Communicable Diseases Intelligence

Using notifications data to increase hepatitis C testing and treatment rates in Queensland

Morris Carpenter, Linda A Selvey, Stephen B Lambert, Robert Kemp
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Abstract

Australia’s goal of eliminating hepatitis C by 2030 requires increases in uptake of and access to testing and treatment. As hepatitis C is a notifiable condition, health departments have access to information about people exposed to the hepatitis C virus (HCV), including the details of notifying clinicians who ordered their diagnostic pathology tests. Hepatitis C RNA testing confirms active infection that requires treatment, whereas a positive antibody test result only indicates prior exposure to the virus.

We undertook a pilot project in Queensland to follow up hepatitis C notifications with clinicians, aiming to increase HCV-RNA testing and treatment uptake. For all individuals with a first-time hepatitis C notification in Queensland between 3 November 2020 and 28 May 2021, we sought information regarding hepatitis C RNA testing from laboratories, excluding those cases diagnosed in prisons.

Cases who did not have RNA testing identified as part of or after their initial diagnostic tests were followed up via their notifying clinician. Interviews with selected clinicians were undertaken to improve our understanding of the follow-up process.

There were 769 new hepatitis C notifications during our study period: 244 had no subsequent RNA test identified and were followed up for this study. Of these, 134 cases were lost to follow-up; 26 were already being effectively case managed; 22 reported previous treatment and no further risk; and 62 were eligible for HCV-RNA testing. Twenty-six cases subsequently started hepatitis C treatment. Thirty-four percent of notifications that required follow-up resulted from testing initially requested in hospital settings.

Following up hepatitis C notifications can result in increased treatment rates; however, the process was resource-intensive and often failed to result in further contact between clinicians and patients. Our findings also highlight the importance of supporting better continuity of care between hospitals and community settings.

Keywords: Hepatitis C; HCV; RNA testing; notifications; direct-acting antivirals; treatment
Introduction

Highly effective direct acting antivirals (DAA) for the treatment of hepatitis C virus (HCV) infection have made the elimination of HCV possible. In line with the World Health Organization’s strategy, Australia has the goal of eliminating viral hepatitis as a public health threat by 2030. In March 2016, DAA treatment was subsidised and became available to patients through the Pharmaceutical Benefits Scheme in Australia. As of December 2021, there were 99,735 people in Australia who had received DAA hepatitis C treatment; that number is around 53% of the people estimated to be living with hepatitis C in 2015.

HCV testing usually involves initial testing for HCV antibodies (HCV-AB), and if positive, this is followed by a test for HCV ribonucleic acid (HCV-RNA). The increasing availability of point of care HCV-RNA testing among people at high risk of HCV infection means that HCV-RNA testing may be done without a preceding HCV-AB test.

In Australia, HCV testing and treatment is available in the community in a range of settings including general practice (GP), sexual health services, and some specialised health services such as alcohol and other drugs treatment services, and clinics specifically for people who inject drugs.

There is limited evidence on the effectiveness of following up HCV notifications to link patients to treatment in Australia. To address this gap, we followed up notifications of hepatitis C with notifying clinicians to obtain further information about testing and treatment, to request case updates on their patients’ HCV status, and to provide links to resources and services that could support further HCV testing and treatment.

Methods

HCV infection is a notifiable condition in Queensland under the Public Health Act 2005 and its subordinate regulation 2018. All HCV-AB positive and HCV-RNA positive results are notifiable by pathology laboratories to the Queensland Government Department of Health (Queensland Health). HCV notifications are stored in the Notifiable Conditions System (NoCS) managed by Queensland Health’s Communicable Diseases Branch. Notifications data from NoCS were accessed for this project. Each week from 3 November 2020 to 28 May 2021, all first-time notifications of individuals with positive HCV test results in Queensland were reviewed, four weeks in arrears (Figure 1). Notification data include the name and date of birth of the person tested, as well as the name and contact details of the clinician who ordered the test (the notifying clinician). All notifications were included in the study, except results from HCV testing undertaken while individuals were incarcerated. Prisoners were excluded as they were engaged with care through prisoner health services, and there was no scope to expand this activity.

