EC Australia
Partnering to eliminate hepatitis C

Using hepatitis C notification data to increase access to hepatitis C treatment and cure in Australia: A formative study

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Acknowledgements

The authors acknowledge the traditional owners of the land on which we collected and analysed data and wrote this report, and we pay our respects to Elders past, present and emerging, and to the Aboriginal Elders or community members who may read this report.

We would like to extend our thanks to the key informants and focus group participants who generously shared their experiences and insights. We would like to thank the Paul Ramsay Foundation for funding this research. We would also like to thank Campbell Aitken for editorial assistance.

This project is an initiative of the Eliminate Hepatitis C Australia (EC Australia) partnership, which is funded by the Paul Ramsay Foundation and coordinated by the Burnet Institute.

EC Australia

The long-term goal of EC Australia is to eliminate hepatitis C as a public health threat by 2030. Bringing together researchers and implementation scientists, government, health services and community organisations, EC Australia supports services to increase hepatitis C testing and treatment among key affected populations, including people who inject drugs, Aboriginal and Torres Strait Islanders, and prisoners. The EC Australia Partnership uses a health system strengthening approach structured around five key components: health promotion and awareness raising, workforce development and health service delivery, implementation research, evaluation and surveillance, and an Aboriginal Health Plan. These components aim to contribute to three major goals of EC Australia:

- Ensure that approximately 15,000 Australians with chronic hepatitis C are treated and cured of their infection annually
- Ensure that people identified with cirrhosis due to hepatitis C infection are treated and cured, and regularly monitored for liver cancer
- Establish a national collaborative framework to facilitate a coordinated response to the elimination of hepatitis C as a public health threat from Australia by 2030.

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Abbreviations

AOD	Alcohol and other drugs
BBV	Blood-borne virus
Clinician	General practitioners (GPs), specialist/consultant physicians and nurse practitioners
Consumer organisation	Organisations representing people with lived experience of hepatitis C and/or a history of injecting drug use
DAA	Direct acting antiviral
GP	General practitioner
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
Key informants	Representatives of government health departments, consumer organisations, clinical practice and academic organisations, who participated in individual interviews
OST	Opioid substitution therapy
PBS	Pharmaceutical Benefits Scheme
PCR	Polymerase chain reaction
Peer workers	Volunteer or paid workers employed by harm reduction and hepatitis community organisations
People with lived experience	People with lived experience of hepatitis C and/or history of injecting drug use, who participated in focus group discussions
RNA	Ribonucleic acid
VIPER	Victorian Initiative for Patient Engagement and Retention
WHO	World Health Organization

Executive Summary

Background and context

In March 2016, the Australian Government funded unrestricted access to direct-acting antivirals (DAA) through the Pharmaceutical Benefits Scheme (PBS)[1] to all people with hepatitis C over the age of 18 years. Relative to previous interferon-based treatments, new DAA therapies achieve high cure rates, have few and mild side effects and offer a simplified all-oral treatment regimen. Their availability supports the Australian government and World Health Organization aim of eliminating hepatitis C as a public health threat by 2030 through treatment scale-up, and subsequent reductions in transmission, liver disease, and deaths attributed to liver cancer (Scott et al., 2018).

Despite these advances, the number of people initiating hepatitis C treatment in Australia fell from 32,610 in 2016 to 11,580 in 2019 (Burnet Institute & Kirby Institute, 2020). Various interventions have been implemented to improve treatment access and reduce structural barriers to accessing DAAs, such as general practitioner and nurse-led models of care, expansion and refinement of prison treatment programs, treatments provided at pharmacies to opioid substitution therapy clients, and training of health care professionals. However, the use of notification systems to identify people with hepatitis C who have not been treated remains relatively unexplored.

Research aims and objectives

The study aimed to explore the potential of using jurisdictional hepatitis C notification data to improve treatment uptake and accelerate the elimination of hepatitis C in Australia. This aim was achieved by:

- Examining the logistical and practical issues and ethical considerations associated with implementing a system of hepatitis C notification follow-up in Australia that would identify and locate people diagnosed with hepatitis C, inform them about DAAs and direct them to treatment services
- Conducting an environmental scan and analysis of health policy, including legislation, strategies and action plans affecting the purpose, collection, use and disclosure of hepatitis C notification data

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[1] Pharmaceutical Benefits Scheme (PBS): Australian Government subsided medicine scheme.

