Structures and Resources in the Management of Hepatitis C

Final Report March 2014

Supported by
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Department of Health
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The Systems and Intervention Research Centre for Health (SIRCH) has three broad research domains for the Centre:

- Suboptimal Health; health promotion, health intervention, environmental health, global health, and public health genomics.
- Workforce and Education; health education, e-learning, safety and quality in health including communication in healthcare and testing new models of service delivery.
- Indigenous Health; working with communities in developing and evaluating innovative models of care, and challenging attitudes of health providers.

The Centre aims to provide a collaborative framework for research to stretch across these domains to improve health care along the continuum of health provision and health populations.

Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>DoHWA</td>
<td>Department of Health Western Australia</td>
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<tr>
<td>ECU</td>
<td>Edith Cowan University</td>
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<tr>
<td>FH</td>
<td>Fremantle Hospital</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
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<td>PHU</td>
<td>Public Health Unit</td>
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<tr>
<td>RPH</td>
<td>Royal Perth Hospital</td>
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<tr>
<td>SCGH</td>
<td>Sir Charles Gairdner Hospital</td>
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<tr>
<td>SIRCH</td>
<td>Systems and Intervention Research Centre for Health</td>
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<tr>
<td>TOPAS</td>
<td>The Open Patient Information System</td>
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<td>WA</td>
<td>Western Australia</td>
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This report provides an analysis and evaluation of the current range of healthcare resources linked to tertiary centres that are dedicated to managing people either infected or at risk of infection with the hepatitis C virus.

The research draws from (1) online surveys conducted of GPs and nurses (2) semi-structured interviews of regional specialists involved in the care of patients with hepatitis C and (3) informal interviews with staff at tertiary liver clinics and HepatitisWA.

Of the general practitioners survey participants who identified no current active involvement in the clinical management of hepatitis, the majority expressed interest in becoming actively involved in hepatitis C clinical management. The geographic areas where these GPs are currently located are included in this report.

Despite the WA Health Infections & Immunology and Digestive Health Networks’ Hepatitis C Virus Model of Care, variation exists between the patient treatment pathways offered by the three tertiary liver clinics, as well as with associated waiting times and outreach services. These differences reflect the individual strengths and cultures of each of the tertiary hospitals. Whilst diversity can have its advantages, we found that opportunities for coordinated care and synergies might be missed. General practitioners and consumers with hepatitis C are unlikely to know differences exist between the services.

It is recommended that:

1. There should be improved communication between the tertiary hospitals, GPs and patients themselves on the treatment pathways, outreach services offered and opportunities for shared care arrangements with GPs provided by each of the tertiary liver clinics. Initially this may involve the establishment of a stakeholder reference group to develop engagement strategies.

2. Allocation of resources should encourage a more coordinated response by the tertiary hospitals by following the Hepatitis C Model of Care to provide better treatment in regional areas and to specific population groups (e.g., prisons).

3. Tertiary hospitals should consider actively engaging GPs in shared care for their patients who have hepatitis C treatment. This will require an agreed understanding of what shared care involves and the development of strategies to promote shared care to GPs.

4. A patient-centred approach should be the basis for improving access to treatment and quality of care.

5. There should be further research to analyse the cost effectiveness of nurse-led clinics and telehealth as models of care.

Hepatitis C epidemiological data relies on regional notifications, with HCV rates overestimated in regions with prisons. In addition, there is a lack of baseline HCV patient data (numbers and types of HCV patients seen) in the tertiary liver clinics.
Introduction

Hepatitis C presents a considerable public health concern with a mounting burden of disease and a poor uptake of available treatments. An estimated 10,000 new infections occur annually in Australia. Approximately only 2% of those diagnosed take up treatment (Holmes, Thompson & Bell, 2013). Increased access to effective pharmacotherapy treatment has the potential to reduce progressive liver disease and significantly improve the quality of life for people with hepatitis C. This project will determine the areas of need for hepatitis C treatment and management in WA, identify which areas have the best potential for developing shared care teams and what is needed to establish shared care teams in these areas.

Background

The establishment of the project
Funded by the Metropolitan Health Service: Royal Perth Hospital (G1001299). The original project brief was amended in collaboration with RPH.

Aims of the Review
1. To determine the areas of need for hepatitis C treatment;
2. To identify areas that have the best potential for developing a shared care team for treatment and management of hepatitis C, and;
3. To identify what support services, training or other services are required to establish shared care teams in areas of identified need.

In addition, the team is to report on the demand for treatment and potential barriers.

Scope of the review
The areas to be reviewed were:
1. Where are the people with hepatitis C?
   1.1 Determine prevalence rates in DoHWA health service areas from epidemiological and notification data.
2. Where are these people currently being treated?
   2.1 Determine the number of people undergoing treatment through tertiary liver clinics and regional specialists.
   2.2 Identify geographical distribution of patients from pharmaceutical companies dispensing records.
3. Why are people with hepatitis C not accessing treatment?
   3.1 Determine the demand for treatment through audits of the wait-lists for tertiary liver clinics and regional specialists.