Four weeks after a positive HCV-AB test notification was reported to NoCS, Queensland pathology laboratory databases were searched to ascertain whether a subsequent HCV-RNA test had been undertaken on or after the date of the initial HCV-AB positive test. Cases with no record of subsequent HCV-RNA testing were followed up via their notifying clinicians, who were randomly assigned to be contacted by either telephone or email, to establish which method of communication facilitated the higher response rate within the limited resources of the pilot project. Notifying clinicians in the email group were sent a questionnaire on a fillable PDF file (Appendix A.1). The others were telephoned and asked the same questions. If hospital-based clinicians reported that they had informed the patient’s GP of the positive HCV-AB test result, follow-up was continued with the GP (Appendix A.2).
If notifying clinicians indicated that an HCV-RNA test had, or would be, requested, pathology laboratory databases were again searched for HCV-RNA test results four weeks after follow-up communication. If no results were found, notifying/managing clinicians were recontacted for a case update. After two attempts to recontact notifying/managing clinicians with no subsequent HCV-RNA outcome, patients were considered lost to follow-up. If HCV-RNA positive test results were found, notifying clinicians were recontacted to confirm intention to treat.
Toward the end of the study, notifying clinicians were purposively sampled and 17 were invited to participate in a semi-structured telephone interview (Appendix B.1–B.3) to discuss HCV testing and treatment and the role of the notifications system; one turned down the request and 16 agreed to participate. Our sample reflected the range and location of clinicians followed-up throughout the project. A thematic analysis was conducted on the qualitative data, which were coded and collated using NVivo 12 (QSR International Pty Ltd., 2018).

Ethics approval to evaluate the project was granted by Darling Downs Hospital and Health Service (DDHHS) Human Research Ethics Committee (HREC), reference number: HREA/2020/QTDD/66248. A waiver of consent for the project was granted by DDHHS HREC to use de-identified data gathered from Queensland Health’s NoCS for project evaluation. Quantitative data were de-identified prior to analysis.

Results

Between 3 November 2020 and 28 May 2021, there were 1,162 new HCV notifications reported to NoCS in Queensland; 393 (34%) were from people who were incarcerated and were excluded from further follow-up activity. The remaining 769 notifications came from tests requested by GPs, hospital doctors, and other health providers, including Aboriginal Medical Services, sexual health services, and alcohol and other drugs services.

Of the 769 cases, 315 (41%) tested HCV-RNA negative at the time of or after notification; 210 (27%) tested HCV-RNA positive at the time of or after notification; and 244 (32%) had no subsequent HCV-RNA test identified (Figure 2).

Of the 244 cases that were followed up, 83 (34%) were tested in hospital wards, out-patients or emergency departments (Table 1). The majority of cases (55%) were lost to follow-up (Table 2); the remaining 110 cases were successfully followed up. Of those who were followed up, 62 (56%) had not progressed to treatment at the time of initial contact and were eligible for further testing and, if necessary, treatment. Of these, 29 tested HCV-RNA positive, 26 of whom were prescribed treatment (Figure 2).

Phone calls were the most effective way of contacting GPs, while email appeared to be better for hospital doctors. Many GPs used personal email addresses, and follow-up questionnaires were often sent to general clinic email addresses. All 65 GPs initially contacted by telephone were spoken to, but four of the 65 initially contacted by email were never successfully reached. It was difficult and time-consuming to contact hospital and emergency department doctors by telephone because of shift patterns and changing rosters, and because they frequently did not have ready access to patient records during the phone call. Hospital doctors usually completed the fillable PDF files electronically and emailed them back themselves from their hospital email addresses. For hospital and emergency department clinicians, four of the 40 contacted by telephone were never reached, and two of the 42 contacted by email never replied.

Searching the pathology laboratory databases for individual patient records was time consuming. The three main pathology laboratories used in Queensland could be searched with online access to their databases. Occasionally, other laboratories were contacted by telephone to check for results, and telephone waiting times were sometimes exacerbated during the coronavirus disease 2019 (COVID-19) pandemic. The project officer spent two days every week working on the HCV notifications data and follow-ups: one day searching pathology databases for test results, and the other in attempting to contact the notifying/managing clinicians.

Qualitative results

Fifteen doctors and one nurse practitioner participated in telephone interviews, which were conducted between 27 August and 30 September 2021 (Table 3).
Figure 2: New HCV case notifications in Queensland, 3 November 2020 – 28 May 2021, that resulted in follow up and subsequent testing and treatment

New HCV case notifications
1162
3 November 2020 - 28 May 2021

Community
769
66% of all cases

HCV RNA positive
As the correct testing procedure had been followed, these cases were not followed up.
315
41% of community total

Prison
393
34% of all cases

HCV RNA negative
and no further action cases
210
27% of community total

Clinician follow-up
Cases where a subsequent RNA test cannot be found (See Table 1 for details)
244
32% of community total

Case managed
Already undergoing further testing and/or treatment
26
11% of follow-up total

Previous treatment
Patients report interstate or international HCV treatment
22
9% of follow-up total

