

CHECCS PILOT PROGRAM

EVALUATION REPORT NOVEMBER 2022

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GLOSSARY

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| CDES | Communicable Disease Epidemiology and Surveillance |
| CDPC | Communicable Disease Prevention and Control |
| CHECCS | Coordinated Hepatitis Response to Enhance the Cascade of Care by Optimising Existing Surveillance Systems in Victoria |
| CHECCS PO | CHECCS Project Officer |
| DAA | Direct-Acting Antiviral |
| DH | Department of Health |
| ESF | Enhanced Surveillance Form |
| FTE | Full Time Equivalent |
| IHCN | Integrated Hepatitis C Nurse |
| ISS | Information Surveillance and Support team (DH) |
| PHESS | Public Health Event Surveillance System |
| PHO | Public Health Officer |
| VACCHO | Victorian Aboriginal Community Controlled Health Organisation |

EXECUTIVE SUMMARY

The Coordinated Hepatitis responses to Enhance the Cascade of Care by optimising existing Surveillance systems (CHECCS) project aimed to improve delivery of care to Victorians living with hepatitis C. The pilot aimed to provide support to diagnosing clinicians to increase follow-up testing and treatment and to improve collection of enhanced surveillance data to improve the analysis of hepatitis C notifications. The Doherty Institute partnered with the Department of Health Victoria and key community groups to develop, implement, and evaluate the pilot.

An evaluation framework was developed to guide the evaluation of the programs impact. This was endorsed by the CHECCS Governance Group on 12th July 2022

The evaluation demonstrates that the CHECCS pilot was successful in supporting healthcare providers to engage individuals in follow-up testing and treatment, generating detailed information regarding the cascade of care, and strengthening linkages between clinical services especially for those who had barriers to their engagement in treatment and care.

Continued incorporation of hepatitis C follow-up and resource provision for diagnosing clinicians within the Local Public Health Units (LPHU) processes is recommended, and expansion to include hepatitis B should be considered. The establishment of routine access to, and improved completeness of, further testing data from laboratories would greatly improve efficiency and should be a priority. The prioritisation of follow-up for people diagnosed in low caseload primary care clinics and in hospital settings is justified based on evidence identified through the pilot regarding care engagement and support needs. The establishment of strong links with Victoria's Integrated Hepatitis C Network was a strength and optimising the use of this network to support diagnosing clinicians in both primary and tertiary settings is highly recommended. In future, consideration should be given to direct follow-up of notified individuals, and retrospective follow-up of notified cases prior to the CHECCS pilot period. This could be prioritised for those cases shown to be at greatest risk of not having been further assessed or treated based on CHECCS findings.

PROJECT OVERVIEW

Background

In 2020 an estimated 25,000 Victorians were living with chronic hepatitis C¹. Hepatitis C is a leading cause of liver cancer which is the 6th most common cause of cancer death in Australia², with the burden of disease disproportionately affecting people with a history of injecting drug use, and Aboriginal and Torres Strait Islander Australians³. Most hepatitis C related deaths from liver cancer or liver failure (due to scarring or cirrhosis) can be prevented if the infection is cured⁴. Highly effective, direct-acting antivirals (DAAs) are available and are 95% effective at curing hepatitis C⁵. Despite the increasing burden of liver disease and the commitment to hepatitis elimination there has been a limited public health response to hepatitis C notifications in Victoria with follow-up of only potential newly acquired cases and any cases reported with a public health risk factor such as tattooing or health care worker⁶. It is estimated 40% of Victorians living with hepatitis C remain untreated and therefore at risk of disease progression, liver cancer and cirrhosis¹.

The Coordinated Hepatitis response to Enhance the Cascade of Care by optimising existing Surveillance systems (CHECCS) pilot was established in April 2021 to pilot an innovative surveillance system-based approach to support the management of new hepatitis C diagnosis in Victoria. It aimed to enhance access to care, and improve outcomes for Victorians living with hepatitis C. It also aimed to improve surveillance data collection and the analysis environment for hepatitis C notifications, monitoring and treatment uptake.

The Aims of CHECCS were:

- To identify people who have been diagnosed with hepatitis C but who had no evidence of follow-up testing or treatment.
- To support diagnosing clinicians to improve delivery of care through follow-up of hepatitis C RNA testing after hepatitis C antibody positive result to determine presence of infection.
- To support diagnosing clinicians, to enhance awareness of next steps in work up and provide resources and guidance for management and treatment of hepatitis C with DAA or referral to an appropriate service that can provide care.
- Improve the collection of enhanced surveillance data for hepatitis C notifications and generate estimates of the cascade of care for newly diagnosed cases.

CHECCS is a partnership between the WHO Collaborating Centre for Viral Hepatitis at The Peter Doherty Institute for Infection and Immunity (Doherty Institute) and the Victorian Department of Health (DH) and is funded by the Eliminate Hepatitis C Australia Partnership (EC Australia).

Victorian hepatitis C surveillance

Hepatitis C is a notifiable condition for both the testing laboratory and diagnosing clinician⁷. In accordance with national case definitions⁸, notifications are classified as either newly acquired (infections acquired in the last 24 months) or unspecified (infections acquired more than 24 months ago or unknown duration), which mostly represent chronic cases. All

notifications prior to CHECCS commencement were reviewed by the Communicable Disease Epidemiology and Surveillance (CDES) team and entered into the Public Health Enhanced Surveillance System (PHESS). Active investigation of cases by Public Health Officers (PHOs) was undertaken for potential newly acquired hepatitis C cases, or cases with a potential public health risk and notifications received from the Department of Home Affairs for people who have undergone a health assessment as part of the Australian visa application.

Under current hepatitis C case definitions, an individual (with no prior evidence of hepatitis C) with detected hepatitis C antibodies is classified as a case. Hepatitis C antibody is an indication of possible current or past infection and persists after cure. Hepatitis C RNA results are required to determine active infection. Hepatitis C RNA positive results are not routinely reported by laboratories. Due to the volume of negative hepatitis C RNA results, accepting and entering these notifications was not possible. Electronic Laboratory Reporting (ELR) has changed the data entry environment at DH with less “faxed” results needing manual input into PHESS. Following an extensive development process over several years, ELR was implemented during the COVID-19 pandemic and to date has now onboarded 4 of the major laboratories; Victorian Infectious Diseases Reference Laboratory (VIDRL), Australian Clinical Labs (ACL), Melbourne Pathology, and Dorevitch Pathology. More laboratories will be included in the future. ELR represents an opportunity to significantly streamline and improve the data environment around a range of notifiable conditions, including hepatitis C.

Both laboratories and diagnosing clinicians are required to notify hepatitis C cases but compliance by diagnosing clinicians has been low. A previous enhanced surveillance program implemented in 2016 aimed to improve the collection of key data including demographic details, risk factors, and potential public health risks (i.e., healthcare worker status)⁶. The program added extra questions to simplified pre-filled forms and contacted diagnosing clinicians by mail to increase data collection. This initiative was successful in improving data collection, improving notifications from diagnosing clinicians and also provided further support to diagnosing clinicians on management of people with hepatitis C.

In Victoria, communicable disease control and surveillance was wholly managed centrally at DH until 2020 when the Victorian Government established 9 Local Public Health Units (LPHUs) to strengthen the public health response to the COVID-19 pandemic, with a plan for other communicable disease and public health issues to be incorporated into their work at a later date. LPHUs work with DH to keep their local communities healthy, safe and well. They use local knowledge, community-based relationships and direct engagement to effectively tailor and deliver public health initiatives and respond to incidents and issues within their local area. In September 2022, the follow-up and management of hepatitis C notifications were integrated to LPHUs.

Project Establishment

The CHECCS project commenced in April 2021, establishing a governance group and creating an operational plan, evaluation plan, workflows, and key indicators. The project team worked closely with DH to ensure CHECCS was embedded within DH normal practice, utilising the Public Health Surveillance System (PHESS).

Resources

A project coordinator (0.4 FTE) and a project officer (PO) (0.6 FTE) were funded to deliver the project, as well as in-kind support from both the Doherty Institute and the Communicable Diseases, Epidemiology and Surveillance (CDES) team at DH. Both roles were seconded to DH to enable access to internal systems and data sources. The project officer was authorised as a PHO to enable follow-up calls to proceed. Throughout the report the project officer role will be referred to as the CHECCS PO. At points during key stages of development and implementation it was identified that resources were insufficient to the projects demands requiring additional days to be worked to meet deadlines. No further funding was available to overcome these shortfalls. In addition, the need for ongoing public health response to the COVID-19 pandemic had a significant impact on the internal resources at DH for addressing other communicable disease impacts, including hepatitis C.

Partnership and collaboration were seen as crucial for working to improve the health and wellbeing of those living with hepatitis C. A participatory, integrated, and collaborative approach was adopted for the development and delivery of CHECCS including the evaluation framework. Advantages of this collaborative approach were:

- Inclusion of priority areas and preferred strategies of the collaborators
- Inclusion of those with lived experience in the development and evaluation of the project.
- Benefits from sharing of expertise among Victorian Aboriginal Community Controlled Health Organisation (VACCHO), LiverWell, researchers from the Burnet and Doherty Institutes, and policy makers and public health practitioners from DH
- Flexibility in developing and implementing frameworks
- Increased likelihood of translation of CHECCS into ongoing surveillance practice.

Project Governance Group

The project team established a Governance Group to oversee and guide the development, implementation, and evaluation of CHECCS. It included representatives from the Burnet Institute / EC Australia, the project partners (Doherty Institute & DH), the peak community organisation LiverWell, and VACCHO and community members with lived experience. Its key functions were to:

- Approve the project plan for delivering CHECCS
- Provide expert advice on the design and delivery of CHECCS
- Provide a forum for decision-making to support CHECCS
- Support the development of the evaluation framework, including the provision of expert advice on the identification of metrics to measure its impact

Review and approve key documents including protocols, scripts, the evaluation framework, and final report for the program.