- Identifying the scope of future initiatives to guide and enhance the use of hepatitis C notifications data to increase hepatitis C treatment uptake in Australia to support achievement of hepatitis C elimination targets.

Research methods

A mixed methods approach was used to gather data. Individual interviews were conducted with 20 key informants, including representatives of organisations whose constituents include people living with hepatitis C and/or people who inject drugs, and professionals with public health and blood-borne virus expertise working in consumer organisations, government health departments, and clinical practice or academic organisations. These interviews aimed to understand professional views and identify potential systems barriers to following up hepatitis C notifications. Twenty-seven people with lived experience of hepatitis C and/or injecting drug use participated in two focus groups to identify their views on using hepatitis C notification data to increase the number of people accessing hepatitis C therapy, including identifying any logistical issues and/or ethical barriers and enablers for implementing such an approach. Focus group participants were presented with several scenarios. For example, they were asked to imagine they had been diagnosed with hepatitis C and had not been treated (or had unsuccessfully received interferon treatment), and how they would feel about being contacted directly about DAA treatment by a practice nurse, a medical doctor or a contact tracer from a health department. Would being contacted via phone, letter or SMS be feasible and acceptable? What would be their biggest concerns? What practices might help reduce potential harms associated with being contacted?

A desk-based environmental scan of Australian state and territory government policies and legislation relating to the collection and use of hepatitis C notification data was conducted, including identifying any privacy legislation affecting the storage of such data, and any potential legal implications related to accessing this data and any policies that govern the sharing of this information.

Key findings

The following is a summary of key findings of the research.

Logistical considerations

- Although a range of logistical concerns were raised, overwhelmingly there was support for the idea of using notification data to contact people with hepatitis C to increase access to treatment, with the potential benefits being viewed as outweighing potential harms.

- Because individuals diagnosed with hepatitis C more than 20 years ago represent those most at risk of developing complications, and treatment can benefit people with advanced liver disease, most participants[2] believed that retrospective case finding should go as far back as possible, even if this presented logistical challenges.
- Most participants were supportive of the idea of using data linkage (e.g., linking notifications to other public data sources to identify the most reliable contact details) to improve the efficiency of follow-up. Data linkage between data sources and within notifications databases was considered useful for screening out unnecessary contacts (e.g., people who had already received treatment, those who had died, those with subsequent negative RNA[3] results). It was highlighted, however, that data linkage between notification systems and other government systems (e.g., My Health Record[4], Centrelink[5], PBS) may threaten people's privacy, particularly for those with histories of involvement in the criminal justice system.
- There were mixed views among participants about who (e.g., government contact tracers, health care professionals such as nurses working within or on behalf of government, diagnosing clinicians) would be the most appropriate person to make initial contact with people previously diagnosed with hepatitis C. There was a widespread view that for people with a history of injecting drug use, contact from a health department (without warning) may provoke anxiety and fear of stigma and discrimination. Participants emphasised various attributes for people undertaking follow-up, including that they were "trusted", had sufficient clinical expertise and knowledge, and could ensure people's privacy and confidentiality. It was noted that expecting clinicians to locate and contact people may be too resource intensive and beyond their scope.
- There was universal consensus that telephoning people would pose fewer risks to individual privacy and safety than text messaging or the post, as the identity of people contacted could be verified, reducing the risk of sensitive and stigmatising information reaching unintended recipients.

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[2] The report uses the term "participant" when describing the findings from both key informant interviews and focus group discussions.

[3] RNA refers to 'ribonucleic acid', the genetic material of the hepatitis C virus. RNA tests (also referred to as PCR [polymerase chain reaction] tests) are used to detect the presence of the virus, unlike the HCV antibody test that detects exposure to the virus.

[4] My Health Record: A shared electronic health summary set up by the Australian government with implementation overseen by the National Electronic Health Transition Authority.

[5] Centrelink: Australian Government service providing financial payments to people who are unemployed (includes carers support, a youth allowance and a disability support pension).

