients – 35%).

**Figure 7: Main person involved in scheduling patient appointments (N=19)**

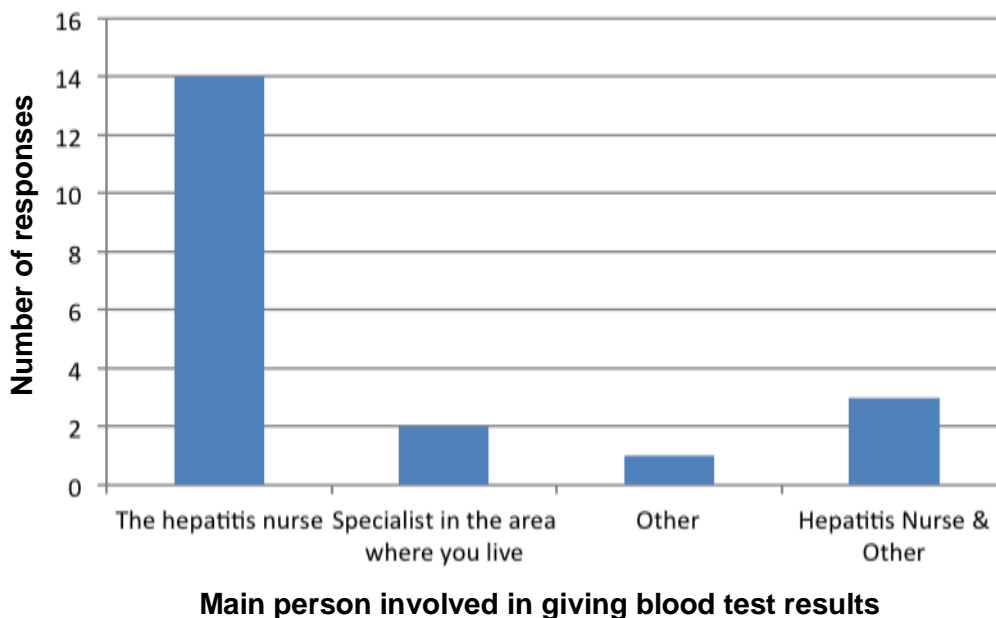


**Main person involved in scheduling appointments**

As identified in Figure 8, the hepatitis nurse was also reported as the main contact person involved in supplying the majority of patients with blood test results while on treatment (14 patients - 70%). Three respondents (15%) named both their hepatitis nurse and the specialist in their local area equally as to whom they receive blood test results from. Two respondents reported that the main person involved in providing blood test results while they were on treatment was their local specialist.

Most patients (15 patients - 75%) reported that they did not access any additional services apart from their GP, hepatitis nurse and liver specialist while receiving hepatitis C treatment. Of the remaining five patients, two patients reported accessing HepatitisWA for information/support, one patient accessed Hepatitis NSW, one patient accessed information online, and one patient reported accessing a local hospital as well as their hepatitis nurse.

**Figure 8: Main person involved in giving blood test results while on hepatitis C treatment (N=20)**



\*Other included specialist in local area and PathWest for other category

### 4.3 Satisfaction levels

Patients were asked about their satisfaction levels relating to three aspects of care whilst receiving hepatitis C treatment. As identified in Table 3, patients reported high levels of satisfaction across the three categories with 85% being highly or slightly satisfied.

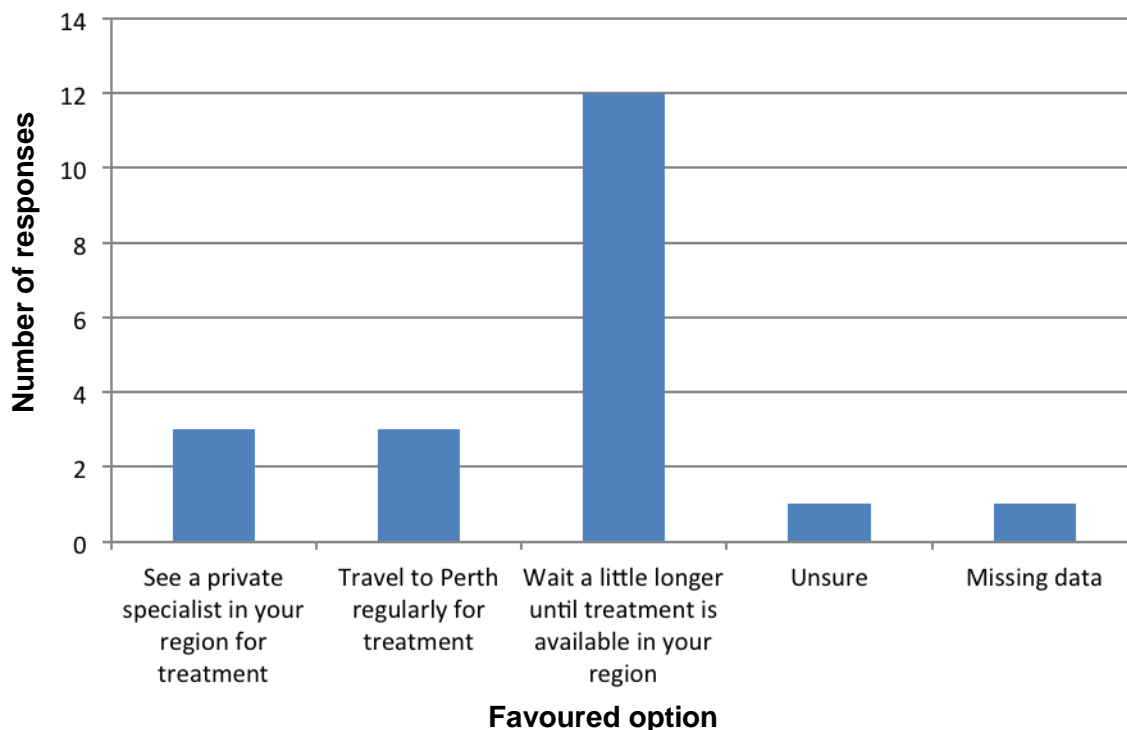
**Table 3: Patient satisfaction levels with differing aspects of care**