Eligible for advancement
post follow-up
62
25% of follow-up total

Tested post follow-up but not treated
33 tested HCV RNA negative
3 tested HCV RNA positive:
2 refused and 1 not advanced to treatment
36
GP=25, Hospital=6, ED=1
SHS-AODS=1, Other=3
58% of eligible for advancement total

Tested and treated post follow-up
Tested HCV RNA positive and received treatment
26
GP=13, Hospital=7, ED=4,
SHS-AODS=0, Other=2
42% of eligible for advancement total

Lost to follow-up
(See table 2 for details)
134
55% of follow-up total
Although clinicians in both community and hospital settings reported trying to contact individuals to inform them of a positive HCV result, patients were sometimes uncontactable. Clinicians reported that some HCV positive patients had complex lifestyles or had competing issues in their lives that they prioritised above a health condition such as HCV:

> Generally, this group of people don’t have a GP, which makes it even harder. So you look on the system, which then gets stuck there. (Senior house officer in regional emergency department)

Challenges to follow-up also occurred with patients of community-based services:

> I’ve only met her three or four times and each time we’ve talked about her hepatitis C and I’ve arranged investigations which she then hasn’t got done… I don’t know what, what has happened to that patient actually. She’s not returned back to the clinic. (GP in a regional town)

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**Table 1: Source of notifications requiring follow-up**

<table>
<thead>
<tr>
<th>Notification source</th>
<th>Cases n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practice</td>
<td>143 (58.6)</td>
</tr>
<tr>
<td>Hospital</td>
<td>49 (20.1)</td>
</tr>
<tr>
<td>Emergency departments</td>
<td>34 (13.9)</td>
</tr>
<tr>
<td>Sexual health services, alcohol and other drugs services</td>
<td>7 (2.9)</td>
</tr>
<tr>
<td>Other medical specialists&lt;sup&gt;a&lt;/sup&gt;</td>
<td>11 (4.5)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>244</strong></td>
</tr>
</tbody>
</table>

<sup>a</sup> ‘Other medical specialists’ includes private endocrinologists, private gastroenterology clinics, private haematology clinics, private fertility clinics, medicals for immigration visas, and outpatient mental health services.

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**Table 2: Reason for loss to follow-up**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Cases n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients did not re-present to clinic&lt;sup&gt;a&lt;/sup&gt;</td>
<td>64 (47.8)</td>
</tr>
<tr>
<td>Patients could not be contacted after follow-up&lt;sup&gt;b&lt;/sup&gt;</td>
<td>53 (39.6)</td>
</tr>
<tr>
<td>No clinician response after second reminder&lt;sup&gt;c&lt;/sup&gt;</td>
<td>10 (7.5)</td>
</tr>
<tr>
<td>Lost to follow-up for other reason&lt;sup&gt;d&lt;/sup&gt;</td>
<td>7 (5.2)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>134</strong></td>
</tr>
</tbody>
</table>

<sup>a</sup> Clinics had already attempted and failed to recall patients before follow-up.
<sup>b</sup> At point of follow-up, patients hadn’t re-presented to clinics; after follow-up, clinicians or clinics made attempts to contact patients but were unable to do so.
<sup>c</sup> Clinician did not respond to Queensland Health’s attempts at contact.
<sup>d</sup> GP named by patient during hospital admission was not current, or patient deceased before Queensland Health follow-up actions.
Hospital and emergency department clinicians sometimes tried to inform a patient’s GP of a positive HCV-AB test result if they could not reach a patient; the direct communication channels or record sharing systems between hospitals and GPs were limited to telephones, faxes, emails, discharge summaries (for inpatients only) and letter writing. Requests to GPs to follow up with further HCV-RNA testing could only be made if patients had provided GP details at the time of hospital admission.

Poor communication between hospital doctors and GPs could also be a barrier to follow-up care after diagnosis:

**Believe it or not, there’s very poor communication systems from within our electronic record back to the GP... Generally, their discharge letter will be given to the patient, unless they're admitted. If they're admitted there's an electronic discharge summary that will be transmitted directly back to their GP, but if they're non-admitted emergency department patients they will just get what's called a statement of attendance, and that's given to the patient. (Emergency department director in regional Queensland)**

Hospital shift work was also a barrier if initial attempts to contact a GP or a patient had not been successful:

*The patient should be called, and the GP should be contacted, or the patient should be told, “You have this positive result. You need to follow up with your GP”... If they have a voicemail with their name on it, I will leave a message... I guess the problem then is if they call back on a day when I'm not on shift... I’ll try two to three times before I give up. (Senior house officer in regional emergency department)*

Given the high proportion of notified cases without subsequent HCV-RNA tests, we asked doctors working in the hospital setting why they tested their patients for HCV. General hepatitis screening and needlestick injuries from tested patients were commonly reported reasons, as well as having several patients presenting to emergency departments who reported injecting drugs. When testing because of a needlestick injury, the purpose of testing was to protect the healthcare worker rather than the patient, and the test was not done with patient follow-up in mind.