This work was undertaken as part of the communicable diseases and surveillance activities, under the oversight of the Public Health and Wellbeing Act and in accordance with all relevant privacy and confidentiality requirements.

The work is strongly aligned to the key priority actions in both the Victorian hepatitis C plan 2022-30 and the previous Victorian hepatitis C strategy 2016-20, which aim to eliminate hepatitis C as a public health concern by 2030.

Pilot Implementation

New notifications of unspecified hepatitis C with an event date between 1st August 2021 and 31st August 2021 were used for a trial of systems

From October 2021, the pilot officially commenced follow-up calls for eligible cases with event date between 1st September 2021 and 31st March 2022. Follow-up calls to diagnosing clinicians regarding cases ceased in June 2022.

Although the aim was to initially collect 12 months of data, at the request of DH and agreed by the Governance Group and funding partner EC Australia, resources of CHECCS were diverted to assist with reviewing and updating existing viral hepatitis response protocols and subsequent training and integration into the work of the LPHUs. In this way, the CHECCS project directly supported the enhancement and integration of hepatitis C into local follow-up by LPHUs.

Summary of follow-up processes and workflows

Testing for hepatitis C occurs in many clinical settings, including hospitals, community (e.g., primary care clinics), correctional facilities, and screening to meet requirements for processes such as immigration, blood donation, or IVF. CHECCS' follow-up approaches varied according to these settings.

Notifications were followed-up directly by attempting to contact the diagnosing clinician with phone calls to hospitals and community settings. CHECCS did not follow up notifications from correctional facilities by phone as they were part of the Justice Health hepatitis C program run by St Vincent's Hospital. Correctional facilities cascade of care data was received by DH directly and securely to the CHECCS PO, under the approval and oversight of Justice Health. Notifications received for processes such as immigration or blood donor screening were not followed up due to the lack of diagnosing clinician information provided by laboratories.

Initial follow-up occurred from four weeks after the event date (the date of notification) to allow time for the clinician independently to organise hepatitis C RNA and maximise data capture. The CHECCS PO attempted to contact the diagnosing clinician via phone, with 3 attempts at contact made before notification follow-up ceased and was recorded as lost to follow-up for the purposes of the project.

The CHECCS PO requested information from the clinician on demographics and indicators of the cascade of care, using CHECCS specific questions in PHESS. Depending on the clinical discussion with the diagnosing doctor, further follow-up was arranged. For example, if the diagnosing clinician was still undertaking clinical work up, or if they identified the case was at risk of being lost to care, a second follow-up call could be scheduled for 8 weeks later to attempt to complete cascade of care information. Where appropriate, the CHECCS PO also offered resources and referral options for diagnosing clinicians to assist with the delivery of care. People who the diagnosing clinician identified were at risk of being lost to care were also identified and additional support to the diagnosing clinician was provided, beyond standard follow-up protocols including linkage to specialised services e.g., state-funded Integrated Hepatitis C Nurses based at a range of health and community services across Victoria.

A CHECCS-specific Enhanced Surveillance Form (ESF) was developed as an alternative option for clinicians who preferred to complete the requested information and provide as a document instead of via a phone call. These forms were sent by secure fax or password protected email. An internal process was developed to direct these returned forms to the CHECCS PO to review and input data.

Contact with most Victorian Integrated Hepatitis C Nurses (IHCN) was initiated at the development stage of CHECCS. Initial calls served to understand the services available in each region, whether the IHCN operated outreach clinics outside of the main hospital, referral preferences and confirmation of contact details. Once consented, IHCN details and how they could assist were then included in the resources provided to diagnosing clinicians upon contact. See Appendix 5 for resource table.

Occasionally throughout the pilot, the CHECCS PO liaised with a specific IHCN via email or phone with queries regarding geography, or program specific information, whilst maintaining confidentiality of the case. CHECCS presented interim findings at the quarterly communities of practice IHCN meeting in September 2022. This was well received and prompted several questions and discussion. Although direct impact could not be measured due to confidentiality considerations, 100 diagnosing clinicians were sent resources which included the details of the IHCN nurses. Anecdotally, IHCNs were appreciative of CHECCS for promoting their service and mentioned doctors they had no previous connection with had reached out, which is not a usual occurrence.

Variation to follow-up processes

Where follow-up was difficult, a prioritisation framework for repeat calls was developed in consultation with the governance group. See Appendix 1 for prioritisation framework.

Follow-up of hospital notifications was challenging throughout the project, with substantial difficulties experienced in identifying and making contact with the diagnosing clinician. Often diagnosing clinicians were junior medical staff with no ongoing connection to the person notified and had already rotated into a different department by the time contact was attempted. Several changes in the follow-up processes were trialled to address the issues. A list of the variation and timelines can be found below.

- January 2022: Backlog was identified in hospital notifications with difficulty contacting clinicians for November and December 2021. Level 1 of the capacity

section of the Prioritisation Framework was enacted and hospital notifications were de-prioritised. Hospital notification follow-up recommenced in late January 2022.

- May 2022: Follow-up of hospital cases shifted to occur immediately rather than wait 4 weeks. Written requests for information were also sent. It was found that requesting discharge summaries was more successful for obtaining necessary data than attempting to speak with the diagnosing clinician alone.
- June 2022: Due to resource constraints, there was a significant backlog of notifications requiring follow-up. Interim analysis of CHECCS results showed that follow-up testing and treatment was less common for people diagnosed in hospital settings when compared with those diagnosed in the community. On this basis, the Governance group advised that given the potentially greater impact on care, that hospital notifications should be prioritized over those from community high caseload notifiers – the latter having typically high levels of linkage to care and treatment.

Insufficient doctor details were common in select settings (e.g., clinical research studies). These were retrospectively added to the exclusion criteria. More details can be found below.

Eligibility criteria

Inclusion and exclusion criteria were established to guide follow-up (Table 1). Workflows were harnessed from PHESS into a Microsoft Power BI interface to automatically filter and extract cases for follow-up, according to the eligibility criteria. Additional exclusion criteria were included as the project progressed (Table 1).

Table 1: Modified inclusion and exclusion criteria for CHECCS

| Inclusion Criteria | Exclusion criteria |
|--|--|
| Newly notified | Meets criteria for newly acquired |
| Confirmed unspecified hepatitis C case | Cases <18 years old |
| Event date 1st August 2021 to 31st March 2022[^] | Cases diagnosed via immigration screening |
| | Cases diagnosed via IVF screening |
| | Cases diagnosed while admitted to inpatient psychiatric facilities |
| | Cases diagnosed via health insurance screening* |
| | Cases diagnosed via clinical research study participant screening* |
| | Cases that met the follow-up criteria of newly acquired but upon follow-up by CDPC were reclassified as unspecified* |

*Retrospectively excluded from follow-up

[^]As above, originally planned to be 31 July 2022 but amended due to LPHU integration (see Pilot Implementation section).

Data collection

Data collection for CHECCS was undertaken by the CHECCS PO in PHESS. The question set included two sections, administration questions to aid in the follow-up workflows and clinical questions to collect cascade of care data.

Administration Questions

Q1. Has contact been made with the diagnosing clinician?

Q2. Follow -up 2 required?

Q3. Has contact been made with the diagnosing clinicians for follow-up 2?

Clinical Questions

Q1. Has the diagnosing clinician ordered an RNA/PCR test?

Q2. What was the result of the patient's RNA/PCR test as reported by diagnosing clinician?

Q3. Has the diagnosing clinician offered treatment to this patient?

Q4. Has the diagnosing clinician prescribed treatment for this patient?

The clinical questions for follow-up 2 were dependent on the data collected during follow-up.

In addition to CHECCS administration and clinical questions the CHECCS PO, by request of DH, also captured key demographic and risk information which was previously captured through enhanced surveillance that had been discontinued during the COVID-19 pandemic.

Demographic and Risk Factor Information Questions

Q1. Is the case of Aboriginal or Torres Strait Islander origin?

Q2. What is the country of birth of the case?

Q3. Has the case ever worked as / is the case in training to be a health care worker?

Q4. Does the case have a history of injecting drug use?

Laboratory data

To improve data collection of active cases a process to include positive and negative hepatitis C RNA from laboratories was explored working with the DH laboratory liaison officer. Due to the ongoing need for manual work to process results received through the ELR system, there was insufficient capacity to process all hepatitis C RNA results, especially due to competing COVID-19 priorities. A trial was attempted with Australian Clinical Laboratories, but they were unable to participate during the timeframe of the project.

Legislation surrounding the provision of negative testing data to DH has progressed throughout the project. Regulations are being developed that will allow negative results to be reported for some communicable diseases, including hepatitis C. This would significantly streamline the approach for assessing which people notified with hepatitis C require follow-up to promote care delivery, with hepatitis C RNA results being available in the system irrespective of the result. This will also have the benefit of being able to ascertain cases of hepatitis C reinfection. Initial timelines suggest that negative hepatitis C RNA testing data will become available in 2023.

A number of other jurisdictions within Australia have access to hepatitis C RNA results via online pathology databases allowing for confirmation of testing results. Access to a similar database in Victoria would reduce the administration burden on DH and allow for targeted follow-up of cases (for example, excluding those known to be RNA negative).

Environmental Impacts

As has been the case for many public health programs in Australia and globally, the COVID-19 pandemic had a substantial impact on the CHECCS project, with resources from both the Doherty Institute and the DH diverted to urgent pandemic response. The pandemic also had personal impacts on staff involved in the project, highlighting the risk in having a single individual responsible for follow-up of communicable disease notifications. Such single points of failure represent a significant challenge for under-resourced, centralised public health functions. Absence due to illness or leave, or diversion of CHECCS PO resources away from follow-up also created a delay, often resulting in a backlog of work. In turn, with the volume of notifications and the time required to follow-up individual cases, not all notifications were able to be followed up.