Number of respondents n=20		Aspect of care		
		Information received about the side-effects of treatment	Level of support received while on treatment	Overall experience of the hepatitis C treatment program
Satisfaction level	Very satisfied	12 (60%)	13 (65%)	13 (65%)
	Slightly satisfied	5 (25%)	5 (25%)	4 (20%)
	Slightly unsatisfied	2 (10%)	2 (10%)	1 (5%)
	Very unsatisfied	1 (5%)	0	2 (10%)
	Total	20 (100%)	20 (100%)	20 (100%)

#### 4.4 Access to treatment

Patients were asked what they would do if hepatitis C treatment was not available in their region. The majority (60%) responded that they would wait until treatment is available in their region (Figure 9).

**Figure 9: Participants' favoured option if hepatitis C treatment was not available in their region (N=20)**



#### 4.5 Patient recommendations for hepatitis C services

Many patients reported that appointments with the hepatitis nurse and specialist were very important and reassuring, and should be maintained regularly throughout treatment. It was recommended by some patients that more information on side effects should be discussed with patients. Also, one patient mentioned that there should be staff members available to temporarily fill the positions of hepatitis nurse/ specialists when they are on leave.

One patient commented on the length of time it takes for a travel claim to be accepted. This patient recommended that patients could have a standard account to be used when accessing services to save time spent registering individual claims. Travel/distance was also mentioned by a few other patients, with one patient reporting that travelling a shorter distance to access medication would better suit their needs.

Two patients mentioned the blood test result process in their responses. One respondent would rather blood test results to be sent directly to them and the other respondent would like to receive blood test results more regularly. The same respondent reported that they would have benefited from being linked to a support group during treatment.



## 5. Overall summary and conclusions

The WA regional nurse-supported hepatitis C shared care program has not been evaluated previously across the three regions. The focus of the evaluation by WACHPR was to answer the following questions:

1. How does the regional nurse-supported hepatitis C shared care program currently operate in WA?
2. Are patients receiving care when they need it?
3. What is the model of care in regions without a nurse-supported hepatitis C shared care program?
4. What are the perceived benefits of having a regional nurse-supported hepatitis C shared care program?
5. What challenges/enablers are associated with implementing the regional nurse-supported hepatitis C shared care program?
6. What are the consequences and implications for regions which do not have a nurse-supported hepatitis C shared care program?
7. What are the critical features of the WA regional nurse-supported hepatitis C shared care program compared with other best practice models of shared care?
8. What elements are crucial to the success of a regional nurse-supported shared care hepatitis C program in WA?

A mixed methods design was used for the evaluation comprising three components. These were: a desktop review, key informant interviews and a patients' survey. The main findings of the evaluation are summarised below using the eight evaluation questions as a framework.

### 5.1 How does the regional nurse-supported hepatitis C shared care program currently operate in WA?

Currently, there are three regions in WA operating a nurse-supported hepatitis C shared care program for patients with chronic hepatitis C; these regions are the Great Southern, South West and the Kimberley. The perceived role of the hepatitis nurse was as a point of contact for patients, patient education, coordination of treatment plans, follow up and monitoring of patients, building rapport with patients, and supporting patients to complete the demanding treatment schedule.

These perceptions were corroborated by the patients' survey data. The 'hepatitis C nurse' or the 'hepatitis C nurse and other' were identified by 80% of patients as the main person who explained hepatitis C treatment to them, and by 85% of patients as their main point of contact during treatment and responsible for returning test results and scheduling appointments. The majority (90%) of patients reported it being 'very easy' or 'easy' to contact the hepatitis C nurse.

The nurse was seen to provide a constant in a context of changing locums in some regional areas. Tertiary centres provided education for GPs, nurses and physicians and advised on complex cases; telehealth was used extensively. Patient compliance with the treatment schedule and the

likelihood of patients completing treatment were very high; 98%-100% compliance rates were reported. Patients with cirrhosis or those requiring a liver transplant were referred to tertiary centres by regional physicians. Mental health and alcohol and drug services were generally available and patients could be referred to these services easily.

The regional nurse-supported hepatitis C shared care program appeared to operate well according to the key informant data collected from participating healthcare providers. Data collected from the patients' survey indicated more than 85% were very satisfied or slightly satisfied with information received about the side effects of treatment, level of support received during treatment and overall experience of the hepatitis C shared care program.