3.2 Consult with hepatology nurses and HepatitisWA to determine what the barriers are for patients.
3.3 Develop an online survey for general practitioners who have previously referred patients with hepatitis C to liver clinics and/or completed the ECU online hepatitis C training program to determine what they perceive the barriers are for patients.
3.4 Develop an online survey for nurses who have previously completed the ECU online hepatitis C training program to determine what they believe are barriers for patients.

4. Why are medical practitioners not providing treatment?
4.1 Contact medical practitioners who have previously referred patients with hepatitis C to RPH and/or completed the ECU online hepatitis C training program to establish level of prescribing, barriers to providing treatment for people with hepatitis C, available support services, training needs and suggestions to overcome barriers.
4.2 Develop an online survey for general practitioners who have previously referred patients with hepatitis C to RPH and/or completed the ECU online hepatitis C training program to determine if they are currently providing services to people with hepatitis C, the extent of these services and the barriers surrounding further involvement.
4.3 Develop an online survey for nurses who have completed the ECU hepatitis C online training program to determine if they currently provide services to people with hepatitis C and if not, if they would be willing to become involved in the clinical management of hepatitis C.
Methodology

The hepatitis C treatment review process began with the development of survey instruments, data collection, data analysis and finally a review of the outcomes. Informal consultation meetings with key stakeholders to encourage open communication and participation took place.

Data collection

A range of methodological approaches were adopted to collect and evaluate the relevant information including:

- Research on epidemiology data and availability of alternative sources of data on the hepatitis C prevalence in Western Australia (WA).
- Informal interviews with tertiary hospital liver clinics and HepatitisWA.
- Semi-structured interviews with infectious disease physicians and general physicians in rural areas.
- Online surveys for general practitioners and nurses.

Ethics approval was obtained from the ECU Human Research Ethics Committee for the online surveys and semi-structured interview.

Semi-structured interviews with infectious disease and general physicians

General physicians and infectious disease physicians in rural areas were identified by Professor Wendy Cheng. The six general physicians and infectious disease physicians were sent an email inviting them to participate in a telephone interview with the Associate Investigator Dr Eric Khong. For those who did not respond, a follow-up call and email were sent one month after the invitation as a prompt to encourage involvement.

One general physician was on long service leave and was unable to participate. One general physician did not feel she had any information about hepatitis C treatment in her region. Two general physicians did not reply to requests to participate in the survey. A total of two telephone interviews were conducted by Dr Eric Khong using a semi-structured interview (Appendix A). Each interview took approximately 15 minutes. The objective of this interview was to determine their views about services that currently exist or are needed for patients with hepatitis C in their area.

GP Survey

General practitioners who had completed the ECU hepatitis C online training module were sent an e-mail (Appendix B) inviting them to participate in an online survey. General practitioners who had previously referred a patient to the Royal Perth Hospital (RPH) liver clinic were sent a letter from RPH (Appendix C) inviting them to participate in an online survey.

Two weeks later, a reminder e-mail was sent to each of the general practitioners, previously invited by ECU, who had not yet completed the survey. The survey was conducted using Survey Monkey which took approximately 15 minutes to complete. GPs were offered an incentive (a draw for iPad minis) to complete the survey.

- Number of GPs invited by ECU: 32
- Response rate: 37.5% (n=12)
- Number of GPs invited by Royal Perth Hospital: 129
- Response rate: 7.0% (n=9)

Nurses Survey

Nurses who had completed the ECU hepatitis C online training module were sent an e-mail (Appendix D) inviting them to participate in an online survey. Two weeks later, a reminder e-mail was sent to each of the nurses, previously invited by ECU, who had not yet completed the survey. The survey was conducted using Survey Monkey, which took approximately 15 minutes to complete. Nurses were offered an incentive (a draw for an iPad mini) to complete the survey.

The objective of this survey was to provide an appreciation of issues in the detection and management of hepatitis C from a nursing perspective.

- Number of nurses invited by ECU: 55
- Response rate: 27.3% (n=15)

Engagement with Hospitals and HepatitisWA

Meetings were held with representatives from the liver clinics of each of the three tertiary hospitals that provide hepatitis C treatment in Western Australia. The questions raised with each of the hospitals are provided in Appendix E. The objective of these meetings was to establish in broad terms the processes that are followed and waiting list timeframes experienced by each liver clinic. These processes and timeframes are provided as flow charts (see, Figures 2, 3 & 4). Notes of meetings were compiled and distributed to each hospital for verification. The flow chart was also sent to the relevant hospital for their approval.

A meeting with HepatitisWA provided information from their perspective for why only a small percentage of patients that are diagnosed annually with hepatitis C undergo treatment.
Timeline

The following table provides an overview of activities for the review process from September 2013 – March 2014.