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**Table 3: Details of clinicians participating in telephone interviews**

<table>
<thead>
<tr>
<th>Clinicians</th>
<th>N</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practitioners</td>
<td>6</td>
<td>Three general practitioners in group practices</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Two general practitioners working in Aboriginal Medical Services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One general practitioner working at a homeless and low socioeconomic status specialist outreach service in Brisbane</td>
</tr>
<tr>
<td>Hospital and emergency department doctors</td>
<td>7</td>
<td>Three emergency department directors from large metropolitan hospitals in south east Queensland</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Two emergency department directors from regional Queensland hospitals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One resident/senior house officer at an emergency department in regional Queensland</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One infectious diseases director at a large metropolitan hospital in south east Queensland</td>
</tr>
<tr>
<td>Alcohol and other drugs services and sexual health service</td>
<td>3</td>
<td>Two sexual health services directors/consultants in regional Queensland</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One alcohol and other drugs service nurse practitioner in regional Queensland</td>
</tr>
</tbody>
</table>
The time taken for HCV-AB and HCV-RNA test results to be processed by pathology laboratories was another barrier to follow-up in hospital settings, as patients were often discharged or transferred before their initial HCV-AB result was known. In these cases, the only information available to a requesting clinician for follow-up with a patient were the contact details entered at intake, or recorded from previous admissions, which may not be correct or up to date.

Pathology labs were responsible for reporting test results to the requesting doctor, who in turn had responsibility for following up results. However, the name of the requesting doctor on the pathology form was not always the same as the clinician who had ordered the test, who may have had little if any contact with the patient:

*The junior medical staff will run the emergency department routinely. They’ll be the ones that mostly see the patients. But they’ll order under the name of the consultant. So the consultant for the shift or the director of the department will be the name on the form. (Director of infectious diseases)*

Many clinicians across different health service sectors agreed that it would be useful to know if an HCV-AB positive test result was the first time a patient had tested positive, as that would make them prioritise follow-up testing and treatment more vigorously. An emergency departments director from regional Queensland said “I think if that was a first positive notification, it certainly highlights that a lot more to the clinician reading that. So I think in that case, they will push further for the follow-up.”

**Discussion**

Of the 769 new HCV notifications received by Queensland Health during the project period (excluding incarcerated individuals), 244 were eligible for follow-up actions with notifying clinicians. Sixty-two of those were tested for HCV-RNA after the follow-ups, and 26 were subsequently prescribed treatment. Although most patients with chronic HCV can be treated in general practice with pan-genotypic direct-acting antivirals,

³ some of the clinicians who were interviewed discussed how being made aware of a first-time diagnosis would emphasise the importance of progressing patients through the correct care cascade for HCV testing and treatment.

Thirty-four percent of the cases who were followed up had HCV testing initiated in hospitals. This was an unexpected finding that may be related to the fact that we only followed up cases who did not have a documented HCV-RNA test after their antibody test, and the challenges associated with managing further HCV testing, and if necessary, treatment, in hospital settings. More work is needed to improve follow-up of individuals initially tested in hospitals and emergency departments, to ensure they have the opportunity for further testing and treatment in a community setting.

This project followed up new notifications (for all individuals not already recorded as HCV positive on the notifications system) four weeks in arrears; this increased the difficulty in reaching inpatients, notified from the hospital system, who had already been discharged. The Coordinated Hepatitis response to Enhance the Cascade of Care by optimising existing Surveillance systems (CHECCS) pilot project was conducted in Victoria in 2021 and 2022, and followed up and supported notifying clinicians of individuals newly diagnosed with HCV who had no evidence of follow-up testing or treatment. The CHECCS project also made initial follow-up phone calls four weeks after the date of HCV notification and found hospital clinicians were challenging to engage with, because the delay meant that junior medical staff with no ongoing connection to patients had often rotated to other departments a month later. As a result of this, several months after the initiation of the CHECCS project, the team in Victoria shifted follow-up of hospital cases to occur immediately after notification rather than wait four weeks. In addition, consistent with our findings, the team found that written requests
were more successful for obtaining necessary project data than was attempting follow-up phone calls to hospital clinicians alone.\(^\text{10}\)