Ethical considerations

- There was consensus among participants that using notification data to locate and inform people about the availability of DAA treatment aligns with the primary purpose of surveillance systems in terms of protecting the health and safety of the community. Many suggested it would be unethical not to use notification systems for this purpose, given that treatment can prevent serious liver damage and consequent liver failure, cirrhosis, cancer and death. It was generally perceived that governments were morally obliged to use information contained in notifications data to facilitate access to treatment.
- Most participants raised concerns that being contacted about a hepatitis C diagnosis by health departments or non-diagnosing clinicians could create stress and fear among people living with hepatitis C, given many would have histories of injecting drug use.
- Participants unanimously agreed that particular care was needed to protect individual confidentiality and privacy when following up hepatitis C notifications, given many people living with hepatitis C may not have disclosed their status to friends, families or service providers. Because of the potential to exacerbate people's fear of disclosure, participants emphasised the need for processes to prevent information reaching unintended recipients or being shared with third parties.
- Participants were of the view that systems need to be in place to avoid follow-up of people in notifications databases who had since been treated for hepatitis C, had spontaneously cleared the virus, were terminally ill or had died, to avoid unnecessary contacts.

Policy analysis

- Hepatitis C notifications are mandated in state, territory and federal legislation.
- Disclosure of information in disease notification systems and obtained under relevant legislation must relate to a purpose proscribed under each Act, be in the public's interest and adhere to guiding principles (if stated).
- Stated objectives of disease notification systems in state/territory public health legislation include the protection, promotion and improvement of public health outcomes and for the detection, management, and control of infectious diseases.
- Most Acts have guiding principles relating to notifiable diseases, which in South Australia (SA), Victoria, Western Australia (WA), Queensland (QLD) and the

Australian Capital Territory (ACT) include individuals' right to receive information about disease and associated treatment, as well as the right to privacy and dignity.
- In New South Wales (NSW), QLD and Victoria, a stated purpose of notification systems and disease registers is to enable individual follow-up, care and treatment.
- In the ACT, SA, Tasmania and WA, disclosure of personal information contained in disease registries may be permitted for the purposes of disease prevention and control, further investigation, follow-up and/or treatment.
- There is implicit support in the Fifth National Hepatitis C Strategy 2018-2022 (Commonwealth of Australia, 2018) to identify everyone currently undiagnosed, partially diagnosed and/or not engaged in active management of their hepatitis C through a range of approaches, including active case-finding strategies.
- QLD is the only jurisdiction to explicitly identify a policy priority within their hepatitis C strategies/action plans to re-engage people diagnosed with hepatitis C prior to July 2016 to promote linkage to care/treatment.
- NSW and Victoria hepatitis C strategies both recognise the importance of follow-up after a notification has been received, but do not explicitly mention the use of historical data.

Summary of findings

Among members of affected communities and sector key informants who participated in this study, there was strong support for using notifications data to follow up people diagnosed with hepatitis C to inform them of and enhance their access to hepatitis C treatment. There was a unanimous view that retrospective case finding should go back as far as possible. Key informants interviewed perceived such activities as aligned with the primary purpose for which notification data was collected. All participants acknowledged the rights of people living with hepatitis C to be provided with information that could reduce their risk of serious disease or even death. There was also recognition that processes established to facilitate the follow-up of people diagnosed with hepatitis C must balance the right to privacy and confidentiality.

The use of hepatitis C notifications data to follow up people diagnosed with hepatitis C in order to increase their access to DAA treatment appears to be within the permitted reasons for information disclosure prescribed within Australian health legislation, and does not appear to conflict with existing privacy legislation or principles in any state or territory. National and state and territory hepatitis C strategies and/or action plans highlight the general need for active case-finding strategies and other approaches that improve hepatitis C testing and treatment uptake.