Table 1: Timeline

<table>
<thead>
<tr>
<th>Time</th>
<th>Task</th>
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<tbody>
<tr>
<td>19 August, 2013</td>
<td>Consultation meeting with Royal Perth Hospital</td>
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<tr>
<td>2 September, 2013</td>
<td>Ethics approval obtained from ECU Human Research Ethics Committee (10125 SIM)</td>
</tr>
<tr>
<td>10 September, 2013</td>
<td>Email from ECU sent to general physicians and infectious disease physicians Email invitation from ECU sent to GPs Email invitation from ECU sent to nurses Survey for nurses went live Survey for GPs went live</td>
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<tr>
<td>13 - 17 September, 2013</td>
<td>Invitation letter from RPH sent to GPs via post</td>
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<tr>
<td>19 September, 2013</td>
<td>Consultation meeting with Sir Charles Gairdner Hospital</td>
</tr>
<tr>
<td>23 September, 2013</td>
<td>Reminder e-mail sent to nurses, GPs, general physicians and infectious disease physicians</td>
</tr>
<tr>
<td>02 October, 2013</td>
<td>Consultation meeting with Fremantle Hospital</td>
</tr>
<tr>
<td>07 October, 2013</td>
<td>Semi-structured telephone interview with Public Health Physician (Pilbara)</td>
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<tr>
<td>10 October, 2013</td>
<td>Semi-structured telephone interview with General Physician (Geraldton)</td>
</tr>
<tr>
<td>31 October, 2013</td>
<td>Survey for nurses closed Survey for GPs closed</td>
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<tr>
<td>06 November, 2013</td>
<td>Consultation meeting with HepatitisWA</td>
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<tr>
<td>November, 2013</td>
<td>Data analysis</td>
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<tr>
<td>January, 2014</td>
<td>Draft report completed</td>
</tr>
<tr>
<td>March, 2014</td>
<td>Final report completed</td>
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Where are the areas of identified need for hepatitis C treatment and management?

Information on the extent of hepatitis C in the Western Australian population is limited to infectious disease notifications received by the Department of Health, WA. As identified in the Department of Health, WA publication on the epidemiology of notifiable sexually transmitted infections and blood-borne virus in WA (2013a) “while notification data underestimate the true incidence of disease, they are… consistent estimates of disease incidence, trends and associated factors” (pg 16).

Table 2 below shows the number of total hepatitis C (newly acquired and unspecified hepatitis C) notifications by public health unit (PHU) received in a five-year period, 2008 to 2012.

Table 2: Number of hepatitis C notifications by public health unit region, WA 2008 to 2012

<table>
<thead>
<tr>
<th>Region</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
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<tr>
<td>Midwest</td>
<td>40</td>
<td>48</td>
<td>26</td>
<td>36</td>
<td>47</td>
</tr>
<tr>
<td>North Metropolitan</td>
<td>502</td>
<td>401</td>
<td>384</td>
<td>404</td>
<td>377</td>
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<tr>
<td>Pilbara</td>
<td>43</td>
<td>26</td>
<td>23</td>
<td>28</td>
<td>20</td>
</tr>
<tr>
<td>South Metropolitan</td>
<td>501</td>
<td>423</td>
<td>373</td>
<td>389</td>
<td>402</td>
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<tr>
<td>South West</td>
<td>85</td>
<td>81</td>
<td>84</td>
<td>75</td>
<td>85</td>
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<tr>
<td>Wheatbelt</td>
<td>39</td>
<td>25</td>
<td>29</td>
<td>17</td>
<td>23</td>
</tr>
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Adapted from: The epidemiology of notifiable sexually transmitted infections and blood-borne viruses in Western Australia 2012 (2013b).

As expected for a large population centre the metropolitan areas of Perth have high hepatitis C notifications and the three tertiary hospitals provide easily accessible care for these patients.

As expected for a large population centre the metropolitan areas of Perth have high hepatitis C notifications and the three tertiary hospitals provide easily accessible care for these patients.

Figure 1 to follow provides information on the number of hepatitis C notifications for regional areas only.
Limitations of this epidemiological data include:

- **Notification from prisons.** Prisoners are routinely offered screening for hepatitis C when they are admitted to prisons, hence public health units with large prisons are likely to have increased numbers of hepatitis C notifications. “The prison health service is one of the biggest single notifiers of hepatitis in Western Australia” (http://www.correctiveservices.wa.gov.au/rehabilitation-services/health-care/default.aspx). Unfortunately notifications from prisons cannot be excluded from the notification data.

- **Notification is related to screening.** The more GPs and health centres in a region are committed to screening their patients for hepatitis C, the more hepatitis C notifications they are likely to make. Notifications also reflect the sites of screening which may not be a true reflection of where people with hepatitis C reside. Similarly, where people with hepatitis C are treated does not necessarily reflect the region when they live as people may chose to seek treatment outside of their region as a result of confidentiality concerns, internment in prison or employment (for instance, fly-in, fly-out workers may receive treatment from a tertiary liver clinic through telehealth in the rural area in which they work).