## 5.2 Are patients receiving care when they need it?

In regions operating a nurse-supported hepatitis C shared care program, waiting times for appointments to see a specialist physician were short (2-4 weeks) and opportunities for longer appointments with the regional hepatitis nurse were possible, either face-to-face or via telehealth. A regional hepatitis nurse could manage treatment and care for up to six patients per day. Treatment could be delayed if the patient load exceeded the capacity of the regional hepatitis nurse since the ability to follow up and monitor patients was critical to the success of the program.

Patient stability, patient circumstances (e.g. place of abode in a rural or remote area or fly-in-fly-out worker, work commitments), delays in obtaining results from psychological investigations, the patient's choice and their willingness and commitment to attend initial appointments and ongoing treatments were noted as key factors influencing ability to initiate treatment in regional areas. The patient's hepatitis genotype was also an influencing factor. Type 1 genotype patients required a different and more demanding treatment regime and were more likely to require care from tertiary centres.

At the time of data collection, there were no Aboriginal people enrolled in the three regional nurse-supported hepatitis C shared care programs although 21% of the notifications in these regions between in 2012 were Aboriginal people. Key informants considered Aboriginal patients' health status including alcohol or drug use were likely to make them unsuitable for hepatitis C treatment. There were no Aboriginal respondents in the patients' survey. The factors influencing access to treatment for Aboriginal people need to be investigated further.

## 5.3 What is the model of care in regions without a nurse-supported hepatitis C shared care program?

In regions without a nurse-supported shared care model, there is some evidence of shared care for patients involving specialist regional physicians and GPs and sometimes practice nurses. In other regions, a lack of GPs and limited capacity of regional physicians requires patients to wait for a referral to a tertiary liver clinic in Perth for treatment and care. There are associated costs for patient travel to tertiary centres and waiting periods for an appointment can be up to 18 months.

The patients' survey indicated that most patients (60%) would prefer to wait for treatment to be available locally than travel to Perth for treatment. However, in regions with closer proximity to Perth, key informants suggested that some patients preferred to travel to Perth for treatment owing to issues of stigma and discrimination associated with hepatitis C and injecting drug use in their local community.

#### 5.4 What are the perceived benefits of having a regional nurse-supported hepatitis C shared care program?

The main benefits associated with the nurse-supported hepatitis C shared care program reported by key informants were shorter waiting times for appointments, longer appointment times, being more responsive to patient needs, access to treatment closer to home (and reduced travel expenses to tertiary centres), increased patient compliance, and continuity of care.

#### 5.5 What challenges/enablers are associated with implementing the regional nurse-supported hepatitis C shared care program?

The main challenges reported with the nurse-supported hepatitis C shared care program were difficulties managing workload, medical registrars on locum/roster, nurse capacity, capacity of physicians to do pre-treatment investigations when patients are referred directly without seeing nurse first, leaving judgment about whether to consult a physician to the nurse, having no regular dedicated time available for the nurse and physician to meet in some regions, and managing expectations of patients for 24/7 availability of the hepatitis C shared care nurse.

Key informants were in agreement that GPs should be more involved in the nurse-supported hepatitis C shared care program but noted several challenges. These included: a high number of locums in regional areas; high caseloads with only a small percentage of caseloads dedicated to hepatitis C; no opportunity for locums to build rapport with patients; the high time investment required to manage hepatitis C patients; and the requirement to keep abreast with complex and changing treatments for chronic hepatitis. The lack of incentives for GPs to participate in hepatitis C shared care was also noted. There were several GPs who were S100 prescriber trained but did not participate in providing treatment for patients.

#### 5.6 What are the consequences and implications for regions without a nurse-supported hepatitis C shared care program?

For regions without a nurse-supported hepatitis C shared care program, there was little awareness of what happened to patients after they were referred to a GP or tertiary centre. It was unclear how much support patients were receiving and what awareness they had of support organisations including HepatitisWA.

Key informants in regions without a nurse-supported hepatitis C shared care program could see the potential benefits of the shared care model but stressed that access to specialist care would

be needed for the service to function well and the availability of specialist physicians and GPs in regional areas was uncertain.

### 5.7 What are the critical features of the WA regional nurse-supported hepatitis C shared care program compared with other best practice models of shared care?

Key informants identified that excellent communications between the hepatitis nurses, GPs, physicians, and the tertiary centres were a critical factor contributing to the success of the regional hepatitis C shared care programs. Telehealth was used extensively, particularly to support health professionals and patients in rural and remote areas.

Continuity of care to provide support for patients and increase their likelihood of completing the treatment schedule was also considered essential and the availability of a dedicated hepatitis nurse was perceived to provide this stability and continuity particularly in a context where availability of GPs was scarce and locum registrars were common.

### 5.8 What elements are crucial to the success of a regional nurse-supported hepatitis C shared care program in WA?

Key informants identified five elements considered crucial to the success of a regional nurse-supported hepatitis C shared care model. These elements were: appropriate funding; ongoing education and training for GPs and physicians; standard protocols for shared care health professionals and guidelines for patients; support for regional GPs; and support for hepatitis nurses.

#### 1. **Appropriate funding.**

Adequate funding should be available for the nurse-supported hepatitis C shared care program so that patients can be started on treatment and workload associated with following up and monitoring patients will be manageable. Funding allocations for nurses should be matched to the local patient population and would be expected to vary across regions. The funding allocations could consider including funds for the hepatitis nurse to accompany the regional physician(s) on visits to remote and rural areas.