The major challenge with the roll-out of similar follow-up projects is the time and resources required to search the pathology databases to determine which cases were eligible for follow-up. An alternative strategy would have been to contact the notifying clinicians of all new notifications, but a previous study found that almost all patients who had an HCV-RNA test before notification follow-up had been linked to treatment.\(^\text{11}\) There is currently no requirement for pathology laboratories to report negative HCV-RNA test results. It is worth considering whether the current Australian case definition for HCV notification is still fit for purpose. If the notification requirements for HCV notifications in Australia were changed to require notification of all HCV-RNA test results, positive and negative, then the task of determining who had received a positive HCV-AB test, but had not yet taken a subsequent HCV-RNA test, would be a much easier and more efficient process as we approach elimination.\(^\text{10}\) Alternatively, making a positive HCV-RNA test result the only HCV notification criterion, rather than a positive HCV-AB test result, would make a significant difference to the way that HCV notifications data could be efficiently used by health departments in their efforts to contribute to Australia’s goal of eliminating HCV by 2030. However, this could only be done if reflexive HCV-RNA testing was routinely done, requiring changes to Medicare Benefits Scheme funding and pathology protocols. There are other advantages to reflexive testing; individuals are not required to make more than one trip to a pathology lab to assess their HCV-RNA status, and drawing blood once is also better for people who may have poor venous access or an aversion to needles.\(^\text{10}\)

A large proportion of eligible cases (55%) in our study were recorded as lost to follow-up (Table 2), and the majority of these (87%) had not re-presented to clinicians following HCV-AB testing. Following up these notifications did not result in any progression to further testing and treatment. A randomised controlled trial, of active case management to support GPs and/or patients for further testing and treatment, did not find any difference between intervention and standard care.\(^\text{12}\) This supports our finding that loss to follow-up is a more significant issue than is clinicians’ understanding of the HCV care cascade. Our findings point to the need for other strategies to support patients testing positive for hepatitis C, so as to address the barriers to them receiving further testing and treatment. These strategies can include peer navigation and support, reflex HCV-RNA testing, and accessible testing and treatment services.\(^\text{3}\)

Further research is needed to establish whether a disconnect in continuity of care between hospitals, emergency departments, and GPs is a factor in addressing the follow-up of first-time HCV notifications. Previous research has identified that the key elements of a discharge summary from emergency departments are discharge diagnosis, treatment received in hospital, results of investigations and the follow-up required.\(^\text{13}\) However, continuity of HCV case management between hospitals and general practitioners may be impacted because first-time positive HCV-AB tests sometimes result from incidental testing, rather than from investigations undertaken to diagnose the patients’ main reasons for presenting to hospitals or emergency departments. Wimsett et al\(^\text{13}\) found that too much information can sometimes impact the quality of discharge summaries, such as listing all results from laboratory tests. In addition, if the patient was discharged from an emergency department or ward before HCV test results were returned, their GP would not have been informed of the positive test result, even if they had received a discharge summary.

This project had some limitations. The resource-intensive nature of the work, and dealing with multiple pathology laboratories and information technology systems, meant that some results may not have been identified. It is also unclear from our work whether there were a higher proportion of cases notified from
hospitals that had not been subsequently tested for HCV-RNA, than those that had received appropriate testing after their initial positive HCV-AB test results. This project also excluded incarcerated individuals.

The follow-up of 769 eligible new HCV notifications in Queensland resulted in 26 individuals (3%) being engaged in care and progressing to treatment. The project was resource intensive and required two days per week of dedicated time. Telephone contact is the best form of follow-up communication for GPs, while emails are more efficient for hospital and emergency department doctors. The high proportion of notifications followed up who were initially tested in hospital and emergency department settings points to the importance of developing strategies to reach and support patients who are tested in these settings. These challenges demonstrate the need to streamline access to testing data and improved communication systems to ensure we can maximise engagement with care, testing and treatment following an initial positive HCV-AB result. The data and skills are available to accelerate HCV elimination, but their implementation is being hampered by complex system barriers.

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Author contributions

All authors designed the project, LAS and MC designed the project evaluation. MC wrote the manuscript. All authors reviewed drafts of the manuscript and approved the final version. The authors declare no competing interests.