Due to intense demand on medical staff during the period of the CHECCS roll out, including clinical care and COVID-19 vaccination programs, contacting diagnosing clinicians was additionally challenging. Staff shortages, increased call wait times to speak with laboratories, clinic reception staff, health information staff and switchboards at hospitals all had an impact on the time it took to follow up each case. The implementation of a state-wide Code Brown during January-February 2022⁹ reflects the significant burden experienced by Victorian hospitals and health care facilities during the time covered by CHECCS, and successive waves of COVID-19 through 2022 have further depleted available health care resources to address a range of other health priorities.

PROJECT FINDINGS

A schematic illustrating detailed case follow-up outcomes and cascade of care measures is provided in Figure 1.

Cases summary

Of the 610 unspecified hepatitis C cases eligible for follow-up, 67.4% were male; the median age was 48.5 years; and 64.8% resided in metropolitan Melbourne. Most cases were diagnosed in community settings (53.9%), with the remainder from hospitals (28.4%) and correctional facilities (11.6%).

Diagnosing clinician contact

Direct contact was made with the diagnosing clinician in 41.3% of cases, while information regarding the cascade collected through indirect means (such as information transfer for those diagnosed in correctional facilities, electronic lab reports, and discharge summaries), in 17.1% of cases. In 10.5% of cases, the diagnosing clinician was not able to be reached despite 3 call attempts, and in a further 9.0%, insufficient details were included to allow identification of the diagnosing clinician. The diagnosing clinician was lost to follow-up in 6.4% of cases (3 unsuccessful call attempts). Finally, 15.9% of cases were deprioritised for follow-up or were not able to be contacted in a timely manner due to pressures associated with the COVID-19 pandemic (see “*Variation to follow-up processes*” section).

There was no disparity in successful contact with the diagnosing clinician according to sex or metropolitan versus regional area of residence of cases, but cases who were older than the median age at diagnosis were less likely to have successful contact with the diagnosing clinician (44.0%) than those who were younger (49.8%). Due to both the de-prioritisation processes applied at the beginning of the pilot (See “*Variation to follow-up processes*” section) and the higher proportion of cases with missing diagnosing clinician data, both attempted and successful contact with the diagnosing clinician was much less common for those diagnosed in hospitals (Table 2).

Cascade of care indicators

Of the cases where cascade of care information was able to be ascertained (N=356, 58% of all cases), the majority had a follow-up hepatitis C RNA test ordered directly by the diagnosing clinician at the time the doctor was contacted (69.9%). A further 6.7% of doctors reported referring the patient to specialist care, 5.6% reported the patient had a record of treatment or a past negative hepatitis C RNA test. Loss to follow-up was reported for 4.5% of cases, and in another 5.3% the diagnosing clinician reported they intended to order the test at the patient's next visit. Overall, in 86.2% of cases the diagnosing clinician reported they had provided care to the patient (ordering a hepatitis C RNA test, referring, or assessing for prior treatment). Of those with a hepatitis C RNA test result available (N=237), half were positive (49.4%).

Follow-up care was less common for those diagnosed in hospital settings (79.1%) compared to correctional facilities (88.4%) or primary care (87.2%). Follow-up care was

also less commonly reported by those diagnosing clinicians who required multiple calls to be successfully contacted (83.8%) compared to those reached on the first call (88.4%). There was no evidence of disparity in the provision of clinical care by case sex, age, or for those of a metropolitan as opposed to rural region of residence.

Assessment of care provision by other demographic and clinical factors is limited by low completeness, as Indigenous status, country of birth, and IDU status were missing in 50.0%, 70.2% and 57.5% of cases respectively. However, in those with status complete, follow-up was also less common in those with a recent history of injecting drug use (73.9%) than those with historical (92.9%) or no (94.4%) injecting drug use reported. Of those with status reported, no evidence of disparity was observed according to Indigenous status, nor for those born overseas compared to those born in Australia.

Of those cases where a positive hepatitis C RNA test was reported (N=117), 38.5% had treatment provided directly by the diagnosing clinician, while 42.7% were referred for specialist care, and intention to prescribe was indicated by 9.4% of diagnosing clinicians.

Reasons for treatment not being offered (occurred for 9.4% of the total) included patient refusal, loss to follow-up, and a need for further resources. Assessment of the provision of care following referral to specialist care was not within the scope of the project but remains a potential gap in the cascade of care, given reported barriers to specialist care in a range of settings¹⁰.

Some of the barriers to their patients receiving care identified by diagnosing clinicians included unstable housing, lack of access to a phone, cases not feeling ready to have treatment for hepatitis C due to competing health priorities, difficulty attending or keeping appointments, Medicare ineligibility and concerns about cost. Many GPs were passionate about these issues and would continue to have conversations with their patients over many months to try and to get them on to treatment.

The issue of hepatitis C diagnosis late in the disease course was highlighted by case details provided by diagnosing clinicians, with 15 identifying that their patients had a history of hepatitis C infection of at least 20 years, another 8 specifying a diagnosis many years after exposure, and another 2 diagnoses occurring in the context of an already existing diagnosis of liver cancer. Though these cases were diagnosed and linked to care, these findings highlight the issue of lack of care engagement and diagnosis for those with historical risks, and the significant problem of late diagnosis for what is a curable condition.

Cases not accessing treatment due to financial factors represented a significant subset, with 6 diagnosing clinicians reporting that the individual with hepatitis C was not eligible for Medicare and therefore could not access subsidised therapy.

Data completeness

Due to the provision of diagnosing clinician contact and seeking of case information, CHECCS improved the completeness of key variables compared to baseline. Compared to hepatitis B, which was not the subject of enhanced follow-up, during the study period completeness for Indigenous status was more than twice as high for hepatitis C (48.7% compared to 19.9%), as was IDU history (29.1% compared to 11.3%). However,

completeness was still below optimal levels, due to the inability to contact a substantial proportion of diagnosing clinicians.

In total, 129 total cases had missing or incomplete doctor details, which required follow-up with testing laboratories; the diagnosing clinician details were only able to be ascertained in just over half of the cases where the details were initially missing (57.3%). Missing or incomplete doctor details was the reason for lack of follow-up in 12.4% of cases where contact was attempted (Figure 2).

Support provided to diagnosing clinicians

Of the 286 diagnosing clinicians contacted, 100 (35%) were provided with resources to assist in hepatitis C management and of these, 28 reported that the public health intervention through CHECCS led to engagement or re-engagement of a person diagnosed with hepatitis C into treatment and care.

As described previously, the majority of diagnosing clinicians had provided or attempted to provide follow-up care after the first call. For those that required a second follow-up call to the doctor due to the case being considered high risk (n=47), 28 (59%) diagnosing clinicians reported that CHECCS follow-up led to engagement or re-engagement of a person diagnosed with hepatitis C:

- 8 cases were referred to a hepatitis clinic, some had already completed treatment at the second follow-up, others were undergoing further treatment work-up
- 8 cases were referred to an Integrated Hepatitis C Nurse (IHCN)
- 5 cases were successfully recalled and treated by their GP, after previously being uncontactable and lost to follow-up of their hepatitis C
- 7 cases were still in discussions with their GP about treatment or had results pending.

Some doctors had referred cases to the IHCN that had previously been difficult to engage in care, however further information was not able to be ascertained for referrals.

Call time resources

At the request of the Governance Group, data on call times were collected between January 2022 - March 2022. CHECCS calls to laboratories (for diagnosing clinician details or further results) and the full call discussion with doctors averaged 4.14 min (n = 22 calls) and 5 min (n = 73 calls) respectively. The total number of calls to leave messages or contact a switch board were 165 for 100 cases, an average of 1.65 call attempts before contact with the doctor was successful. The average total time spent leaving messages was 4.89 min per case, which was higher than expected. The final message to a doctor for a call back was only 20 sec (estimated) so a significant amount of time (approximately 4.7 min) was spent on hold, being transferred through switch boards. Although time consuming, this was the only avenue available for the CHECCS PO at the time.