The limitations to the available epidemiological data mean that identifying areas of need for hepatitis C treatment cannot be determined by the epidemiological data. Information from calls to HepatitisWA regarding hepatitis treatment was considered. However this information was considered too random to be of use. Unfortunately to our knowledge no other source of prevalence or incidence data for hepatitis C exists in Western Australia.

**Where are these people currently being treated?**

Royal Perth Hospital (RPH) treats approximately 120-150 patients per year (W.Cheng, personal communication, 3 March, 2014). In 2012, RPH held back treatment for patients who preferred to wait for the soon-to-be-available new treatments. As a result, RPH only treated 100 patients that year – the lowest number for many years (W.Cheng, personal communication, 3 March, 2014). Approximately 20 patients are currently undergoing treatment through the support of telehealth services. Between 2006 and 2010, 50 patients were treated through telehealth by RPH, although no locations were specified, 35 of these patients who responded to a follow-up survey would otherwise have had to travel between 300 and 6,430 km (round trip) to attend appointments in Perth (Nazareth, Kontorinis, Muwanwella, Hamilton, Leembruggen, & Cheng, 2013).

Sir Charles Gairdner Hospital (SCGH) confirmed approximately 80 patients underwent antiviral treatment in 2012.

Fremantle Hospital (FH) treated about 100 patients in 2012 (W.Cheng, personal communication, 3 March, 2014). Fremantle Hospital also confirmed they currently have approximately 20 incarcerated patients on treatment.

Whilst we have the approximate gross numbers of patients treated within each hospital, a lack of information about the liver clinics’ workforce and complexity of patients’ health status, makes it difficult to compare between them.

The public health physician in the Pilbara stated there were 22 new cases of hepatitis C in 2012, however as this...
physician was not treating patients, the number in treatment cannot be confirmed. The general physician in Geraldton reported that approximately 20 patients started hepatitis C treatment through his practice in 2012.

No information on the location of people accessing hepatitis C antiviral medications could be obtained from pharmaceutical companies, or the Pharmaceutical Benefits Scheme (PBS).

The data available from the PBS does not include information on the geographical location of hepatitis C treatments, only drug name, form and strength, pack size, and cost. Furthermore, if the treatment was provided by a public health service then the PBS would not have a record of this treatment occasion.

In summary, no comparable information from the tertiary hospitals or public health units regarding the number of patients undergoing treatment for hepatitis C is available.

**Why are people not accessing treatment?**

Responses collated from the survey questions that relate to the resources needed to assist in detection and management of patients with hepatitis C are detailed below by survey category:

Of the GPs actively involved in antiviral treatment (n=4), the main issues for patients deciding whether to start treatment for hepatitis C include:

- Dependence on alcohol and other substances
- Psychosocial stability
- Fear of side effects
- Level of liver damage

The most common challenge for patients staying on treatment was considered to be the side effects (n=3).

Similar responses were obtained from those GPs who are not involved in prescribing antiviral treatment, but have had patients undergo hepatitis C treatment (n=9). Additional reported comments from patients included:

- Reluctance to undergo treatment when feeling generally well
- No guarantee of treatment success

Nurses that are currently active in the clinical management of patients with hepatitis C reported similar issues for patients who were deciding whether to start treatment for hepatitis C. Additional issues included:

- Other health issues took priority
- “Prison settings have fewer stressors”

We have interpreted the comment about prison settings having fewer stressors, to mean that inmates living in a closed living environment may experience less of the stressors associated with life in the general community. As discussed earlier, the Department of Corrective Services has responsibility and funds for the provision of primary healthcare to prisoners, with tertiary hospital involvement if care cannot be provided by the prison health service. With regards to hepatitis C, there may be incentives under the new Activity Based Funding model for tertiary liver clinics to seek treatment opportunities with prisons.

Responses collated from a meeting with HepatitisWA confirmed similar issues to the above. In addition, HepatitisWA stressed the need for patient-centred approaches where patients are offered hospital and community resources commensurate with their individual needs.

Responses collated from meetings with the three tertiary hospitals indicate that the waiting list times for treatment are varied with the time to the first appointment at Royal Perth Hospital averaging 18 months, Sir Charles Gairdner Hospital at 4 to 6 months and Fremantle Hospital at 3 months. The hospitals were unanimous in their response that any increase in demand for treatment would further extend waiting time to first appointment due to the lack of staff and resources.