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Appendix A: Questionnaires sent to clinicians/general practitioners

Appendix A.1: Questionnaire for clinicians

CONFIDENTIAL: Hepatitis C Notification Follow-up

TO: Dr
Clinic:
Email/fax:
Date:

FROM Morris Carpenter
Hepatitis C Follow-up Officer
Phone: Contact details removed for publication
Fax: 
Email: 

Re: DOB: Sex:
NOCS ID: Notification Date:

Dear Doctor,
You are being contacted about your patient listed above who was reported to the Health Department with a positive hepatitis C (HCV) antibody test result.
Before commencing antiviral treatment, patients need to be screened for HCV RNA (PCR) to confirm current infection.
Please tick appropriate boxes and answer the following questions then return to: Morris Carpenter at the Communicable Diseases Branch on the fax or email listed above.
Thank you for your assistance.

Q1. Have you ordered a HCV RNA (PCR) test for your patient?
□ Yes (Go to Q2)
□ No, patient lost to follow up/has not re-presented (No further answers required)
□ No, HCV antibody test result provided to the patient’s general practitioner, details below:
  GP Name: ___________________ GP Clinic: ___________________ (No further answers required)
  □ No, other: provide details ________________________________________________________________ (Go to Q3)

Q2. What is your patient’s HCV RNA (PCR) status?
□ HCV RNA (PCR) positive. Laboratory Provider: ________________
□ HCV RNA (PCR) negative. Laboratory Provider: ________________ (If negative, no further answers required)
□ Waiting for Test results

Q3. Your follow-up plan for this patient (answer all that apply):
□ I have provided a script for HCV treatment: Date script provided to patient ________________
□ I have ordered a HCV RNA (PCR) test but not yet received a result
□ If patient HCV RNA (PCR) positive, I intend to treat and know how to do this
□ If patient HCV RNA (PCR) positive, I intend to treat but will need support (see details below for support options)
□ Other: _________________________________________________________

Further resources and advice are available to assist and guide hepatitis C case management.
Your local Healthpathways portal can help you to access support, advice and referral to specialists if you are not experienced in hepatitis C case management. Please log onto Healthpathways and look up Hepatitis C.
Healthpathways links: https://clinicalexcellence.qld.gov.au/resources/clinical-prioritisation-criteria/healthpathways
Appendix A.2: Questionnaire for general practitioners

**CONFIDENTIAL: Hepatitis C Notification Follow-up**

<table>
<thead>
<tr>
<th>TO: Dr</th>
<th>FROM Morris Carpenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic:</td>
<td>Hepatitis C Follow-up Officer</td>
</tr>
<tr>
<td>Email/fax:</td>
<td>Contact details removed</td>
</tr>
<tr>
<td>Date:</td>
<td>for publication</td>
</tr>
</tbody>
</table>

**Re:**

**NOCS ID:**

**DOB:**

**Notification Date:**

**Sex:**

**Dear Doctor,**

You are being contacted about your patient listed above who was reported to the Health Department with a positive hepatitis C (HCV) antibody test result.

Before commencing antiviral treatment, patients need to be screened for HCV RNA (PCR) to confirm current infection.

Please tick appropriate boxes and answer the following questions then return to: Morris Carpenter at the Communicable Diseases Branch on the fax or email listed above.

Thank you for your assistance.

---

**Q1. Have you ordered a HCV RNA (PCR) test for your patient?**

- [ ] Yes (Go to Q2)
- [ ] No, patient lost to follow up/has not re-presented (No further answers required)
- [ ] No, other: provide details _____________________________________________________________ (Go to Q3)

---

**Q2. What is your patient’s HCV RNA (PCR) status?**

- [ ] HCV RNA (PCR) positive. Laboratory Provider: __________________
- [ ] HCV RNA (PCR) negative. Laboratory Provider: __________________ (If negative, no further answers required)
- [ ] Waiting for Test results

---

**Q3. Your follow-up plan for this patient (answer all that apply):**

- [ ] I have provided a script for HCV treatment: Date script provided to patient ______________
- [ ] I have ordered a HCV RNA (PCR) test but not yet received a result
- [ ] If patient HCV RNA (PCR) positive, I intend to treat and know how to do this
- [ ] If patient HCV RNA (PCR) positive, I intend to treat but will need support (see details below for support options)
- [ ] Other: ____________________________________________________________________________

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**Further resources and advice are available to assist and guide hepatitis C case management.**

Your local Healthpathways portal can help you to access support, advice and referral to specialists if you are not experienced in hepatitis C case management. Please log onto Healthpathways and look up Hepatitis C.