Implications and actions

In light of the findings described in this report, we recommend:

- Undertaking further national community and stakeholder consultations to establish agreement on acceptable approaches to using HCV notification data for follow-up
- Implementing a national consultation process with Aboriginal and Torres Strait Islander organisations and communities to determine acceptable and effective approaches to using HCV notification data to follow-up Aboriginal and Torres Strait Islanders diagnosed with hepatitis C, including notifications emerging from Aboriginal Community Controlled Health Services
- Using the findings from this review of Australian legislation and policies related to the use of notifications data as the basis for further consultation with state and territory health departments, with the aim of reaching consensus on the permissible use of hepatitis C notifications data for follow-up
- Working with state and territory governments to identify and address operational and technical challenges to undertaking effective follow-up of hepatitis C notifications
- Implementing and evaluating hepatitis C follow-up projects that align with existing state and territory activities and operating environments to identify optimal strategies for using HCV notifications data to enhance treatment uptake
- Establishing systems that use hepatitis C notifications and related data to create sustainable national evaluation and reporting frameworks to monitor and guide Australia's progress towards hepatitis C elimination.

1. Introduction

In Australia, at the end of 2018, an estimated 129, 640 people were living with chronic hepatitis C infection (Kirby Institute, 2020). Hepatitis C is an infectious viral disease, primarily affecting the liver. Left untreated, chronic hepatitis C infection may lead to liver disease, including cirrhosis and hepatocellular carcinoma (Ghany & Liang, 2016).

Since 1991, interferon and pegylated interferon in combination with other drugs have been used to treat hepatitis C. These drugs often caused severe adverse side effects, including flu-like symptoms, fatigue, muscle aches, anaemia, insomnia and nausea (Manns, Wedemeyer, & Cornberg, 2006) and at best achieved cure in only 40–50% of people with genotype 1, and 70–80% of those with genotype 2 or 3 (Palumbo, 2011). Harmful side effects of these treatments and complex dosing regimens, taken over 24 or 48 weeks, required hospital-based models of care. This, combined with a lack of knowledge and information about treatment availability and the absence of symptoms for many people with hepatitis C (Grebely et al., 2008; Jordan et al., 2013; McGowan & Fried, 2012; Treloar & Holt, 2008), resulted in low rates of people initiating treatment (Grebely et al., 2009).

1.1 Direct-acting antivirals

In 2014, direct-acting antivirals (DAAs) became available for the treatment of hepatitis C. They have revolutionised hepatitis C care: they are highly effective irrespective of hepatitis C genotype (cure rate of over 95%), have minimal adverse effects, and require only 8–12 weeks of once-daily tablets. The advent of this cure has made the elimination of hepatitis C as a public health threat possible. Since March 2016, the Australian Government has provided unrestricted access to DAAs through the Pharmaceutical Benefits Scheme (PBS) to all people with hepatitis C over the age of 18 years (Dore & Hajarizadeh, 2018). Wide-scale uptake of these treatments is predicted to substantially reduce hepatitis C transmission and deaths from liver cancer and other liver disease in line with the World Health Organization (WHO) goal of eliminating viral hepatitis C as a public health threat by 2030 (Scott et al., 2020).

While the Australian Federal Government provides strategic leadership and a substantial proportion of health service funding in Australia, health systems are governed and implemented by the states and territories. Although state and territory governments are making efforts to increase the number of people accessing treatment for hepatitis C, the response across the country is variable.

By the end of 2019, it is estimated that 85,910 people had initiated DAA treatment (Kirby Institute, 2020; Burnet Institute & Kirby Institute, 2020). DAA treatment initiation rates in

Australia were extremely high in the months following DAAs being listed on the PBS, but then declined and plateaued, largely credited to a “warehouse” effect, in which people with hepatitis C were forgoing access to previous treatment options and waiting to initiate new treatments (Kirby Institute, 2018). Of particular concern is that the number of people initiating DAA treatment fell from 32,610 in 2016 to 11,580 in 2019 (Burnet Institute & Kirby Institute, 2020). Furthermore, modelling studies (Kwon et al., 2019; Scott, et al., 2020) have found that the number of hepatitis C-exposed people identified and tested needs to be increased by at least 50% (Scott et al., 2020), and that 17,100 treatment initiations in 2018 and 13,680 treatment initiations annually from 2019 onward were required to put Australia on track to achieve WHO elimination targets of treating 80% of people living with chronic hepatitis C and an 80% reduction in hepatitis C incidence by 2030.