#### 2. **Ongoing education and training for GPs and physicians.**

Hepatitis C treatment is rapidly improving and GPs, physicians and nurses require ongoing education about new research, status of new treatments, side effects and protocols for treatment and referrals. Adequate training of nurses involved in hepatitis C shared care is essential and a central coordinating body for nurse training and status of regional shared care would be beneficial.

#### 3. **Standard protocols for shared care health professionals and guidelines for patients.**

The roles and responsibilities for shared care, including how to treat patients, whom to treat, when to refer, frequency of bloods, and interpreting bloods, should be clearly stated

in standard protocols for all shared care health professionals. a database accessible by tertiary and regional centres with all patient results and patient history would enable better communication between health professionals involved in shared care. Guidelines for patients are also needed to avoid confusion. These guidelines would include dates of appointments, frequency of bloods, whom to call for what service and when.

**4. Support for regional GPs.**

GPs who express interest in participating in the hepatitis C shared care program require support given limited bulk billing in regional areas and the unpredictability of some hepatitis C patients in committing to appointments. For regions without a dedicated hepatitis nurse, providing a practice or clinic nurse with some dedicated time to support hepatitis C patients or involving Medicare Locals could incentivise more GPs to participate in shared care service delivery. Increased involvement of regional GPs in shared care services would increase regional capacity to treat patients.

**5. Support for hepatitis nurses.**

Hepatitis C nurses are required to decide when to refer patients to the physician and this places a significant responsibility and burden on nurses. Adequate support for hepatitis nurses is needed either from peers or during scheduled meetings with the physician. Allocating regular time for regional hepatitis nurses and physicians to meet and not just when problems arise would provide additional support for nurses. The option to access support from tertiary centres via telehealth is effective and expansion of this service should be considered. The availability of the hepatitis nurse needs to be managed carefully. Allowing patients to have access to the nurse '24/7' – i.e. seven days a week, 24 hours a day, may lead to a higher turnover of hepatitis nurses.

The patients' survey data also included suggestions for improving the regional hepatitis C shared care services. These suggestions were: more information on treatment side effects; improvements to the travel claims procedure; access to support when usual shared care health professionals were sick or absent; access to a hepatitis C support group; and improvements to the process for accessing blood test results. The feasibility of these suggestions could be investigated further in future studies.

## 5.9 Study limitations

This evaluation study was associated with the following limitations. Firstly, only one GP was available to be interviewed for the study. Since GPs are considered to play an important role in delivering hepatitis C shared care services, yet few regional GPs deliver shared care services, it would be beneficial to consult with additional regional GPs to better understand the barriers and enablers they face in participating in regional hepatitis C shared care services.

Secondly, the patients' survey yielded a 43% response rate of all patients (47) currently enrolled in the regional nurse-supported hepatitis C shared care program. While this represents a reasonable response, it should be noted that the majority (70%) of respondents resided in the South West

region (20% in the Great Southern and 10% in the Kimberley region) and therefore the survey data is mainly representative of patients' experiences in the South West region.

Thirdly, the scope of the evaluation did not permit following up patients who did not complete the survey, people who were not receiving treatment e.g. Aboriginal people, or the collection of feedback from patients receiving treatment in regions without a nurse-supported hepatitis C shared care service. Future studies could explore the feasibility of using other data collection methods, for example telephone interviews with patients conducted by regional nurses and culturally acceptable methods to collect feedback from Aboriginal people diagnosed with hepatitis C to understand if they face barriers to accessing treatment, and if so, how these barriers may be addressed.

## 5.10 Conclusions

For regional patients who want hepatitis C treatment in regions with a hepatitis nurse, the waiting time to start treatment and the support services available seem to be as good, if not better, than in Perth. The majority of patients (85%) responding to the patients' survey expressed high levels of satisfaction with the services available. More than 60% of patients responding to the survey also indicated that they preferred to access treatment locally. Furthermore, should hepatitis C treatment and care not be available in their region, they would prefer to wait until services were available locally rather than travelling to Perth for treatment.

It is of interest that while the number of new notifications for hepatitis C in the Great Southern, South West and Kimberley regions in 2012 included approximately 21% Aboriginal people, no Aboriginal people were currently receiving hepatitis C treatment. More information is required about the barriers to Aboriginal people accessing treatment and how they can be overcome.

There is a limit to the number of patients that a hepatitis nurse and physician can support on treatment (about 5-6 patients per day that the nurse is employed). Given the demands of the role in following up and supporting patients, having more than one part-time nurse may be a more sustainable option than a full-time nurse. Nurse allocations should be considered based on expected regional patient caseload.

There are very few incentives for regional GPs to get involved in something as complicated and time-consuming as long-term care of a patient on hepatitis C treatment. Given that rural GPs are in short supply and long-term GPs are few in number, it seems to be unrealistic and idealistic to imagine that training of GPs as s100 prescribers is a viable option on a large-scale, state-wide basis. However, there is a small number of GPs who are dedicated and motivated to work in this area and resources could be directed to supporting these GPs with hepatitis C patients and retaining them in the region.

For regions that do not have a hepatitis nurse, the barriers to a patient starting treatment are significant and the likelihood is that patients will be unable to start treatment, unless they have a long-term GP and are able to travel back and forth to Perth. Both scenarios are unlikely given the demographic of the 'average' patient with hepatitis C and the scarcity of GPs in regional areas.

## 6. Key recommendations

The findings of the evaluation of the WA nurse-supported hepatitis C shared care program informed the development of the following recommendations for future service provision.