Figures 2, 3 & 4 to follow provide visual representation of the patient journey through each of the tertiary hospital liver clinics. Clearly access to treatment initiation is a concern as tertiary hospital waiting lists are a barrier to patients accessing treatment.
Figure 2: Flow chart of patient journey at Royal Perth Hospital

1. **HCV referral from GP**
2. **Royal Perth Hospital (RPH)**
   - Liver Clinic
   - Appointment for patient made by Clerk – Involves seeing Hepatologist
   - Ward Clerk sends PathWest blood forms with appointment
     
     *(18 month wait-list unless identified as cirrhotic by GP)*

3. **Cirrhotic Patients (identified by GP) are fast-tracked**
4. **First appointment with Hepatologist**
5. **Not suitable for treatment:**
   - Monitor by RPH
6. **Appropriate for treatment:**
   - Screened by Nurse Practitioner
8. **Depression / eating disorder**
   - Consultant Psychiatrist
9. **Alcohol drinkers counselled by Nurse-Led Clinic**

10. **Treatment / Follow up / Telehealth**
    - If suitable for treatment: commence at next available Nurse-Led Clinic
    - Nurse-Led Clinic Mon, Wed, Thur

11. **Treatment Complete**
    - Patients with advanced fibrosis or cirrhosis followed by Nurse-Led Hepatocellular Carcinoma Surveillance Clinic
Figure 3: Flow chart of patient journey at Sir Charles Gairdner Hospital

HCV referral from GP

Sir Charles Gairdner Hospital (SCGH)
Liver Clinic
Appointment for patient made by Clerk – Involves seeing Hepatologist
(4-6 Month wait-list)

Not suitable or not wanting treatment. Monitor by SCGH

S100 Tues Clinic (Cirrhotic Patients or Patients with other co-morbidities)

Mid Track (Well compensated Cirrhotic Patients)

Fast Track (Uncomplicated patients for Nurse-Led Management)

Depression/alcohol
Next Step, Fresh Start

Treatment / Follow up / Telehealth
3 Doctors: each sees 2 new patients & 6 follow up patients
(Total 6 new & 18 follow-up patients / week)
(2 month waiting list)

Treatment Complete
(F3/F4 cirrhotics remain in clinic even if they have HCV clearance due to risk of liver cancer)
Figure 4: Flow chart of patient journey at Fremantle Hospital

HCV referral from GP

Fremantle Hospital (FH)
Receiving Centre Infectious Disease Department
Appointment for patient made through TOPAS – Involves seeing Doctor & Nurse
(3 Month wait-list)

Not suitable for treatment
Monitor by FH

Complicated cases remain at Fremantle
(High ALTs)

Less complicated cases sent to Armadale or Rockingham
Nurse-Led Clinic
Immediate Treatment

Depression / alcohol
FH Psychologist, Next Step, GP

Fibroscan if required
(4 Month waiting list)

Treatment / Follow up / Telehealth
(10 clinics / week)

Treatment Complete
Which areas have the best potential for developing a shared care team for treatment and management of hepatitis C?

From the survey responses we can determine the areas where nurses and general practitioners are currently involved in treatment of patients with hepatitis C and where nurses and general practitioners are interested in becoming involved in the treatment of patients with hepatitis C.

Of the general practitioners who completed the survey and identified that they are not involved in prescribing antiviral treatment (n=11), all were interested in becoming involved in hepatitis C shared care. The areas where these GPs currently work are:

- Metro: Bedford, Duncraig, Butler, Cannington, Dianella, Northbridge, Kwinana, Forrestfield, South Perth, Subiaco, Joondalup
- Rural: No responses

GPs who completed the survey who are involved in prescribing antiviral treatment (n=4) for patients with hepatitis C work in the following areas:

- Metro: Applecross, Bull Creek
- Rural: South West (Bunbury and Mandurah)

Nurses who completed the survey and identified that they are currently active (n=8) in clinical management of patients with hepatitis C work in:

- Metro: Warwick, Armadale, South Guildford, Maylands
- Rural: Great Southern (Albany), South West (Bunbury), Mid West (Carnarvon and Geraldton)

Of the nurses who completed the survey and identified that they are not currently actively involved in the clinical management of hepatitis (n=6), the majority (n=5) would like to be involved in hepatitis C clinical management. The areas where these nurses currently work include:

- Metro: Byford
- Rural: Kimberley (Broome), South West (Bunbury), Goldfields (Esperance), Mid West (Geraldton)

What is required to establish shared care teams in areas of identified need?

The survey participants provided the following information:

**GP responses**

Of the GPs that are involved in prescribing antiviral treatment for patients with hepatitis C (n=4) all are confident in explaining hepatitis C treatment options to patients. Half of these GPs (n=2) confirmed that it is easy to get advice although one stated this was the case “from certain public hospitals”. One GP was neutral in terms of getting advice since as they only occasionally contact a liver clinic for help and one GP identified that they had not sought advice from a liver clinic. In terms of additional support required one of the four GPs suggested that more GP colleagues are required (Mandurah) and another suggested “a system … so that GP who are interested in treating hepatitis C can prescribe and manage … with co-ordination from hepatitis clinic”.

Responses from GPs who are not currently involved in antiviral treatment (n=11) predominantly concerned the availability of online resources and education (n=6) and having ready access to a specialist or nurse (n=4).