Figure 1a: CHECCS notifications - inclusion and contact flow chart

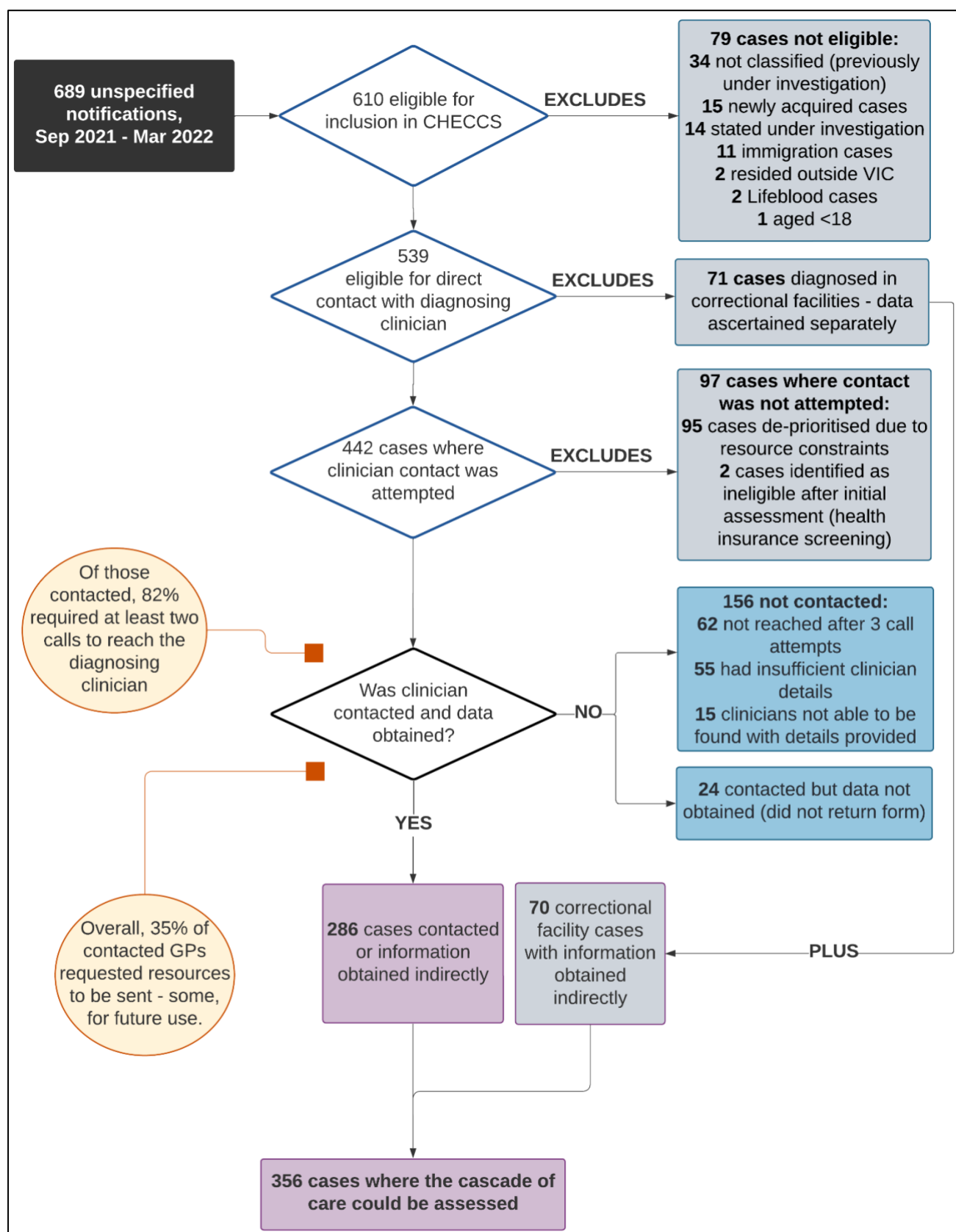


Figure 1b: CHECCS notifications – cascade of care flow chart

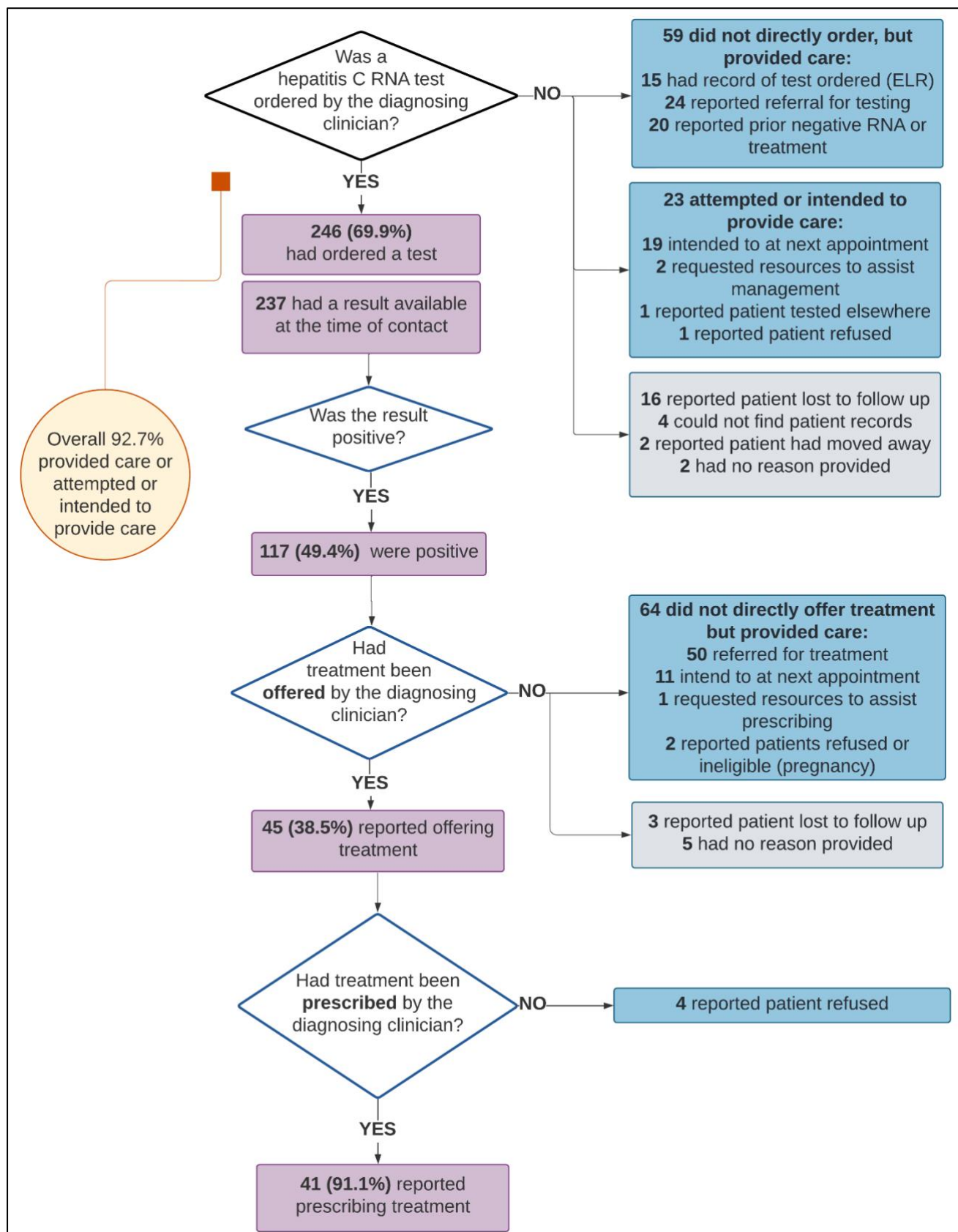


Table 2: Diagnosing clinician contact and cascade of care by diagnostic setting

| Setting | Number of cases | <i>Number of cases de-prioritised for contact</i> | Number of cases attempted to be contacted or data sought (proportion of total) | Number of cases contacted / data ascertained (proportion of total attempted) | <i>Number where multiple calls required</i> | Number of cases provided RNA, referred or assessed for history of treatment / RNA (proportion of those with data) | Number of cases offered or referred for treatment (proportion of those with positive RNA) |
|-------------------------|------------------------|---|---|---|---|--|--|
| Community | 337 | 36 | 301 (89.3%) | 239 (79.4%) | 181 | 209 (87.4%) | 64 (78.0%) |
| Hospitals | 177 | 60 | 117 (66.1%) | 44 (37.6%) | 16 | 34 (77.3%) | 5 (55.6%) |
| Correctional facilities | 71 | - | 71 (100%) | 70 (98.6%) | - | 62 (88.6%) | 26 (100.0%) |
| | | | | | | | |
| TOTAL | 610^ | 97 | 513 (84.1%) | 356 (69.4%) | 197 | 307 (86.2%) | 95 (81.2%) |

^Total includes 25 cases with setting not able to be ascertained from notifying information; in all cases contact with the diagnosing clinician was not attempted.

PROJECT EVALUATION

The evaluation of CHECCS was undertaken by the project team under the guidance of the Governance Group. There was no budget available for external evaluation. The focus of the evaluation was analysis of key data and the process of implementation across the following domains.

- **Relevance and acceptability**

Whether the objectives and outcomes of the program were consistent with hepatitis C public health response needs and priorities; whether the program aligned with the Department's operational structure, systems and processes; and whether/how the program could be integrated into normal business for the Department.

- **Impact**

The proportion and demographics of cases reached by the program and proportion of those who received appropriate follow-up care; and the number of diagnosing clinicians where additional information was provided.

- **Effectiveness and efficiency**

The extent to which the program objectives were achieved. Considerations included program processes, outcomes, budget and resource demands; the timeliness of follow-up; the economic benefits of the outcomes delivered; and the development of recommendations for future hepatitis C surveillance processes if the program were to be integrated into usual business for the Department.

- **Sustainability and flexibility**

Whether the program can continue and provide benefits once funding has ceased, and the cost/resource demand of this delivery; and how the program adapted to changing operating conditions including recommendations for how the program could be scaled to account for variable resource availability.

- **Data quality**

The extent to which existing notification data met the needs of the program in terms of quality and completeness, and modifications to data collection systems that would enhance the program's effectiveness and efficiency.

Evaluation was undertaken across these domains above in accordance with the framework described in Appendix 1 Key indicators for CHECCS are described in Table 2.