***Recommendation 1: Maintain existing regional nurse-supported hepatitis C shared care programs.***

Access to and uptake of hepatitis C treatment and patient compliance with treatment schedules are facilitated with a nurse-supported hepatitis C shared care model. The demanding treatment regimens and travel distances between regional areas and Perth do not make it practical for patients living in regional and remote areas of WA to start hepatitis C treatment without access to local treatment and care. Existing hepatitis nurse FTE allocations should be revisited based on current and predicted patient caseloads. Funding for additional hepatitis nurse FTE should be sought if required.

***Recommendation 2: Investigate requirements and feasibility of nurse-supported hepatitis C shared care services in other regions.***

Ethical considerations arise if equitable access to healthcare services for all patients in all WA regions is not possible. However, several factors influence whether the nurse-supported hepatitis C shared care model should be implemented in all WA regions. These factors include burden of disease, patient demographics, distance to tertiary clinics, issues associated with stigma and discrimination, networks available for telehealth, access to allied health services, and the availability of healthcare professionals including regional physicians, nurses and GPs. Access to specialist care is essential for regional shared care services to function optimally. The feasibility of providing nurse-supported hepatitis C shared care services in all regions in WA should be explored further.

***Recommendation 3: Investigate barriers to accessing treatment for Aboriginal people.***

Aboriginal people constituted approximately 21% of the total number of notifications in the regions with nurse-supported hepatitis C shared care programs during 2012. However, there are currently no Aboriginal people accessing treatment in these regions. The barriers to accessing treatment for Aboriginal people should be investigated. Factors including cultural security of health care services, cultural competency of healthcare providers and the role of local Aboriginal Medical Services in hepatitis C shared care should be considered. Aboriginal patients may also require access to more allied health services including drug and alcohol counselling.

***Recommendation 4: Increase participation of GPs in existing regional nurse-supported hepatitis C shared care services.***

A scarcity of GPs in regional areas has contributed to limited GP involvement in the provision of hepatitis C shared care services. The demands of looking after hepatitis C patients, remaining abreast of new treatment developments and the limited availability of bulk billing discourage many GPs from participating in shared care. Options to provide adequate education, training,

support and incentives to increase GP participation should be explored. These could include: involvement of Medicare Locals; the development of standard protocols for treatment, care and referrals; regular updates on changes to treatment and research developments; the development of guideline for patients; and training of practice or clinic nurses to provide support for GPs by providing patient education and following up and monitoring patients during treatment. Further involvement of GPs in shared care, if this can be achieved, is likely to increase access to and uptake of hepatitis C treatment.

***Recommendation 5: Investigate options for expanding telehealth services to enable local hepatitis C treatment and care and reduce waiting times for tertiary clinic appointments.***

Telehealth has been shown to be effective in regional and remote areas and reduces the need for patients to travel long distances for treatment and care and reduces the travel costs associated with patient transport to tertiary clinics. Telehealth support for hepatitis nurses and patients is available from tertiary clinics. Raising awareness of regional healthcare professionals of this service and options for expanding telehealth hepatitis C services to all regions should be explored.



## Appendix 1: Desktop review

The desktop review included the following documents:

### Journal articles

- Horwitz, Brener and Treloar. (2012). Evaluation of an integrated care service facility for people living with hepatitis C in New Zealand. *International Journal of Integrated Care* 12.
- Lambert et al. (2011). General practitioner attitudes to prescribing hepatitis C antiviral therapy in a community setting. *Australian Journal of Primary Health* 17(3) 282-287.
- Nazareth et al. (2008). Innovative practice in the management of chronic hepatitis C: introducing the nurse practitioner model. *Australian Journal of Advanced Nursing* 25(4):114.

### Western Australia documents and reports

- Evaluation of nursing structure and resources in the management of chronic hepatitis C project proposal (2013-2014). Systems and Intervention Research Centre for Health (SIRCH) in conjunction with Royal Perth Hospital Liver service and the Infections and Immunology Health Network.
- Funding agreements between WA Health SHBBVP and WA Country Health Service regions, and six-monthly reports produced by regional hepatitis nurses (2004-2013).
- Western Australian Notifiable Infectious Diseases Database (WANIDD) for new hepatitis C notifications data in the period 1 January 2012 – 31 December 2012.
- WA hepatitis C Model of Care Implementation Plan 2010-2014 (2011).
- WA Health Hepatitis C Virus Model of Care (2009).
- Hepatitis C Shared Care: Interim Report. October 2008. Prepared by Systems and Intervention Research Centre for Health (SIRCH), Edith Cowan University.
- WA Hepatitis C Action Plan, 2006-2008.

### Queensland report

- Report of the evaluation of the Queensland Health Hepatitis C Shared Care Initiative (2009).

### South Australia documents and reports

- South Australian Hepatitis C Action Plan 2009-2012.
- Nursing Model of Care for Hepatitis C Treatment in South Australia.

### Victoria report

- Hepatitis C Shared Care Program: A guide for general practitioners (Melbourne Health).

**National documents and reports**

- Carruthers (2013). Hepatitis C and its treatment within Australian custodial settings. To establish the current situation and determine the barriers and enablers to receiving treatment for hepatitis C within an Australian prison.
- Economic evaluation of hepatitis C in Australia (2005).