1.2 Eliminating hepatitis C in Australia

Australia’s commitment to providing broad access to DAAs positions the country as one of few capable of achieving hepatitis C elimination within the WHO 2030 timeframe (Burnet Institute & Kirby Institute, 2019). However, without a renewed focus on increasing hepatitis C treatment, Australia will fail to achieve these elimination goals (Scott, et al., 2020).

Although most people who are living with hepatitis C in Australia have been diagnosed, most have not initiated treatment (Scott et al., 2020). Several studies have identified individual and system-level barriers preventing DAA treatment initiation, including limited knowledge and misconceptions about hepatitis C and the treatment, patients managing multiple health and social priorities that interfere with keeping medical appointments, and experiences of stigma within health services (Madden, Hopwood, Neale, & Treloar, 2018; Masson et al., 2020).

It is important that efforts to engage people in hepatitis C care include strategies to improve knowledge of the availability, simplicity and effectiveness of new treatments (Crowley et al., 2018). Strategies and interventions are being implemented that aim to increase hepatitis C treatment uptake and linkage to care, including broadening who is able to prescribe DAAs and making treatment available through primary care (e.g., general practices), in prisons and at pharmacies that administer opioid substitution therapy (OST), and building the capacity of health care professionals in community services to screen and treat people (Bajis et al., 2017; Kronfli et al., 2018). However, declining numbers of treatment initiations by specialists are not being sufficiently offset by increasing numbers of initiations in primary care and other treatment settings (Burnet Institute & Kirby Institute, 2019; Scott et al., 2020).

Stigma and discrimination have been identified as leading causes for missed diagnoses of viral hepatitis and for the failure of people living with these conditions to engage with the health system and seek timely treatment (Crooks, Lorenz, & Campbell, 2016). The harmful impact of stigmatising and discriminatory attitudes and behaviours within the health care system is considerable and can take many forms, including denial of care, barriers to care, inferior care, and a lack of respect not only for the individuals involved, but for efforts to reduce the prevalence of hepatitis C in the community. In Australia, hepatitis C is primarily transmitted through the sharing of injecting equipment. As injecting drug use is already subject to widespread stigma and discrimination, this same lens is often applied to people with hepatitis C, even if they contracted hepatitis C through other means (Lancaster, Santana, Madden, & Ritter, 2015).

1.3 Notification systems and surveillance

Hepatitis C has been classified as a notifiable infection Australia-wide since 1995 (Department of Health, 2020). Public health legislation in each state and territory requires that medical practitioners, clinicians, pathology services and/or hospital CEOs report confirmed cases of hepatitis C to their respective government health authority. Reportable surveillance information, although varying across jurisdictions, generally includes the name and contact details of the person diagnosed, demographic and clinical data, risk factors and likely mode of transmission. Prior to submitting such information, the diagnosing practitioner is required to inform the patient that information relating to their diagnosis will be provided to the relevant health department. While the stated aims of the surveillance systems differ between states and territories, overall, their primary goal is to enable prompt identification and public health responses to select communicable diseases. Privacy of notification data and other health information is protected by federal, state and territory legislation.

All state and territory health departments are required to notify all new diagnoses of hepatitis C to the Commonwealth's National Notifiable Diseases Surveillance System (Department of Health, 2020). Notifications in this data set are deidentified, and include a unique record reference number, the notifying state or territory, a disease code and notification date. Where evidence is available, infections are classified as "newly acquired", acquired "greater than two years" ago or "unspecified". The primary objective of the national surveillance system is to monitor trends in communicable diseases, support responses to outbreaks and guide policy development. The data includes all people diagnosed as being exposed to hepatitis C (based on their antibody test result), rather than only those who have been exposed and then resolved the infection.

Despite the potential utility of hepatitis C notification data to increase the number of people diagnosed with hepatitis C accessing treatment, two recent systematic reviews of interventions to increase linkage to care and hepatitis C treatment uptake (Bajis et al., 2017; Kronfli et al., 2018) were unable to identify any studies of the utility of surveillance or notification system-based interventions.

HIV notification data for linking people to care

Notification data has been used in efforts to improve engagement with HIV care. Given hepatitis C has commonalities with HIV, including route of transmission (injecting drug use), its highly stigmatised nature, and that it often affects people involved in the criminal justice system, it is likely previous work undertaken on HIV can inform similar approaches to hepatitis C.