Relevance and acceptability

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| <p>Are the project's outcomes aligned with viral hepatitis public health needs and priorities?</p> | <p>Aligned with key priority actions in Victoria's Hepatitis C Strategy 2016-2020:</p> <ul style="list-style-type: none"> • Priority focus area 4: Victorians with hepatitis C have access to best practice evidence-based treatment and care <ul style="list-style-type: none"> ○ <i>Treatment services meet the needs of those affected through integrated pathways</i> ○ <i>Actively promote treatment with DAAs</i> ○ <i>Provide a systematic response to notifications of hepatitis C by providing advice and information to diagnosing doctors on assessment and treatment, and connections to specialist support</i> • Priority focus area 5: The Victorian workforce has the skills, knowledge and attitudes needed to deliver best practice treatment and care <ul style="list-style-type: none"> ○ <i>Provide ongoing support to primary care clinicians on how to treat and manage people living with hepatitis C in the primary care settings</i> • Priority focus area 6: Systems and settings are integrated to meet the needs of people affected by hepatitis C <ul style="list-style-type: none"> ○ <i>Link tertiary and primary care services so that people have access to appropriate services close to where they live</i> ○ <i>Develop health pathways between specialist services and primary care for people who are newly diagnosed, and build the capacity of existing clinical services to deliver care and support</i> • Priority focus area 7: Hepatitis C services and outcomes are improved in Victoria by increasing the quality and completeness of data and supporting research <ul style="list-style-type: none"> ○ <i>Complete and accurate data are collected from notifiers and across the continuum of the hepatitis C pathway to measure outcomes and improve service delivery</i> ○ <i>Assess gaps in data reporting across the continuum of the hepatitis C pathway and identify opportunities to address these</i> ○ <i>Use cascade of care data to inform service improvements</i> |
| <p>Does the program align with departmental operational structure, systems and processes?</p> | <ul style="list-style-type: none"> • In collaboration and consultation with DH, workflows and a project plan were developed that embedded an expanded scope of work (the follow-up of unspecified cases) into DH's existing processes and surveillance system (PHESS). • Process development and implementation was complex and spanned multiple teams within DH including, Information & Surveillance Support (ISS) team, BBVSTI Surveillance team, |

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| | <p>Communicable Disease Prevention and Control (CDPC) team, and Sexual Health and Viral Hepatitis team.</p> <ul style="list-style-type: none"> CHECCS supported the review and updating of DH hepatitis C protocol and best practice examples in preparation for LPHU integration of hepatitis C follow-up; assisted with training of LPHU staff in hepatitis C public health responses. |
| To what extent has effective coordination and collaboration with existing interventions, as identified through the programs delivery and partners been addressed and achieved? | <ul style="list-style-type: none"> CHECCS harnessed and promoted existing clinical resources, programs and models of care, rather than creating new pathways and systems. In this way, the program catalysed existing investments in service delivery, including integration between primary and tertiary care (Integrated Hepatitis C Nurses) and workforce development (e.g. VHHITAL and ASHM resources). The Victorian Integrated Hepatitis C Services (IHCS) were identified early as a vital link to assist diagnosing clinicians with difficult to engage clients. The relationships built with the Victorian IHCS nurses enabled the CHECCS PO to have an increased awareness of programs, including outreach clinics that were available in each region. Thus, tailoring resources provided to diagnosing clinicians that were local (if possible) to their area, or close to where their patient lived. Collaborated with St Vincent's Hospital to receive and review cascade of care data in custodial settings. This reduced unnecessary follow-up of correctional facility cases. |
| Is the program acceptable to general practitioners? | <ul style="list-style-type: none"> The program was accepted by diagnosing clinicians who gave direct feedback about the utility of the program. Only three diagnosing clinicians (out of 286 contacted) expressed discomfort about sharing data under the auspices of CHECCS. Multiple diagnosing clinicians expressed interest in the pilot and were keen to discuss their treatment pathways or barriers they face linking their patients into care and were open to receiving additional resources. |
| How should the program be integrated into routine surveillance for hepatitis C in Victoria? | <ul style="list-style-type: none"> Follow-up of unspecified cases of hepatitis C was shown to be feasible. CHECCS processes were adopted and integrated into the Local Public Health Units (LPHU) as best practice in the follow-up of both hepatitis B and C. Clear efficiencies and priority areas were identified to maximise the impact of future hepatitis C follow-up by LPHUs – e.g. those patients least likely to be linked to care. Increased integration of further testing data from laboratory data with surveillance processes and support for diagnosing clinician notification will improve efficiency for ongoing follow-up. Reporting and entry of hepatitis C RNA results into PHESS through optimised ELR is now possible from a regulatory perspective and will significantly reduce unnecessary follow-up and allow the establishment of an inclusive surveillance-based cascade of care. |

"We "do" hepatitis C every day, we have skills and connections that are not easily accessible in primary care and we are very willing and able to share these skills wherever required. I think the CHECCS project demonstrates we need to work collaboratively to get the best outcomes for patients and the simplicity of having a phone contact to the right person can streamline care for people who don't always fit into mainstream care models."

- Victorian Integrated Hepatitis C Nurse

A GP described the resources as an amazing help and was able to ensure their complex patient was cared for closer to home, due to a recent move, and with someone they could develop a rapport with (IHCN). This patient had taken 6 months of discussions to have a hepatitis C RNA taken with significant liver function derangement, despite their youth.

Impact and reach

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| What was the reach of the project? | <ul style="list-style-type: none"> • Contact was attempted (or information sought indirectly) for 71.6% of all newly diagnosed hepatitis C cases from Sep 2021–Mar 2022. • Contact was able to be made, or information ascertained via electronic records, from 80.5% of those where contact was attempted, however this was lower for patients diagnosed in hospitals (see Table 2). |
| What proportion of cases notified with chronic hepatitis C received RNA testing? | <ul style="list-style-type: none"> • A hepatitis C RNA test was ordered in 74.1% of cases where contact with the diagnosing clinician was able to be made, 43.3% of all cases eligible for CHECCS follow-up and 38.3% of total Victorian cases (Figure 1). • In the vast majority of cases where the cascade of care was ascertained, either a hepatitis C RNA test, a referral, and/or ascertainment of prior RNA testing/treatment had been provided. • Hepatitis C RNA testing appeared to be less common among those diagnosed in a hospital setting, however data gaps limit interpretation. |
| What proportion of diagnosing clinicians report cases diagnosed with chronic hepatitis C were provided with advice regarding treatment options after CHECCS contact? | <ul style="list-style-type: none"> • The majority of diagnosing clinicians had provided or attempted to provide follow-up care after the first call. • For those that required a second follow-up call to the doctor due to the case being considered high risk (n=47), 59% reported that CHECCS follow-up led to engagement or re-engagement in care. |
| What impact has CHECCS had on Victorians receiving treatment for hepatitis C according to the surveillance-based algorithms established? | <ul style="list-style-type: none"> • CHECCS has enhanced awareness and provided resources to diagnosing clinicians for the management and treatment of hepatitis C. In total, 100 diagnosing clinicians were provided with these resources which also included appropriate referral pathways. • Further contact with diagnosing clinicians for cases identified as higher risk of being lost to follow-up prompted patient recall and further referral. • Despite barriers imposed on information sharing between DH and IHC nurses due to data privacy concerns, referrals to initiatives such as the IHCN assisted in building ongoing linkages across the Victorian health care system, benefiting future individuals diagnosed by these doctors. • 28 cases were directly attributable to being linked back into care due to CHECCS follow-up. However, follow-up resulting in linking to care could have been more given better resources (hepatitis C RNA results) and contact with hospital clinicians. |

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| <p>What were, if any unanticipated outcomes (desirable or undesirable)?</p> | <p><i>Cascade of care gaps</i></p> <ul style="list-style-type: none"> The proportion of cases where the diagnosing clinician had not yet provided care at first contact was lower than anticipated, and a substantial proportion of patients who had not received care was due to loss to follow-up, rather than lack of diagnosing clinician awareness or resources. This reduced the potential impact of CHECCS in improving care uptake. In response, CHECCS was adapted to emphasise further support to doctors caring for those at risk of loss to follow-up and provide resources for management of future patients. <p><i>LPHU Integration</i></p> <ul style="list-style-type: none"> In June 2022 the decision was made to decentralise public health follow-up and response to hepatitis C notifications within DH to LPHUs, and it was decided to adapt CHECCS protocols and learnings into DH best practice protocols for use by LPHUs, including diagnosing clinician follow-up. CHECCS team members also assisted DH in the training sessions conducted to support this transition. As a result, direct follow-up of hepatitis C notifications is anticipated to be ongoing and continue past this pilot, a highly desirable outcome. |
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"The CHECCS program recently forged a new connection to a new GP working in our region who was previously unknown to our service. The GP reached out with a couple of questions around access to Fibroscan and issues with hepatitis C PCR costs, on the day we were able to assist with an appointment and some trouble shooting. Subsequently we received two referrals from this GP that have ended up bringing treatment to patients with long standing hepatitis C that had not been previously treated. Both patients were treated in nurse led clinics with phone consultations and intense follow-up, both completed treatment. We look forward to hearing from our new GP friend again!"