ASHM also have resources to support hepatitis C treatment: [https://ashm.org.au/resources/hcv-resources-list/decision-making-in-hcv/](https://ashm.org.au/resources/hcv-resources-list/decision-making-in-hcv/)

If your patient would benefit from peer support to help them manage their treatment regime, please contact QuHIN’s Peer Support Workers at CONTACT DETAILS REMOVED FOR PUBLICATION.
Appendix B: Scripts followed in semi-structured telephone interviews with invited clinicians/general practitioners

Appendix B.1: Interview guide for hospital clinicians

Interview Guide for Notifying Clinicians (Hospitals)

Introductory script

I’m part of a team at UQ that is studying and evaluating the follow-up of Hep C notifications with clinicians, to see if we can make any effective changes the way notification data is used.

The way it will work today is that I will ask some questions to get us started and keep us on track, but we’ll see where the discussion takes us. There are no right or wrong answers, I’m just interested to hear about your experiences.

If it’s OK with you I’m going to record our conversation today, so that I can get it transcribed later.

Our conversation will be treated in confidence. Nobody at UQ or Queensland Health will be given access to any of the recordings or transcriptions unless they are part of the evaluation team, and any identifying information will be deleted from the transcriptions. Both the recordings and the transcriptions will be stored on UQ’s secure Research Data Management System.

I’m going to start recording now.

I sent you the information and consent forms. Do you have any questions before we begin?

Are you happy to give verbal consent to participate, and for me to sign the consent form on your behalf?

Introductory questions

- What position do you currently hold?
- Where are you based?
- How long have you worked at your current hospital?
- Can you give me a brief overview in terms of what your job involves in terms of patient contact, staff supervision, administration, etc..

In relation to hepatitis C notifications in a hospital context

- Do you see many patients who are at risk of hepatitis C? If so, approximately how many per week?
- Are there particular challenges that high risk Hep C patients give clinicians?
Evaluation of Queensland Health’s Notifiable Conditions System Follow-up of New Hepatitis C Cases

• What are some of the frustrations in terms of treating HCV within the current rules, for example are there issues with Medicare rules or anything like that that it’s frustrating to deal with?

• I have sometimes found that the doctor whose name that is attached to the pathology lab test request, and therefore the notification, hasn’t always treated the patient themselves, do you know why that happens? Would it be better if that changed?

• In the hospital context, how are a patient’s test results notified to a treating doctor?

• Do you know how long it takes to get a result for a hep C test?

• I have been following up Hep C Antibody positive test results, where there is no evidence of a subsequent RNA test four weeks later, that seems to be a good time frame for GPs, but in the hospital context, what do you think would be an appropriate delay before following-up?

• The notification has no real relevance or impact on the treating doctor (or does it)?

• I have initiated follow-ups where a person has been notified for the first time on the Qld system, would it be useful to tell a notifying clinician that a patient hadn’t previously returned a Hep C Antibody +ve test result in Queensland?

• In your workplace, if a patient returns a positive antibody test, what should happen next?

• (Depending on the answer to previous question) Does that always happen? If not, what are the reasons why not?

• Whose responsibility is it to act on the Hep C Antibody test result, and if necessary, discuss it with the patient, and order an RNA test?

• What are some of the issues that might prevent the correct hep C care cascade (testing and treatment) from occurring in a hospital or ED

• If a patient has been discharged from hospital before a positive Hep C test result is returned, what should happen to follow-up with the patient?

• Taking a more strategic view of how notifications work, and are linked to follow-up testing or treatment, do you think that there is anything that could or should be done to improve treatment outcomes.

• Is there anything that Queensland Health could do, or offer to clinicians or patients, that would help to overcome some of the challenges to testing and treatment?
• Do you have any suggestions about how the follow-up of hepatitis C notifications could be improved? If so, what are they?

• Is there anything else about Hep C testing and treatment that we haven’t talked about that you would like to mention?
**Interview Guide for Notifying Clinicians (EDs)**

**Introductory script**

I’m part of a team at UQ that is studying and evaluating the follow-up of Hep C notifications with clinicians, to see if we can make any effective changes the way notification data is used.

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Are you happy to give verbal consent to participate, and for me to sign the consent form on your behalf?

**Introductory questions**

- What position do you currently hold?
- Where are you based?
- How long have you worked at your current hospital?
- Can you give me a brief overview in terms of what your job involves in terms of patient contact, staff supervision, administration, etc..

**In relation to hepatitis C notifications in an ED context**

- What are some of the reasons why a Hep C test might be requested by an ED Doctor?
- I have sometimes found that the doctor whose name that is attached to the pathology lab test request, and therefore the notification, hasn’t always treated the patient themselves, do you know why that happens?
Evaluation of Queensland Health’s Notifiable Conditions
System Follow-up of New Hepatitis C Cases

- In the hospital context, how are a patient’s test results notified to a treating doctor?

- Is that system just relevant to your HHS, or is that the same Queensland wide?