## Appendix 2: Examples of interview schedules

### WA Regional Nurse-Supported Hepatitis C Shared Care Program Evaluation Key Informant Interviews (Regions without a program)

The questions below outline the major areas of inquiry and are given as examples of questions that may be asked to guide the semi-structured interviews with key informants.

#### Ice-breakers

- How long have you worked in the region?
- What is your role in hepatitis C services?

#### Defining existing hepatitis C services

1. What hepatitis C services are provided in your region?
  - a) Who is involved in providing hepatitis C services in your region? What are their roles?
  - b) Which groups are affected by hepatitis C in your region? You would try to get a sense of male : female ratio, age groups, and any sub-groups e.g. gay men, people who inject drugs
  - c) Take me through the process for an average patient?
  - d) On a scale of 1 to 10, 1 being least satisfied and 10 being most satisfied, how satisfied are you with the program in your region

#### Demographics

2. How do the patients in your region differ from metro patients?
  - a) What additional services do they require?
  - b) What co-morbidities do they have, if any?

#### Barriers

3. What challenges do you face in providing hepatitis C services in your region and how do you manage these?
  - a) How accessible is the program for those who need it?
  - b) Do most patients complete the treatment? If not, why not? And is there a particular period when patients are most likely to drop out of care and might need more support?

#### Enablers

4. What features would you like to see on your region? How would these improve the overall effectiveness of the program?
5. How do you think these could be achieved?

Ask more detailed questions about specific barriers/enablers as required.

**WA Regional Nurse-Supported Hepatitis C Shared Care Program Evaluation  
Key Informant Interviews (Liver Clinic Staff)**

The questions below outline the major areas of inquiry and are given as examples of questions that may be asked to guide the semi-structured interviews with key informants.

**Ice-breakers**

- How long have you worked at the liver clinic?
- What is your involvement in the regional nurse-supported hepatitis C shared care program?

**Impact of the program**

6. What is the impact of the regional nurse-supported shared care program on hepatitis C services?
  - a) How has the program affected services provided by the liver clinic?
  - b) How has the program affected the workload at the liver clinics?
  - c) What types of patients do you see at the liver clinic? Has the program affected the types of patient you see at the liver clinic?
  - d) What input does the liver clinic provide for an average patient on the program? How often do you see them? Is the contact face-to-face or via telehealth?
  - e) How do the liver clinic and the regional staff communicate with each other? Who is the main point of contact?
  - f) How does the liver clinic communicate with GPs providing hepatitis C services in the regions?
  - g) What are the key differences between the services provided at the liver and the services provided in the regions?

**Barriers**

7. What challenges do you face in providing hepatitis C services to the regions and how do you manage these?
  - a) How accessible is the program for those who need it?
  - b) Do most patients from the regions complete the treatment? If not, why not? And is there a particular period when patients are most likely to drop out of care and might need more support?

**Enablers**

8. What features would you like to see in the regional programs? How would these improve the overall effectiveness of the program?
9. How do you think these could be achieved?

Ask more detailed questions about specific barriers/enablers as required.

### Appendix 3: List of key informants

KEY INFORMANT	POSITION
<b>KIMBERLEY REGION</b>	
Miranda Dibdin	Clinical nurse specialist - Hepatology
Dr Jaye Martin	Regional physician
Dr Sarah Woodlands	GP
<b>GREAT SOUTHERN REGION</b>	
Dr John Lindsay	Consultant physician
Erica Whinnen	Clinical nurse specialist - Hepatology
<b>SOUTH WEST REGION</b>	
Camilla Hey	Clinical nurse specialist - Hepatology
<b>OTHER REGIONS</b>	
Dr Marisa Gilles	Public health physician, Midwest
Dr Mya Yee	Consultant physician, Goldfields
Susie Ridderhof	Public health nurse, Wheatbelt
Phillipa Jones	Public health nurse, Pilbara
<b>METROPOLITAN</b>	
Professor Wendy Cheng	Consultant physician, Royal Perth Hospital Liver Service, Dept of Gastroenterology & Hepatology, Royal Perth Hospital

## Appendix 4: Patients' survey



### Patient Information Sheet/Consent Form

#### Hepatitis C Shared Care Program Evaluation: Patient Satisfaction Survey

##### **Introduction**

The Department of Health and Curtin University are reviewing the hepatitis services in regional WA. As part of the evaluation, we wish to hear your views on the hepatitis C services provided in your region.

##### **What does participation involve?**

Participation involves filling in an anonymous questionnaire on your experience of hepatitis C care in your region. The questionnaire should take 5 minutes to complete. Please return the completed questionnaire and signed consent form in the pre-paid envelope before 31<sup>st</sup> July 2013.

##### **What are the benefits of participation?**

As a patient of hepatitis C health care service program, your feedback is valuable to us and may inform future planning of hepatitis C services in your region. The questionnaire is confidential and anonymous. Any comments you make which could potentially identify you will not be used.

##### **What are the drawbacks of participation?**

We do not expect your participation in this project to have any risks or drawbacks.

##### **Further information**

If you want any further information concerning this project you can contact Dr Roanna Lobo at Curtin University on **08 9266 1101**

##### **Complaints or concerns**

If you should have any complaints or concerns about the way in which the study is being conducted, you may contact the Chairperson of the WACHS Research Ethics Committee via 0417 068 594.