- Integrated Hepatitis C Nurse

Effectiveness and efficiency

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| <p>To what extent were the objectives of the program achieved?</p> | <p>CHECCS was successfully executed with the pilot objectives achieved.</p> <p><i>1. Improve the co-ordinated delivery of care to Victorians living with chronic hepatitis C</i></p> <ul style="list-style-type: none"> CHECCS enhanced the delivery of care through the provision of clinical resources and linkage to clinical networks for diagnosing clinicians, and directly resulted in cases being linked back into care, through engagement and linkage with services such as IHCNs. It established referral pathways to the IHCS and engaged diagnosing clinicians to consider undertaking further training/support to prescribe in the future. One-third of diagnosing clinicians contacted requested further resources, either for the current or for future cases, bridging the gap in access to and utilisation of appropriate resources and improved health care worker capacity. <p><i>2. Improve surveillance data collection and analysis environment for hepatitis C notifications, follow-up testing and treatment</i></p> <ul style="list-style-type: none"> The CHECCS program successfully established and embedded hepatitis C cascade of care data capture points into the Victorian hepatitis C surveillance system, and for the first time provided timely data regarding the cascade of care for Victorians newly diagnosed with hepatitis C. <p>Following a request by DH and endorsement by the Governance Group, CHECCS also collected demographics and risk factor information upon the cessation of enhanced follow-up by DH, improving data completeness for key demographics compared to baseline (see Project Findings).</p> <p>CHECCS provided a case study for the potential impact of systematic reporting and collation of negative hepatitis C RNA test results, and through its implementation, supported improved reporting. This will have a long-standing impact on the monitoring environment moving forward and allow for more efficient and targeted follow-up of cases, and establishment of a surveillance-based cascade of care at a population level.</p> |
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| <p>Were program processes effective and what should be modified to enhance the program?</p> | <ul style="list-style-type: none"> • CHECCS provided effective follow-up of included cases. The timeframes established ensured timely linkage with diagnosing clinicians engaged in providing hepatitis C care, with modifications introduced to improve access to diagnosing clinicians in hospitals. • Follow-up via telephone was a highly effective method, while email/mail follow-up failed to provide substantial cascade of care data, with minimal forms returned and request for discharge reports largely unanswered (Figure 2). • The notification form was available online throughout the pilot, however with the LPHU integration work, the form was revised to include cascade of care questions after the completion of the pilot. • As previously discussed, automatic reporting of hepatitis C RNA results by laboratories would reduce the follow-up caseload by around 50% based on data collected (Figure 2). Access to online laboratory databases would similarly reduce follow-up resources required. • Onboarding all laboratories onto ELR would improve data completeness, particularly in relation to diagnosing clinician details. • Data linkage with other DH datasets could also be utilised to complete missing demographic and risk factor details when available in other datasets (such as hospital records). |
| <p>What was the cost of delivering the program and the economic benefits of the outcomes delivered?</p> | <ul style="list-style-type: none"> • CHECCS was developed and delivered over 21 months with a Project Coordinator (0.4 FTE) and a Project Officer (0.6 FTE) for a total of \$184,934. In addition, significant in-kind support was provided by both the Doherty Institute and DH. • The economic benefit of the CHECCS program improving linkage of cases into care and treatment would be realised via the prevention of disease progression, future medical costs and lost productivity, and reduction in new hepatitis C infections. Health service efficiency benefits could include improved care provision processes, reduced unnecessary referrals, and decreased time identifying linkages to other care providers. Specific assessment of these longer-term benefits is not within the scope of the project; however, the findings of this evaluation suggest CHECCS did lead to improvements in linkage to care connections between health service providers. |
| <p>Were the budget and resources (including funding and in-kind contributions) for the program sufficient?</p> | <ul style="list-style-type: none"> • Ensuring the project was delivered within the available budget resulted in resource demands exceeding resources available at multiple stages throughout the project. Rapid development and implementation timeframes, and the need for ongoing adjustments to rollout, led to backlogs of work and some communications plans being ceased. |

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| | <ul style="list-style-type: none"> • Additional work required outside of the project scope resulted in a deficit of resources, which was resolved revising notification follow-up time frames and processes (See Appendix 1 & 6) • Significant additional in-kind contributions were required of both the Doherty Institute and DH in order to meet project objectives. |
| What were the challenges in delivering this program and how were these addressed? | <ul style="list-style-type: none"> • The CHECCS pilot faced a number of challenges in delivering the program, in particular the impact of COVID-19. • An organisational restructure at DH in (August 2021) in addition to the pressures of COVID resulted in the ceasing of enhanced surveillance program forms being sent to diagnosing clinicians to obtain additional information key to assessment of the impact of CHECCS. In response, ascertainment of key demographic and risk factors (see “Variation to follow-up processes” section, page 11) was incorporated into the follow-up protocol at the request of DH. • Timely entry of notifications and testing results were key to effectively following up cases, and backlogs in data entry presented a challenge. To improve efficiency, relevant data were sought for CHECCS as part of the broader DH ELR implementation. This reduced delays and missing doctor details, decreasing the administrative demand on the CHECCS PO. Although it was pursued, access to negative hepatitis C RNA results was not achieved during the pilot, though this would have further improved efficiency. • Due to several unanticipated factors, it was ascertained in January 2022 that follow-up of all eligible cases may not be possible, therefore the prioritisation framework was enacted (see “<i>Variation to follow-up processes</i>” section, page 11). This occurred a number of times during the project, highlighting the dynamic nature of the work and the importance of adaptability. • The use of a risk register and close monitoring of the pilot allowed the project team to quickly identify emerging issues and allow adaptation in consultation with the Governance Group. |

Sustainability and flexibility

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| <p>To what extent can the activities and the benefits of the program continue after external funding has ceased?</p> | <ul style="list-style-type: none"> • The CHECCS pilot harnessed existing investments in capacity for hepatitis C management in the community, particularly IHCNS. This catalytic approach supported connections to the IHCN program and created additional linkage of care between doctors and IHCN's, with evidence that these linkages will continue post CHECCS pilot. • Provision of existing clinical resources to diagnosing clinicians has enhanced knowledge for hepatitis C care, again leveraging existing investments and improving sustainability following program cessation. • The greatest contribution to ongoing program activities following CHECCS funding ceasing is the support for integration of public health response of hepatitis C notifications into the work of LPHUs, as part of Victoria's future public health environment. Specifically, elements of the CHECCS pilot have been incorporated into best practice for hepatitis C surveillance and will continue to be delivered by LPHUs. |
| <p>How can the program be adapted or scaled to changing operating conditions, including variable resource availability?</p> | <ul style="list-style-type: none"> • During the pilot several adaptations to processes and timeframes were implemented to meet changing operating conditions and demonstrated that the program and its processes could adapt flexibly to a dynamic public health environment in the midst of a pandemic. • The method of follow-up for hospitals was amended to alleviate resource demands and ensure maximum follow-up with limited resources. The Prioritisation Framework was established and enacted due to capacity restraints and reduced the scale of follow-up. There was a focus on follow-up for identified increased risk cohorts to attempt maximum impact on clinical care outcomes. • As described above, CHECCS supported the early adoption of early automatic data collection for hepatitis C as part of the broader DH ELR implementation. This reduced delays and missing doctor details, decreasing the administrative demand on the CHECCS PO. |
| <p>What are the operational and resource requirements for long-term implementation of the program?</p> | <ul style="list-style-type: none"> • Under the model used, the workload to deliver the complete CHECCS program exceeded the capacity of CHECCS PO resourcing allocated (0.6 FTE), due to factors identified in "Project implementation- environmental impacts section" on page 15. • Under a model where ELR was providing more complete diagnosing clinician details and follow-up hepatitis C RNA test results irrespective of whether these are positive or negative, this would allow the establishment of a surveillance-based cascade of care at the individual and population level. |

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| | <ul style="list-style-type: none"> • This would eliminate the need for follow-up of cases with a negative RNA result whilst also reducing the data entry burden, improving the feasibility and efficiency of the program • Continuing to work towards this approach will support the efficient and sustainable follow-up and linkage to care of Victorians diagnosed with hepatitis C by LPHUs into the future • The reliance on a single CHECCS PO for follow-up was a liability, with anticipated back-up for the role impossible due to workforce constraints and the need to prioritise pandemic responses. Recognition of this 'single point of failure' risk should be built into future public health priority work. |
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Data Quality

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| <p>Did existing notifications data meet the needs of the program? To what extent was missing data an issue?</p> | <ul style="list-style-type: none"> • Approximately 40% of notifications did not have complete diagnosing clinician details, which required additional resources to obtain details from laboratories and allow for follow-up. Implementation of ELR significantly improved completeness of clinician details, however this remained an issue for many cases. • As discussed above, collection of enhanced data was added to the program at the request of DH to improve the epidemiological assessment and to analyse trends in the cascade of care. • Duplication of hepatitis C cases is common due to the high volume and missing or different identifying information. The CHECCS follow-up process facilitated the identification of several duplicate cases, improving the quality of existing surveillance data. |
| <p>What modifications to data collection systems would enhance the program?</p> | <ul style="list-style-type: none"> • If negative hepatitis C RNA results were notifiable to DH, this would greatly improve the efficiency of program delivery and establishment of a surveillance-based cascade of care as described previously. • Improving the accuracy and completeness of diagnosing clinician reporting by pathology laboratories will directly improve the efficiency of follow-up for all notifiable diseases where this is required • Higher uptake of notification by diagnosing clinicians would improve capture of key demographic and risk factor information, with electronic notification forms preferable to reduce administrative burden. The capture of additional information provided by diagnosing clinicians to laboratories (such as intention to treat) via ELR would also reduce the need to contact doctors. As part of the integration of hepatitis B and C surveillance with LPHUs, key cascade of care elements were incorporated into a revised notification form, supporting ongoing sustainability and data consistency. • Some demographic information, such as country of birth, Indigenous status, and key risk factors was difficult to obtain even when doctors were contacted, as it had not been collected in primary care health records. Linkage to other datasets, such as hospitalisations, could be utilised in order to complete this information. • The potential for reflexive testing of hepatitis C antibody positive samples for RNA has been proposed as a mechanism to improve uptake and reduce the risk of loss to follow-up, and this would also assist with efficiencies in relation to enhanced surveillance programs. |

CONCLUSIONS & RECOMMENDATIONS

This evaluation demonstrates that the follow-up of hepatitis C cases with diagnosing clinicians can provide detailed information regarding the cascade of care, and support healthcare providers to engage individuals in follow-up testing and treatment and overcome barriers to care.

The program has been well-received by diagnosing clinicians and, for some, strengthened the link between GPs and IHCNs for people diagnosed with hepatitis C who had been lost to follow-up, or experienced barriers to their engagement in treatment and care.

A range of recommendations are included in the section above. In summary, the key recommendations drawn from the evaluation of the CHECCS program include:

- 1. Continue to conduct enhanced surveillance**

Continued incorporation of public health response and follow-up of all hepatitis C notifications within the LPHU processes, as part of routine hepatitis C enhanced surveillance and follow-up as developed by the CHECCS program. This pilot has indicated follow-up on the cascade of care provides valuable data and assists in linking individuals back into care, which will reduce the risk of adverse outcomes such as liver disease and cirrhosis. It will also contribute to reducing onward transmission of infection. LPHUs will be particularly well placed to deliver follow-up due to their position within the health system and local communities and care providers and ability to create individually and locally tailored responses.