- If it takes a day or two for the pathology results to be returned, and the patient is no longer in the ED, how are the results actioned? Is there a process for following up the test results with the patient or another clinician (EG. GP?)

- In your workplace, if a patient returns a positive antibody test, what should happen next?

- (Depending on the answer to previous question) Does that always happen? If not, what are the reasons why not?

- Whose responsibility is it to act on the Hep C Antibody test result, and if necessary, discuss it with the patient, and order an RNA test?

- What are some of the issues that might prevent the correct hep C care cascade (testing and treatment) from occurring in a hospital or ED

- If a patient has been discharged from hospital before a positive Hep C test result is returned, what should happen to follow-up with the patient?

- I have been following up Hep C Antibody positive test results, where there is no evidence of a subsequent RNA test four weeks later, that seems to be a good time frame for GPs, but in the hospital ED context that’s obviously not relevant, what would be the best way to follow up that test result, viewer, patient details, GP? Etc.

- The fact that Hep C is a notifiable condition has no real relevance or impact on the treating doctor (or does it)?

- I have initiated follow-ups where a person has been notified for the first time on the Qld system, would it be useful to tell a notifying clinician that a patient hadn’t previously returned a Hep C Antibody +ve test result in Queensland?

- Hep C challenging cohort of patients to treat, (recent incarceration, PWID, low SES, etc) are some of these patients using EDs for healthcare that isn’t an emergency, is this somewhere to catch these high risk Hep C patients?

- Is there anything else about Hep C testing and treatment that we haven’t talked about that you would like to mention?
Appendix B.3: Script for general practitioners

Evaluation of Queensland Health’s Notifiable Conditions System Follow-up of New Hepatitis C Cases

Interview Guide for Notifying Clinicians (GPs)

Introductory script

I’m part of a team at UQ that is studying and evaluating the follow-up of Hep C notifications with clinicians, to see if we can make any effective changes the way notification data is used.

The way it will work today is that I will ask some questions to get us started and keep us on track, but we’ll see where the discussion takes us. There are no right or wrong answers, I’m just interested to hear about your experiences.

If it’s OK with you I’m going to record our conversation today, so that I can get it transcribed later.

Anything that you say today will be treated in confidence. Nobody at UQ or Queensland Health will be given access to any of the recordings or transcriptions unless they are part of the evaluation team, and any identifying information will be deleted from the transcriptions. Both the recordings and the transcriptions will be stored on UQ’s secure Research Data Management System.

I’m going to start recording now.

I sent you the information and consent forms. Do you have any questions before we begin?

Are you happy to give verbal consent to participate, and for me to sign the consent form on your behalf?

Introductory questions

• What position do you currently hold?

• Where are you based?

• How long have you worked at your current practice?

In relation to hepatitis C notifications in a GP context

• Are you familiar with Hepatitis C case management? If so do you usually treat yourself or prefer to refer?

• Do you see many patients who are at risk of hepatitis C? If so, approximately how many per month?

• Are there particular challenges that high risk Hep C patients give GPs?
• How are a patient’s Hep C test results notified by the pathology labs to your practice?

• Do you know how long it takes to get a result for a Hep C test?

• I have been following up Hep C Antibody positive test results, where there is no evidence of a subsequent RNA test. If a patient returns a positive antibody test, what should happen next?

• (Depending on the answer to previous question) Does that always happen? If not, what are the reasons why not?

• The notification has no real relevance or impact on the treating doctor (or does it)?

• I have initiated follow-ups where a person has been notified for the first time on the Qld system, would it be useful to tell a notifying clinician that a patient hadn’t previously returned a Hep C Antibody +ve test result in Queensland?

• What process do you use at your practice for recalling patients for further testing and/or treatment?

• What are some of the issues that might prevent the correct hep C care cascade (testing and treatment) from occurring for your patients?

• Do you think there is anything that could improve testing and treatment rates for Hep C patients? (If no answer, prompts: Reflexive testing & incentives – discuss issues with this – MBS rebates for RNA testing, administering incentives, giving Hep C patients money/vouchers for testing/treatment)

• What are some of the challenges facing you and your patients in the testing and treatment of hepatitis C?

• Is it helpful for Queensland health to follow up with GPs where a HCV Antibody positive test result hasn’t been followed by an RNA test?

• Is there anything that Queensland Health could do, or offer to GPs or patients, that would help to overcome some of the challenges to testing and treatment?

• Do you have any suggestions about how the follow-up of hepatitis C notifications could be improved? If so, what are they?

• Is there anything else about Hep C testing and treatment that we haven’t talked about that you would like to mention?