##### **Confidentiality**

Your identity will be kept anonymous at all times. The questionnaire will not seek to obtain information by which you can be identified. All electronic data will be kept in locked excel spreadsheets in secure premises to which only the investigators have access. Any publications that arise will not have any information that identifies you.

**Declaration by Participant**

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in the Hepatitis C Shared Care Program Evaluation as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

If I have any further questions regarding the study I may contact: Dr Roanna Lobo at Curtin University on phone number: 08 9266 1101

I understand that I will be given a signed copy of this document to keep.

Name of Participant	_____
Signature	_____
	Date _____

*For office use only*

**Declaration by Study Doctor/Senior Researcher**

The participant has received an information sheet explaining the procedures and risks of the research project and has returned a signed consent form.

Name of Study Doctor/ Senior Researcher (please print)	_____
Signature	_____
	Date _____

## Hepatitis C services: How Are We Doing?

Please leave blank. For researcher use only

ID: \_\_\_\_\_

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

Please take a few minutes to fill out this survey on your experience of the hepatitis C services provided to you. The WA Department of Health welcomes your feedback. Thank you for your participation.

### Question 1:

Are you?

- Female  
 Male  
 Transgender

### Question 2:

How old are you?

Years old

### Question 3:

Are you Aboriginal and/or Torres Strait Islander?

- Aboriginal  
 Torres Strait Islander  
 Both Aboriginal and Torres Strait Islander  
 Non-Indigenous



Other – Please state

**Question 4:**

Were you born in Australia?

Yes – Go to Question 6

No – Go to Question 5

**Question 5:**

Where were you born?

**Question 6:**

What is the postcode where you currently live?

**Question 7:**

Which of the following best describes your work status now? Please tick all boxes that apply

Employed (including self-employed and including part-time)

Student

Unable to work due to illness

Home duties

Retired

Currently looking for work

Other - Please state



**Question 8:**

In what year were you diagnosed with hepatitis C?

**Question 9:**

How long did you have to wait from being referred to starting treatment?

**Question 10:**

a. Who is the **MAIN** person you contact when you have problems relating to hepatitis C?

- The hepatitis nurse
- My GP
- Specialist at the Liver clinic in Perth
- Specialist in the area where you live
- Other – please state

b. How easy is it for you contact this person?

- very difficult
- difficult
- easy
- very easy

**Question 11:**

Who is the **MAIN** person involved in explaining details of hepatitis C treatment to you?

- The hepatitis nurse
- My GP
- Specialist at the Liver clinic in Perth

Specialist in the area where you live

Other – please state

### Question 12:

Who is the **MAIN** person involved in scheduling your appointments?

The hepatitis nurse

My GP

Specialist at the Liver clinic in Perth

Specialist in the area where you live

Other – please state

### Question 13:

Who is the **MAIN** person involved in giving you blood test results while you are on treatment?

The hepatitis nurse

My GP

Specialist at the Liver clinic in Perth

Specialist in the area where you live

Other – please state

### Question 14:

Apart from your GP, the hepatitis nurse and the liver specialist, were there any other services that you used during your hepatitis C treatment? Please tick all that apply to you.



Drug and alcohol services. Please specify which service (e.g. Rehab, methadone programme, detox, needle and syringe programme etc.)

Mental health counsellor

Psychiatrist

Sexual health clinic

Family planning clinic

Hepatitis WA

Other - Please specify

**Question 15:**

How satisfied were you with the information you received about the side-effects of treatment?

very unsatisfied     slightly unsatisfied     slightly satisfied     very satisfied

**Question 16:**

How satisfied were you with the level of support you received while on hepatitis C treatment?

very unsatisfied     slightly unsatisfied     slightly satisfied     very satisfied

**Question 17:**

How satisfied were you overall with your experience of the hepatitis C treatment program?

very unsatisfied     slightly unsatisfied     slightly satisfied     very satisfied



**Question 18**

What would you do if hepatitis C treatment was not available in your region?

- Travel to Perth regularly for treatment
- See a private specialist in your region for treatment
- Wait a little longer until treatment is available in your region
- Other – Please specify

**Question 19:**

What could be changed to make Hepatitis C services more suited to your needs?

Thank you for your participation

**PLEASE RETURN THE QUESTIONNAIRE AND THE SIGNED CONSENT FORM DIRECTLY TO CURTIN UNIVERSITY IN THE PRE-PAID ADDRESSED ENVELOPE PROVIDED BEFORE 31<sup>st</sup> July 2013.**

## Appendix 5: Hepatitis C shared care programs in other states and New Zealand

### South Australia hepatitis C shared care program (7)

The desktop review identified the following fundamental principles of the hepatitis C shared care program in South Australia (SA):

- Patient centred care
- Collaboration between specialist and primary health care providers
- Multi-sectoral and holistic approach
- Quality improvement and evaluation mechanisms
- Evidence based and quality care
- Access for priority populations.

The SA program aims to improve access to high quality care for people with hepatitis C, integrate the different tiers of service delivery and target priority populations.

### Queensland hepatitis C shared care model (6)

Similarly, the Queensland (QLD) hepatitis C shared care model aims to improve access to anti-viral therapy and supports co-ordinated care between primary care and specialist liver clinics. The QLD program also aims to reduce the number of appointments at specialist liver clinics.