- 2. Continue to monitor implementation**

As more communicable diseases are integrated into LPHU follow-up, it is conceivable that competition for LPHU staff time will build, and the impact of this will need to be monitored. Ongoing support for continuing enhanced surveillance is needed, and ongoing monitoring and evaluation of the cascade of care and surveillance data completeness is recommended to ensure continued quality improvement.

- 3. Improve access to laboratory data**

Establish routine access to further testing laboratory data in ongoing surveillance practices, to improve efficiency of cascade of care assessment and prioritisation of follow-up. In the context of hepatitis C, this should include all RNA test results, whether positive or negative, to allow establishment of a surveillance-based cascade of care. This will also support the identification of cases which meet the upcoming revised national case definition which includes cases of reinfection. DH will utilise the existing ELR platform for this improvement and implementation of the revised case definition.

- 4. Improve clinician detail completeness**

Lack of diagnosing clinician details represents a real barrier to enhanced surveillance approaches and more importantly, an inability to ascertain whether the person diagnosed had received appropriate treatment and care following notification. Improving the accuracy and completeness of diagnosing clinician reporting by

pathology laboratories will directly improve the efficiency of follow-up for all notifiable diseases where this is required.

5. Prioritise by setting

Prioritise follow-up for people diagnosed in low caseload primary care clinics and in hospital settings for follow-up. Analysis of CHECCS data revealed that these settings are less likely to have already arranged follow-up testing and treatment for their patients than were general practitioners who diagnosed a higher number of people with hepatitis C

6. Continue providing resources

Provision of existing resources was welcomed by a large number of diagnosing clinicians and should continue. Supporting low caseload primary care clinicians at the time of diagnosis in particular has the potential to have ongoing benefits for appropriate treatment and care in the community and is leveraging existing investment in resource development at a time when these resources are most useful – at the time of diagnosis.

7. Optimise use of IHCN

Victoria's Integrated Hepatitis C Network, funded by the Department of Health, has been in place for approximately 10 years. These nurses are highly experienced and have a focus on delivering care at the interface between primary and tertiary care. Once safeguards on data privacy have been addressed, including completion of DH privacy threshold assessment, optimising the use of this network to support diagnosing clinicians in both primary and tertiary settings is highly recommended and would increase linkage to treatment and care for people newly diagnosed with hepatitis C using an existing and stably funded resource provided by the Department. Ensuring maximal integration of care by supporting referral directly to IHCNs by LPHUs as appropriate should be implemented, particularly for people diagnosed in hospital settings which the CHECCS data show have the lowest levels of follow-up testing and treatment.

8. Continue engagement with correctional facilities

A high level of treatment was observed in correctional facilities - ongoing reporting of cascade of care should be captured for this priority population. If current care arrangements change, direct follow-up with diagnosing clinicians in correctional facilities could be considered.

9. Consider individual follow-up

The CHECCS approach restricted follow-up to diagnosing clinicians. Where this clinician had no ongoing relationship to the patient (e.g., hospital doctors who had rotated, GPs for whom the patient had been lost to follow-up), consideration should be given to direct follow-up of notified individuals by PHOs to ensure linkage to care. Precedents for this approach span a range of communicable diseases, including tuberculosis, STIs, enteric diseases, vaccine preventable diseases, and of course recently, COVID-19 on a huge scale. COVID Positive Pathways represents an example of this referral to appropriate linkage to care using the point of diagnosis as an entry.

10. Consider retrospective follow-up

With the additional resources available for follow-up of hepatitis C with public health

response and follow-up integrated into LPHUs, consideration should be given to retrospective follow-up of notified cases prior to the CHECCS pilot period. This could be prioritised for those cases shown to be at greatest risk of not having been further assessed or treated based on CHECCS findings.

11. Expand to hepatitis B

Incorporate hepatitis B enhanced surveillance as part of routine surveillance of hepatitis B in Victoria. The relative success of CHECCS despite the limited resourcing available, and in the face of real challenges due to the ongoing impact of the COVID-19 pandemic, supports the adoption of this approach and provides justification to incorporate enhanced surveillance for hepatitis B as part of the routine surveillance of hepatitis B in Victoria. Gaps also exist in linkage to care and data completeness for hepatitis B in Victoria, and treatment of hepatitis B not only greatly reduces the risk of adverse outcomes such as liver disease and cirrhosis, it also prevents onward transmission of infection. The follow-up of cases further provides an opportunity for tracing and the offering of vaccination of susceptible contacts, and for focus on prevention in the perinatal setting. The learnings from CHECCS should be applied to hepatitis B, including adaptation of data collection tools and setting specific follow-up protocols. As is the case for hepatitis C, the integration of hepatitis B into LPHU follow-up provides a unique opportunity to realise these benefits for all Victorians diagnosed with chronic viral hepatitis.

12. Address barriers to care

Although out of scope for the project, CHECCS identified barriers to care including Medicare ineligibility and cost of DAAs as reasons raised by diagnosing clinicians for patients unable to access treatment. As hepatitis B disproportionately affects people from overseas backgrounds, further work to ensure equal access to treatment for viral hepatitis for these affected populations should be progressed, in line with the recent changes in relation to HIV.

13. Consider incorporation of immigration diagnoses

Although out of scope for the project, the follow-up of notifications originating from immigration health undertakings conducted by the Department of Home Affairs to increase linkage to care for this priority population would be highly recommended. Consideration regarding scope of LPHUs to undertake this important work is recommended, as LPHUs are ideally located to progress this work within their local communities with the guidance of refugee and migrant special interest groups.

APPENDIX

Appendix 1: Prioritisation Framework

CHECCS Pilot program prioritisation framework

| | Event | Impact | Changes to be implemented |
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| Enhanced Surveillance Data | In the event of enhanced data surveillance program ceasing the data captured wont be available to the CHECCS project for evaluation purposes. | Key demographic information and risk information would be missing from project | Data to be captured in PHESS by CHECCS project officer: Country of Birth, IVDU, Aboriginal or Torres Straight Islander status(ATSI), Healthcare worker status |
| Notifications | <p>Notifications being entered into PHESS being delayed.</p> <p>Note: Ongoing implementation of ELR project will reduce this risk over time. E.G ACL notifications all electronic.</p> | <p>Capacity for follow up</p> <ul style="list-style-type: none"> • Insufficient cases for follow up • Delay of notification into PHESS for follow up falling outside 12 weeks time frame for cases eligibility | Use 0.2 FTE capacity in CHECCS project officer role to enter in new notifications into the PHESS system for follow up. Prioritise Cases pertinent to pilot calls. |
| Capacity | Number of cases eligible for follow up may exceed capacity to follow up | Cases for follow up may not be followed up, Cases being followed up may not be key target cases for project (e.g Prisons and Hospitals) | <p>Level 1. Cease follow up for</p> <ul style="list-style-type: none"> • Hospitals • Prisons <p>Level 2. Cease follow up of</p> <ul style="list-style-type: none"> • Clinics with good established hep C programs. e.g Sexual Health Clinics, <p>Level 3. Prioritise by Demographic</p> <ul style="list-style-type: none"> • All ATSI cases (no age restrictions) • Age: Prioritise cases over 40. |

Appendix 2: Evaluation framework

| Domain | Evaluation questions | Scope | Data sources | Methodology |
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| Relevance and acceptability | <ul style="list-style-type: none"> Are the project's outcomes aligned with Hepatitis C public health needs and priorities? Does the program align with departmental operational structure, systems and processes? To what extent has effective coordination and collaboration with existing interventions, as identified through the programs delivery and partners been addressed and achieved? Is the program acceptable to general practitioners? (<i>Noting inclusion of this may not be feasible</i>) How should the program be integrated into normal business for the department? | <ul style="list-style-type: none"> Consideration of program objectives and outcomes against relevant Victorian government strategies (including Victorian Hepatitis C strategy 2016), departmental business plans and departmental operating environment. Sector stakeholder priorities Acceptability/benefit to general practitioners (if feasible). | <ul style="list-style-type: none"> CHECCS pilot program data and other program records. Consultation with managers, project team members, implementation and Governance group. Consultation with sector stakeholders Consultation with GPs who were contacted by the program (if feasible) | Qualitative analysis |
| Impact | <ul style="list-style-type: none"> What was the reach of the project? | <ul style="list-style-type: none"> Demographics of notified cases, including diagnosis setting and cases unable to be followed up (missing doctor details). | <ul style="list-style-type: none"> CHECCS pilot program data, particularly indicators 1 and 2a (refer to Table 2). | Quantitative analysis |
| | <ul style="list-style-type: none"> What proportion of cases notified with chronic hepatitis C received RNA testing? | <ul style="list-style-type: none"> Number of cases contacted and number of those cases where RNA testing had been offered. | <ul style="list-style-type: none"> CHECCS pilot program data, particularly indicators 3a, 3b, 3c, 3d and 4 (refer to Table 2). | |
| | <ul style="list-style-type: none"> What proportion of diagnosing clinicians report cases diagnosed with chronic hepatitis C were provided with advice regarding treatment options after CHECCS contact? | <ul style="list-style-type: none"> Number of cases contacted and number of those cases where follow-up has been offered after resources were provided. | <ul style="list-style-type: none"> CHECCS pilot program data, particularly indicators 2b, 5a, 5b and 5c (refer to Table 2). | |