Several programs have aimed to use HIV notification system data as a single intervention or as part of a combined intervention to improve retention in HIV-related care. Most commonly, these programs have sought to use notification data to identify people who appear to be "out of care" (defined as people who have previously had a HIV viral load or CD4 count[6] blood test, but who have had neither of these tests within the preceding 9–12 months, or people who have had a positive HIV test but never had a CD4 or viral load test [Buchacz et al., 2015]).

The Victorian Initiative for Patient Engagement and Retention (VIPER) project (McMahon et al., 2015) used clinical patient data from hospital and clinical services to identify people with HIV who had not received a viral load test for at least the previous nine months, to seek to re-engage them in HIV care. Cross-referencing and phone tracing was conducted to see if patients had been transferred or retained in care at other sites, if viral load tests had been conducted elsewhere, or if patients had died (via death notifications); from 85.9%–95.8% to 91.4–98.8% of people were successfully re-engaged in care.

In New York City in 2008, health department staff reviewed citywide surveillance records to identify people with HIV who had not had a CD4 or viral load blood test in the preceding nine months (Udeagu et al., 2013). Follow-up from health department staff via phone, postal mail or hand-delivered mail was used to determine why patients were not accessing care, provide HIV education and offer re-linkage to care (Udeagu et al., 2013). Just over half of those contacted (57%) returned to care (defined as attending a follow-up HIV clinic appointment or having a subsequent viral load or CD4 count blood test). Similar programs

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[6] CD4 count: An indicator of immune function in patients living with HIV.

have been conducted in Washington state (Buskin et al., 2014), Washington DC (Project Inform, 2012), Louisiana (Magnus et al., 2012), Indiana, Philadelphia (Bertolli et al., 2013) and San Francisco (Buchacz et al., 2015). Incremental structural, legal and policy changes provided a foundation for many of the aforementioned programs and collaborations.

Although some interventions report being built upon formative work, including acceptability assessments, these have not been published. Furthermore, few published reports include rigorous evaluations of the effectiveness of using notification data for engagement with HIV care, and when evaluations have been undertaken, the independent effect of notification data on linkage to care is difficult to ascertain, because most programs simultaneously included other interventions to enhance access to care. These additional interventions included reimbursements and linkage to trained peer navigators (Buskin et al., 2014), intensive follow-up activities to re-engage people in care (Project Inform, 2012), and electronic health record alerts when “out of care” patients presented to clinicians for other services (Magnus et al., 2012).

Sweeney et al. (2013) reviewed the ethical and practical implications of health departments using HIV notification data to find people who appeared to be out of care. They described procedural and strategic issues associated with following up HIV cases, and used an ethical framework to argue that the advent of antiretroviral drugs as lifesaving treatments warranted the use of HIV surveillance data to facilitate optimal HIV care. They contended that, whilst privacy concerns regarding the use of HIV surveillance data persist, there are ethical implications of not using surveillance data to maximise the benefits of HIV care and treatment. Moreover, they argued that effective and ethical use of surveillance interventions for HIV follow-up requires engaging stakeholders and establishing legal, policy and governance infrastructure, as well as developing client communication or follow-up protocols that protect privacy (Sweeney et al., 2013).

Amongst the interventions that aim to link people with HIV to treatment and care, most were undertaken in the United States, where gaps in health service access and the structure of the health system make comparisons with other developed countries difficult. Moreover, most interventions were accompanied by other processes in addition to simply contacting/following-up patients. While studies of the effectiveness of HIV notification follow-up to improve uptake of treatment has helped inform HIV prevention and care strategies, the paucity of published evidence of the utility of this approach for hepatitis C represents a significant gap in knowledge.

Hepatitis C surveillance data for linking people to care

The use of hepatitis C notification data for linkage to care is an emerging strategy. The largest reported intervention using hepatitis C surveillance data to link people to care is currently underway in the United Kingdom. The project, which is being administered by Public Health England, matches historic notification data with other national datasets, and to date has identified approximately 50,000 people who returned a positive hepatitis C antibody test between 1996 and 2017 and appear to have not been treated. Attempts to contact the identified individuals, either directly or via their general practitioners (GPs), and link them to further testing and treatment are ongoing, and preliminary outcomes are yet to be reported (Public Health England, 2018).