**Nurse responses**

Responses from the nurses actively involved in treatment (n=8) regarding resources required to provide improved services for patients in their area with hepatitis C included:

- Collaboration between tertiary and primary care
- Advanced training for nurses
- Fit packs from DoHWA
- Facility required in Geraldton
- Education for CALD communities in relevant languages

Responses from nurses not yet actively involved in treatment regarding resources (n=6) required to provide improved services for patients in their area with hepatitis C included:

- Funding for additional nurse time in Broome
- Nurse specialists (Geraldton)
- Decent referral/testing for new onset
Information from tertiary hospitals and HepatitisWA
Following the meetings with each of the tertiary hospitals it was apparent that each hospital’s definition of shared care is somewhat different. RPH stated that they do not do shared care and that they fully monitor all their patients, through Nurse-Led clinics. Should a patient want to see their GP however, they can do so at any time. Patients who have related medical problems are encouraged to see their GPs.

The meeting held with HepatitisWA clarified our finding that the three tertiary hospitals have different cultures. This may suit different consumers, however the lack of communication between the hospitals means that general practitioners and consumers with hepatitis C are unlikely to know the differences between the services and support offered by each hospital and therefore benefit from them.

HepatitisWA is currently involved in running focus groups with patients who are currently undergoing treatment or who have just recently finished treatment at Fremantle Hospital. The aim of the focus groups is to understand the social, physical, psychological and clinical aspects of patients undergoing treatment. The objective is to learn how to open doors and remove fear of treatment.

Information from rural public health physicians and infectious disease physicians
From the interview conducted with the public health physician in the Pilbara the most evident concern raised was the lack of communication between the tertiary hospitals.

A telehealth service (in conjunction with RPH) was about to start, however the SCGH gastroenterologists had recently started visiting the Pilbara to provide treatment and therefore the telehealth service was abandoned. However, Royal Perth Hospital continues to see some patients living in the Pilbara with other liver problems (W.Cheng, personal communication, 3 March, 2014).

From the interview with the general physician from Geraldton, the most pressing concern raised was the lack of nursing support for him and as a consequence, patients do not receive the best possible care. The addition of a nurse practitioner would potentially mean a “10x increase in the number of people treated in his area”. He suggested that all his patients are involved in shared care and this works to a point, however waiting times to see a GP in Geraldton can be up to 2 weeks and most GPs in Geraldton do not bulk bill.
Discussion

The following section provides a discussion of the information gathered during the review process:

Service Provision / Current Services

What was clear from this review is the variety of patient treatment pathways at the tertiary liver clinics, the differing waiting times and outreach services offered. This variability is exemplified by the lack of uniformity in the use of the term “shared care”, taken by some to mean GPs taking on supportive care for patients, and others as GPs taking on the anti-viral prescribing for patients once they have commenced treatment. Shared care for specialist services has a specific meaning for each service in terms of the participation of GPs. However, it could be argued that all general practice is a form of shared care since GPs coordinate care for patients, sharing care with multiple providers. GPs who refer to a hepatology clinic are providing ongoing care of the whole patient, not only dealing with other conditions apart from hepatitis, but also providing explanation and supportive ongoing care in relation to the hepatitis, which might not be obvious to specialist services.

Variations in clinics also reflect the different strengths and cultures of each of the tertiary hospitals. For instance, Royal Perth Hospital has a strong nurse-led model where the role of the nurse practitioner is key to how the hepatology clinic assesses and provides treatment. Fremantle Hospital has a long history of shared care programs and has provided a well-coordinated GP shared care program for well over a decade, with good communication between the hospital and general practices having been established through a strong partnership with the then Fremantle Regional Division of General Practice. There is variation in the patient case-mix of the different liver clinics as well. Sir Charles Gairdner Hospital has the Liver Transplant Unit, which provides specialist care for people with advanced disease.

Whilst it is possible to obtain information on the number of hepatitis C patients seen each year by the tertiary hospitals, it is difficult to compare between them as liver patients are not homogenous, and treatment pathways offered to patients and the shared care arrangements in place differ.

We recommend that information on the treatment pathways, outreach services offered and opportunities for shared care arrangements with GPs provided by each of the tertiary liver centres are better communicated between the tertiary hospitals, GPs and patients themselves. This would ensure better coordination and reduce replication of services offered across the State as well as provide people with hepatitis C with informed choice with regards to their treatment options.

In all hospitals there is a current waiting list for access to appointments and treatment. A new outpatient clinic referral system for GPs has been implemented from the 24 February 2014.

The Central Referral Service (www.gp.health.wa.gov.au) aims to improve the access to the public health system. However, strategies to reduce the time to appointments without additional resources may not be effective.

Potential service provision

The GP survey indicated that the majority of GPs are knowledgeable about hepatitis C and are interested in shared care (all 11 GPs who were not currently prescribing antivirals were receptive to shared care). Additional support requested by GPs included easily available clinical advice from specialist, clear guidelines and additional training (8 of these 11 GPs were not aware of the hepatitis C online training modules available through ECU). Since people with hepatitis C will always be a small proportion of the average GP’s service population and GPs will therefore not easily recall specific information about clinical issues and service pathways, having easily accessible information and support is critical.