The QLD program was evaluated using similar methods to the current evaluation. Key informants were interviewed and service users' perspectives were sought using a patient satisfaction questionnaire. Information sought included:

- Identifying the numbers of enrolled and treated patients
- The level and success of collaboration between nurses, GPs and specialists
- Information on administrative issues
- Relationships with patients using the program
- Perspectives on the effectiveness of the shared care program.

### New Zealand Community Assessment and Support Programme (8)

The Community Assessment and Support Programme in New Zealand provides patients with direct support in the community, and with access to other services. The community nurse works with other professionals and organisations to support patients, and provide an integrated model of care. This means, instead of the patient dealing directly with GPs, specialist doctors, and other health providers separately, the community nurse liaises with these people on the patient's behalf.

### **Liverwise Program - Victoria Integrated hepatitis C Service (9)**

The key aim of the Liverwise Program is to increase the number of Victorians successfully completing antiviral treatment. Strategies include:

- Specialty Programs: Aboriginal people, prisoners, young people, CALD
- Pre-treatment assessment and education of clients with chronic hepatitis C virus (HCV) infection
- Service coordination and consultation between clients, Specialist Physician and GP during pre-treatment assessment, treatment of chronic HCV infection and post-treatment phase
- Case management of clinically indicated clients
- Consultation with, and education of, GPs and Practice Nurses regarding pre-treatment assessment, treatment monitoring and post-treatment care of clients with chronic HCV infection.

See the following link for further information: <http://www.lchs.com.au/service-info.html?sid=91>

### **Royal Melbourne Hospital & Victorian Infectious Diseases Service Shared Care program (10)**

The aims of the shared care hepatitis C program in Victoria are:

- GPs benefit from active participation in treating a patient with hepatitis C and being involved from referral right through to the final outcome
- Improving the likelihood of good clinical outcomes
- Reducing the frequency of visits to the Royal Melbourne Hospital
- Reducing travel costs for patients
- Reducing interruption to patients' lives.

### **New South Wales Hepatitis C Shared Care Program Model of Care (11)**

Following the cessation and final evaluation of the New South Wales/Australian Capital Territory HCV Community Prescribing Pilot in 2007, an ongoing program of shared care was endorsed by the Highly Specialised Drugs Working Party. Under this program, accredited medical practitioners may prescribe hepatitis C drug treatment for maintenance therapy in a shared care arrangement following initiation of therapy by a specialist associated with an authorised public health service hepatitis C Treatment Centre.

Key features of the program are:

- A specialist associated with an authorised public health service hepatitis C Treatment Centre must initiate treatment
- Dispensing of HSD s100 therapy must be from a public hospital pharmacy

- This model is intended to provide safe but also flexible access to care in a wide range of primary care settings. It incorporates a highly developed training and certification component to ensure care is provided by suitably trained medical practitioners
- Under this model, patients can have the majority of treatment and monitoring completed by their accredited community prescriber. As visits to the hepatitis C treatment service are reduced, in rural areas this can result in reduced travel costs and travel times for the patient.



## References

1. Department of Health Western Australia. The Epidemiology of Notifiable Sexually Transmitted Infections and Blood-Borne Viruses in Western Australia 2012. Communicable Disease Control Directorate, 2014.
2. Gidding HF, Law M, Amin J, Ostapowicz G, Weltman M, Macdonald GS, J., et al. Hepatitis C treatment outcomes in Australian clinics. *The Medical Journal of Australia*. 2012;196(10):633-7.
3. Australian Government Department of Health and Ageing. Third national hepatitis C strategy 2010-2013. Canberra: Commonwealth Department of Health and Ageing, 2010.
4. Department of Health Western Australia. Hepatitis C virus model of care. Perth: Health Networks Branch, Department of Health, Western Australia, 2009.
5. Nazareth S, Piercey C, Tibbet P, Cheng W. Innovative practice in the management of chronic hepatitis C: Introducing the nurse practitioner model. *Australian Journal of Advanced Nursing* (Online). 2008;25(4):107-13.
6. McNally S, Wallace J, Johnson P. Report of the evaluation of the Queensland Health hepatitis C shared care initiative. Melbourne: Australian Research Centre in Sex, Health and Society La Trobe University 2009.
7. Government of South Australia. Nursing model of care for hepatitis C treatment in South Australia. South Australia: Communicable Disease Control Branch, n.d.
8. The Hepatitis Foundation of New Zealand. Hepatitis C programmes. hepCentral hepatitis C in New Zealand; n.d.; Available from: <http://www.hepatitisfoundation.org.nz/index.php/hepc/the-hep-c-programme/>.
9. La Trobe Community Health Service. Liverwise Program - Victorian integrated hepatitis C service (VIHCS). n.d.; Available from: <http://www.lchs.com.au/service-info.html?sid=91>.
10. Mellor K. The Royal Melbourne hospital & general practitioner hepatitis C shared care program: a guide for general practitioners treating patients with hepatitis C. Melbourne: The Royal Melbourne Hospital, Victorian Infectious Disease Service and hepatitis Clinic, n.d.
11. The Australasian Society for HIV Medicine. NSW hepatitis C shared care program model of care. ASHM, 2012.



Western Australian Centre for Health Promotion Research  
School of Public Health | Faculty of Health Sciences  
PO Box U 1987 | Bentley | Western Australia | 6845  
[www.wachpr.curtin.edu.au](http://www.wachpr.curtin.edu.au)

CRICOS Provider Code 00301J  
(WA), 02637B (NSW)