On a smaller scale, in New York City, notification data was used to contact people who had returned a positive antibody result but had not had follow-up RNA tests recorded. An evaluation of this program found that the rate of subsequent RNA test uptake was consistent whether contact was via text message or the post. However, whether contact via any method (post or text message) compared to no contact translated to improved treatment uptake remains unknown (Moore, Ip, Johnson, & Laraque, 2016).

Some Australian jurisdictions are piloting the use of hepatitis C notification systems to follow up and link people recently notified with hepatitis C to care and treatment. Although results from these activities are yet to be published, preliminary outcomes are promising.

For example, a South Australian project, piloted from August 2018 to January 2019, involved the direct referral of new notifications of hepatitis C to specialist viral hepatitis C nurses. Nurses followed up all cases not already known to the specialist service by contacting the clinician by telephone and discussing optimal care and treatment options. Cases that had already proceeded to HCV PCR tests and were negative received no further follow-up. For the remaining cases, forms of support were follow-up and the provision of information on optimal care only, follow-up with hepatitis nurse support, or follow-up with referral to a specialist or hepatitis nurse. Over a trial period of six months, 303 hepatitis C notifications were received; 247 (82%) were successfully followed up, of which 142 were RNA positive. Of the 142 notifications with RNA-positive results, 110 (77%) were followed up for further assessment and consideration of treatment.

In Western Australia, the GP Liaison Project funded by the Western Australia Department of Health and administered by HepatitisWA is aiming to support GPs and practice nurses to manage their own patients with hepatitis C rather than referring them to specialist services (HepatitisWA, 2020). The project entails GPs and practice nurses receiving a letter from the Department of Health informing them they have notified one or more cases of hepatitis C in the preceding two years (the identities of the cases are not provided). The letter advises that, unless they choose to opt out, the practice will be contacted by a GP-liaison nurse from HepatitisWA to offer them information, education and support around prescribing hepatitis C treatments (including pathways for referral). A previous pilot project in Western Australia aimed to improve awareness and uptake of new treatments among people with a previously recorded positive hepatitis C antibody test (Miczkova et al., 2018). Nurses from the Western Australian Country Health Service used notification data (extracted from the statewide Western Australian Notifiable Diseases Database) to identify 246 individuals who had recorded a positive hepatitis C antibody result between January 2011 and December 2016 (i.e., before subsidised DAAs were available via the PBS). Among 79 individuals identified for follow-up by phone (i.e., people who were not currently being treated, had not had a subsequent negative HCV PCR result, were alive and had not relocated to another jurisdiction), 30% were successfully reached. Reasons for non-contact included disconnection of the phone number supplied at the time of notification, the call being answered by someone else, or the call being terminated by the individual. Since the original notification, some individuals had also been incarcerated. No attempt was made to contact these individuals or engage with prison health services, because this was beyond the scope of the project.

Although n increasing number of projects (both globally and locally) are piloting the use of notification systems to increase hepatitis C treatment uptake, as highlighted above, few have published results. Moreover, no published studies have examined the impact or acceptability of these approaches from the perspectives of the people most affected (people with, or at risk of hepatitis C). To unlock the potential and maximise the impact of hepatitis C notification systems for enhancing treatment coverage, it is important to understand the barriers and facilitators of using this data from their perspective, and the perspective of key government and sector stakeholders. Consideration of the policy, regulatory and legislative factors that govern the use of health data when designing and implementing a system to follow up notifications is also needed. This work will be crucial to guiding future interventions that can be trialled, rigorously evaluated and inform evidence-based approaches globally.

1.4 Research aims

This formative study aimed to explore the potential of using jurisdictional hepatitis C notification data to improve treatment uptake and accelerate the elimination of hepatitis C in Australia. We reviewed legislative and other policy documents relevant to using notification data to identify people diagnosed with hepatitis C who have not been cured, and examined barriers and enablers to implementing such an intervention from the perspectives of people with lived experience (of hepatitis C and/or injecting drug use) and key informants (representing government health departments, consumer organisations, clinical practice and academic organisations).