The GPs who responded to the survey also demonstrated a comprehensive understanding of their patients’ lifestyle, mental health and issues related to starting and staying on treatment for hepatitis C. The GPs’ responses to the questions about how easy it was to get advice from the liver clinics and the specialist’s communication with patients and with them was mixed. A few GPs commented that specialist communication with patients was excellent but letters and information took a lot of time to reach the GP. Unlike letters from private specialists which arrive within days, letters from hospital outpatient clinics usually took weeks and sometimes months.

Although the response rate for the GPs survey was low, it is clear that many GPs are interested in shared care, with support from the tertiary liver clinics and additional training (or better promotion of existing training). GPs and health centres committed to screening patients for hepatitis C are likely to practice in regions with high notification rates (as previously discussed in the analysis and results section). As detection is an opportunity to institute treatment, the epidemiological data provides information about where potential service provision can be implemented.

Resources

From our discussion with stakeholders as well as the responses from the GP and nurse survey it is evident that every patient with hepatitis C has different needs and challenges when considering and remaining on treatment. The need for a patient centred approach to treatment and management of people with hepatitis C was the universal commitment of all stakeholders. As a result we are recommending better use of available resources within the community and hospitals.
## Recommendations

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Recommendation 1</strong></td>
<td>There should be improved communication between the tertiary hospitals, GPs and patients themselves on the treatment pathways, outreach services offered and opportunities for shared care arrangements with GPs provided by each of the tertiary liver clinics. Initially this may involve the establishment of a stakeholder reference group to develop engagement strategies.</td>
</tr>
<tr>
<td><strong>Recommendation 2</strong></td>
<td>Allocation of resources should encourage a more coordinated response by the tertiary hospitals by following the Hepatitis C Model of Care to provide better treatment in regional areas and to specific population groups (eg. prisons).</td>
</tr>
<tr>
<td><strong>Recommendation 3</strong></td>
<td>Tertiary hospitals should consider actively engaging GPs in shared care for their patients who have hepatitis C treatment. This will require an agreed understanding of what shared care involves and the development of strategies to promote shared care to GPs.</td>
</tr>
<tr>
<td><strong>Recommendation 4</strong></td>
<td>A patient-centred approach should be the basis for improving access to treatment and quality of care.</td>
</tr>
<tr>
<td><strong>Recommendation 5</strong></td>
<td>There should be further research to analyse the cost effectiveness of nurse-led clinics and telehealth as models of care.</td>
</tr>
</tbody>
</table>
References

Department of Health, Western Australia. The epidemiology of notifiable sexually transmitted infections and blood-borne viruses in Western Australia 2011. Perth: Department of Health Western Australia, 2013a.

Department of Health, Western Australia. The epidemiology of notifiable sexually transmitted infections and blood-borne viruses in Western Australia 2012. Perth: Department of Health Western Australia, 2013b.


Appendices

Appendix A: Semi-structured interview questions

1. Location of practice

2. Do you see patients with hepatitis C in your practice?
   - Yes (Approximately how many?)
   - No (Why not?) Skip to Q5

3. Do you initiate antiviral therapy for patients with hepatitis C?
   - Yes (Have you had any problems?)
   - No (Why not?)

4. Do you prescribe antiviral therapy for patients with hepatitis C?
   - Yes (Have you had any problems?)
   - No (Why not?)

5. When a patient is recently diagnosed with hepatitis C in your area, how are they managed?
   Prompt: What is the process? Who do they see? Where do they go for treatment?

6. For you what are (or would be) the most challenging aspects of managing patients with hepatitis C?

7. What do you feel would improve the diagnosis and treatment of hepatitis C in your region?
   (For those that answered No in Q2, skip to Q12)
   Prompt: resources, workforce

8. Are you involved in a shared care program for patients with hepatitis C, in conjunction with a GP?
   - Yes (How many? How does it work? Have you experienced any problems?)
   - No (Why not?)

9. From your experience, what are patients’ reasons for:
   i. for wanting to start antiviral treatment for hepatitis C
   ii. for continuing treatment for hepatitis C
   iii. for prematurely stopping treatment for Hep C

10. What do you feel are the barriers for patients in your area:
    i. to start antiviral treatment
    ii. to staying on antiviral treatment

11. How easy has it been to get advice about hepatitis C and support for managing patients from the tertiary liver clinic/s?
    - Not easy (please explain)
    - Yes

12. Do you have any nurse support?

13. Is telehealth used for patient consultation in your area?

14. Are you aware of the Edith Cowan University e-learning modules?
Appendix B: Invitation email to general practitioners sent by ECU

Survey about hepatitis C in your region

Dear Dr [FirstName]

According to our records, you have completed the 3rd module of the hepatitis C online learning program: http://hepatitis.ecu.edu.au/

We are currently undertaking a project funded by the Royal Perth Hospital Liver Clinic, titled “Structures and resources in the management of hepatitis C” to determine:

- the areas of need for hepatitis C treatment in WA;
- which areas have the best potential for developing shared care teams and;
- what is needed to establish shared care teams in these areas of need.