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| | <ul style="list-style-type: none"> What impact has CHECCS had on Victorians receiving treatment for hepatitis C according to the surveillance-based algorithms established? | <ul style="list-style-type: none"> Number of cases contacted and number of those cases where treatment progressed due to contact by the program. | <ul style="list-style-type: none"> CHECCS pilot program data, particularly indicators 6 and 7 (refer to Table 2). | |
| | <ul style="list-style-type: none"> What were, if any unanticipated outcomes (desirable or undesirable)? | <ul style="list-style-type: none"> Anecdotal or demonstrable outcomes observed during the program. | <ul style="list-style-type: none"> CHECCS pilot program data and other program records. Consultation with managers, project team members, implementation and Governance group. | Qualitative analysis |
| Effectiveness and efficiency | <ul style="list-style-type: none"> To what extent were the objectives of the program achieved? Were program processes effective and what should be modified to enhance the program? What was the cost of delivering the program and the economic benefits of the outcomes delivered? Were the budget and resources (including funding and in-kind contributions) for the program sufficient? What were the challenges in delivering this program and how were these addressed? | <ul style="list-style-type: none"> Outcomes of case follow-up processes on the cascade of care (refer to pilot program indicators), including timeliness of follow-up. Resources committed to and resources leveraged by the program Environmental influences. Process changes during the pilot program. Systematic or process changes required for integration of case follow-up into normal business. Lessons learned. | <ul style="list-style-type: none"> CHECCS pilot program data and other program records and documentation. Consultation with managers, project team members, implementation and Governance group. | Qualitative and quantitative analysis |
| Sustainability and flexibility | <ul style="list-style-type: none"> To what extent can the activities and the benefits of the program continue after external funding has ceased? How can the program be adapted or scaled to changing operating conditions, including variable resource availability? What are the operational and resource requirements for long-term implementation of the program? | <ul style="list-style-type: none"> Resource (staffing and budget) requirements for case follow-up. Systematic or process changes required for integration of case follow-up into normal business. | <ul style="list-style-type: none"> CHECCS pilot program data and other program records. Number of notified cases eligible for follow-up (from departmental notifications in PHESS). Consultation with managers, implementation group and project team members. Review of program and processes documentation. | Qualitative and quantitative analysis |

| | | | | |
|--------------|---|---|---|---------------------------------------|
| Data quality | <ul style="list-style-type: none"> • Did existing notifications data meet the needs of the program? • To what extent was missing data an issue? • What modifications to data collection systems would enhance the program? | <ul style="list-style-type: none"> • Data Quality. • Data Completeness. • Data Security. • Data Collection. | <ul style="list-style-type: none"> • CHECCS pilot program data particularly indicator 8 (Table 2) and other program records. • Consultation with managers, implementation group and project team members. | Quantitative and qualitative analysis |
|--------------|---|---|---|---------------------------------------|

Appendix 3: CHECCS pilot program indicators

| Indicator | | Numerator | Denominator | Additional data |
|-----------|---|--|--|--|
| 1 | Clinician contact attempted (3 attempts before considered lost to care. Contact attempts outcomes captured in detail via PHESS questions package) | Number of cases where contact with diagnosing clinicians was attempted: | Number of cases | Reasons for inability to attempt contact, if applicable Variation by demographic factors and diagnostic setting |
| 2a | Clinician contact made | Number of cases where contact with diagnosing clinician was able to be made and question package delivered. | Number of cases | Number of contact attempts made |
| 2b | Clinician requested resources | Number of cases where the diagnosing clinician requested resources or contact information to assist with management | Number of cases where contact was able to be made | Type of resources or information provided |
| 3a | Reported uptake of hepatitis C RNA testing | Number of cases where diagnosing clinician reports that RNA testing has been provided | Number of cases where contact was able to be made | Reasons test not provided, if applicable Variation by demographic factors, diagnostic setting and risk factors |
| 3b | Reported uptake of hepatitis C RNA testing at the time of initial contact | Number of cases where diagnosing clinician reports that RNA testing has already been provided at the time of initial contact | Number of cases where contact was able to be made | |
| 3c | Reported uptake of hepatitis C RNA testing after support provided | Number of cases where diagnosing clinician reports that RNA testing has been provided, after support was provided by CHECCS | Number of cases that had support provided by CHECCS at RNA testing stage | Type of support required |
| 3d | Reported uptake of attempt to provide follow-up care | Number of cases where diagnosing clinician reports that RNA testing was provided, offered and declined, or previous treatment was reported | Number of cases where contact was able to be made | Variation by demographic factors, diagnostic setting and risk factors |
| 4 | RNA positivity | Number of cases where RNA test is reported as positive | Number of cases with an RNA test result reported | |

| | | | | |
|-----------|--|--|--|--|
| 5a | Reported uptake of offered treatment | Number of RNA-positive cases that have been offered treatment by the diagnosing clinician | Number of cases with a positive RNA test result reported | Reasons treatment not offered, if applicable Variation by demographic factors, diagnostic setting and risk factors |
| 5b | Treatment had been offered at time of initial contact | Number of RNA-positive cases where diagnosing clinician reports that treatment has already been offered at the time of initial contact | Number of cases with a positive RNA test result reported | |
| 5c | Treatment offered after support provided | Number of RNA-positive cases where diagnosing clinician reports that treatment has been provided, after support was provided by CHECCS | Number of cases that had support provided by CHECCS at treatment testing stage | Type of support required |
| 6 | Reported uptake of treatment prescribing | Number of RNA-positive cases where diagnosing clinician reports treatment has been prescribed | Number of cases with a positive RNA test result reported | Reasons treatment not prescribed, if applicable Variation by demographic factors, diagnostic setting and risk factors |
| 7 | Overall number of cases not prescribed treatment | Number of RNA-positive cases that have not been prescribed treatment | | Reasons treatment not prescribed, if applicable |
| 8 | Completeness of key non-routine demographic and risk factor fields: - Indigenous status - Country of Birth - Injecting Drug Use status - Health care worker status | Number of cases with field complete | Number of cases | Comparison to period prior to CHECCS project |

Appendix 5: Resource table for diagnosing clinicians

| Clinical resource | Link | Description |
|---|---|---|
| ASHM 2-page decision making tool | https://www.ashm.org.au/resources/hcv-resources-list/decision-making-in-hcv/ | Info on when to test, test results & actions, pre-treatment assessment, treatment, monitoring, follow-up Link to REACH-C form for 24-hour specialist approval APRI calculator for assessing fibrosis Additional: ASHM website for further resources |
| GESA 2-page clinical guidance wall chart | https://ashm.blob.core.windows.net/ashmpublic/GP-algorithm-v10-June-2020.pdf | Info on when to test, test results & actions, pre-treatment assessment, treatment, monitoring, follow-up APRI calculator for assessing fibrosis. Treatment Protocols |
| Referral pathways | Link | Description |
| Victorian Primary Health Networks & health pathways | https://www2.health.vic.gov.au/public-health/preventive-health/sexual-health/primary-health-networks-and-health-pathways | Link to local health pathways site by PHN |
| Integrated Hepatitis C Nurses | Website content currently under development. Contact details will be available via this link soon: https://nwmphn.org.au/about/partnerships-collaborations/vhital/ | Contact details of your local integrated hepatitis C nurse who can assist in linking your patient into appropriate care. Includes referral form link |
| ASHM Prescriber locator map | https://ashm.org.au/prescriber-maps/ | Search tool to locate community prescriber for hepatitis C |
| Patient Resource | Link | Description |
| St Vincent's Hospital, Melbourne. "Hepatitis story, good news about treatment" | https://www.svhm.org.au/health-professionals/specialist-clinics/g/gastroenterology/resources#publications | An easy-to-understand booklet about hepatitis C: "Hepatitis story, good news about treatment". Includes information on other services available to patients, including harm reduction Victoria |
| LiverWell Hepatitis Infoline | https://liverwell.org.au/services/liverline/ | LiverLine is a free, confidential and non-judgmental phone service that provides information, support and referrals for people living in Victoria |
| Workforce Development | Link | Description |

| | | |
|--|---|--|
| VHHITAL | https://nwmpnh.org.au/about/partnerships-collaborations/vhhital/ | Training for GPs and practice nurses |
| ASHM | https://www.ashm.org.au/HCV/training/ | Training for GPs and practice nurses |
| Comprehensive resources | Link | Description |
| Eliminate C APPENDIX for GP's | https://ecpartnership.org.au/system/resource/103/file/EC_Partnership_Toolkit_doc_VIC_Appendix_v3.pdf | A handy document with info on testing and treatment specifically for GP's- includes remote consultation form |
| Australian recommendations for the management of hepatitis C virus infection | https://www.hepcguidelines.org.au/ | Consensus statement |
| Better Health Channel website | https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/hepatitis-c | General advice on hepatitis C |
| Eliminate C Practice Toolkit | https://ecpartnership.org.au/system/resource/80/file/EC_Partnership_Toolkit.pdf | If GP practice is interested in engaging further |

Appendix 6. Table timelines of variation to processes

| Date actioned | Variation to processes | Time period impacted |
|---------------|---|--------------------------|
| January 2022 | Follow-up of delayed hospital notifications de-prioritised due to CHECCS resource constraints. | November & December 2021 |
| May 2022 | Follow-up timeframe of hospital notifications amended to immediately after event date (instead of 4-week delay) due to difficulty contacting hospital doctors. | Some of March 2022 |
| June 2022 | Follow-up of hospital notifications prioritised over high-caseload notifications due to preliminary data analysis indicating linkage to care in hospitals was less than in primary care. | Some of March 2022 |
| August 2022 | Amendment to CHECCS project timelines due to CHECCS resources re-allocated to LPHU integration of viral hepatitis. Follow-up timeframes and backlog of notifications was now outside of project follow-up timelines, follow-up ceased from notifications April 2022 onwards. Proposal endorsed to only include completed data in analysis from Sept 2021-31 st March 2022 (Revised from original 12 months of data) | |

*April-July data not included in final analysis and report due to incomplete data and cessation of follow-up due to LPHU integration.

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