We are very interested in your views about services that currently exist or are needed for patients with hepatitis C in your area. The information will be used to inform future business cases and grant applications related to improving hepatitis C care for patients in WA.

We invite you to participate in an online survey that should take no more than 15 minutes. Please log on to: http://www.surveymonkey.com/s.aspx At the end of the survey please provide your name and address to enter the draw for one of 10 mini iPads (with a better than one in 10 chance of winning).

We hope that you will participate in this survey, which will close on the 30 September, 2014. If you have any questions or are interested in the feedback we receive from the survey, you are welcome to contact us by email at hepatitis@ecu.edu.au or telephone (08) 6304 3538.

Kind regards

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Appendix C: Invitation letter to general practitioners sent by RPH

Dear Dr

RE: Improving the care of your patient with hepatitis C

According to our records, you recently referred a patient with hepatitis C to the Royal Perth Hospital Liver Clinic. We are very interested in your views about services that currently exist or are needed for patients with hepatitis C in your area.

Edith Cowan University is currently undertaking a project funded by the Royal Perth Hospital Liver Clinic, titled *Structures and resources in the management of hepatitis C* to determine:

- the areas of need for hepatitis C treatment in WA;
- which areas have the best potential for developing shared care teams and;
- what is needed to establish shared care teams in these areas of need.

The Chief Investigator for the study is Professor Moira Sim and the Associate Investigator is Dr Eric Khong. We invite you to participate in the Edith Cowan University’s online survey that should take no more than 15 minutes at [http://www.surveymonkey.com/s/GPhepatitis](http://www.surveymonkey.com/s/GPhepatitis).

The closing date of this survey is the 14 October 2013. At the end of the survey please provide your name and address to enter the draw for one of 10 mini iPads (with a one in 10 chance of winning).

The information will be used to inform future business cases and grant applications related to improving hepatitis C care for patients in WA.

Please note, Edith Cowan University has not been provided with your name and the survey is voluntary.

If you have any questions or are interested in the feedback received from the survey, please contact Professor Moira Sim or Dr Eric Khong from Edith Cowan University at [hepatitis@ecu.edu.au](mailto:hepatitis@ecu.edu.au) or phone (08) 6304 3538.

Kind regards

Royal Perth Hospital Liver Clinic
Appendix D: Invitation email to nurses sent by ECU

Survey about hepatitis C in your region

Dear [FirstName]

According to our records, you have completed the 3rd module of the hepatitis C online learning program: http://hepatitis.ecu.edu.au/

We are currently undertaking a project funded by the Royal Perth Hospital Liver Clinic, titled “Structures and resources in the management of hepatitis C” to determine:

* the areas of need for hepatitis C treatment in WA;
* which areas have the best potential for developing shared care teams and;
* what is needed to establish shared care teams in these areas of need.

We are very interested in your views about services that currently exist or are needed for patients with hepatitis C in your area. The information will be used to inform future business cases and grant applications related to improving hepatitis C care for patients in WA.

We invite you to participate in an online survey that should take no more than 10 minutes. Please log onto: http://www.surveymonkey.com/s.aspx At the end of the survey please provide your name and address to enter the draw for a mini iPad.

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Kind regards

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Appendix E: Questions raised with hospitals

- What is the process from the time the liver clinic receives the referral from a GP?
- Info on waiting lists and what would happen if there was a sudden increase in patients
- What is the reason for the waiting lists?
- How long is the waiting list (in terms of time & numbers)?
- Does the patient make the 1st appointment with the liver clinic?
- What information does the GP get back about their patients? How much and what sort of liaison between the liver clinic and the GP?
- What happens when a patient comes into the liver clinic (What's the process… Hepatologist for first appointment… treatment clinic… nurse practitioner, is further testing done?)
- How long is a typical appointment? Does the patient see the doc & nurse in the same day? How long do they need to be at the liver clinic during treatment and after treatment?
- Are more complicated patients dealt with any differently… ie depression, eating disorders?
- What happens when someone is rural – how often do they need to visit the clinic?
- Any country consults done by hepatologists and/or teleconferencing / telehealth?
- Of those referred to the liver clinic, how many are not eligible for treatment? Are GPs contacted if they refer those that are not eligible? How are those that are not eligible for treatment managed?
- What other services does the liver clinic offer other than antiviral treatment?
- How many patients that were referred to your liver clinic, and are eligible for treatment (in 2012 for example) have or are undergoing antiviral treatment?
- If a patient doesn’t want to start treatment, is their referral valid for 1 year only?
- What will happen if they decide to start treatment after referral expired? Do they go back to their GP and start the whole process again?
- What happens when someone stops treatment before complete?
- How are incarcerated patients dealt with?