Key research objectives were to:

- Examine the logistical and practical issues and ethical considerations associated with implementing a system of hepatitis C notification follow-up in Australia that would identify and locate people diagnosed with hepatitis C, inform them about DAAs and direct them to treatment services
- Conduct an environmental scan and analysis of health policy including legislation, strategies and action plans affecting the purpose, collection, use and disclosure of hepatitis C notification data
- Identify the potential and scope of future initiatives to guide and enhance the use of hepatitis C notifications data to increase hepatitis C treatment uptake in Australia to support achievement of hepatitis C elimination.

2. Research methods

Low-risk ethics approval for this project was received from the Alfred Health Human Research Ethics Committee (Project No: 387/19). Data collection methods were guided and informed by an investigator group with research, clinical and public sector experience and expertise in hepatitis C, and the experiences of people living with hepatitis C and/or histories of injecting drug use. The research involved individual and focus group interviews with key informants and people with lived experience of hepatitis C and/or histories of injecting drug use, and a desk-based policy review. Verbal consent was obtained from all participants prior to interviews and focus groups.

2.1 Individual interviews & focus groups

Individual interviews and focus groups were conducted with key informants and people with lived experience of hepatitis C and/or injecting drug use to understand their views and perceptions of using notification data to locate people with hepatitis C, inform them of the availability of a hepatitis C cure, and link them to treatment services.

All participants were asked to consider a system that involved the use of notification data to identify and locate people with hepatitis C and inform them of the availability of a cure and link them to treatment services, and the following questions and issues:

- Could it be justified from a health and personal/human rights perspective?
- Ethical considerations and how these should/could be addressed
- Potential harms, particularly relating to confidentiality and exacerbation of stigma/discrimination for people with hepatitis C, and how these could be prevented and/or minimised
- The most acceptable/safe methods for contacting individuals (e.g., postal mail, telephone, email), and by whom (clinician, government health department or peer worker)
- Any other logistical and practical considerations.

In addition, key informants were invited to consider:

- Any regulatory or legal implications and how these should/could be addressed
- Issues related to the use of data linkage to address information gaps.

Key informant interviews

From September 2019 to March 2020, 16 face-to-face or telephone interviews were conducted with 20 purposively selected key informants. These participants were identified and recruited from the investigators' professional networks, in particular people with experience in hepatitis C monitoring and surveillance, and the treatment and management of people with hepatitis C. Participants included representatives of organisations whose constituents include people living with hepatitis C and/or people who inject drugs, and professionals with public health and blood-borne virus (BBV) expertise working in consumer organisations (n=5), government health departments (n=12), and clinical practice or academic organisations (n=3). A semi-structured interview schedule was used to guide the research interviews (see Appendix 3).

Focus groups with people with lived experience

Harm Reduction Victoria (the peak body representing people who use drugs in Victoria) and Hepatitis South Australia (the jurisdictional peak body representing people with or affected by hepatitis C) were approached to support the recruitment of participants for two focus group discussions. Eligibility for participation included experience with injecting drug use and/or living with hepatitis C. Eligible participants were given information (see Appendix 1 & 2) describing the research project and what it would mean to be involved, prior to consenting to participate. Voluntary verbal consent was obtained from all participants.

The first focus group discussion was held with Harm Reduction Victoria participants in December 2019 and involved 15 people, all of whom had experience with injecting drug use and hepatitis C. A second focus group was held at Hepatitis South Australia in February 2020 and involved 12 participants, all who had lived with hepatitis C and some with injecting drug use experience. Participants in both focus groups were reimbursed A$40 for their time, travel costs and effort. A semi-structured interview guide (see Appendix 4) was used to guide focus group discussions, and participants were presented with several scenarios for consideration. For example, they were asked to consider a situation in which they had been diagnosed with hepatitis C and not treated (or had unsuccessfully received interferon treatment); how they would feel about being contacted directly about the DAA treatment by a practice nurse, a medical doctor or a contact tracer from the health department? Would being contacted via phone, letter or SMS be feasible and acceptable? What would be their biggest concerns? What might reduce any potential harms associated with being contacted (see Appendix 5 for more detail)?

Analysis and reporting

All data presented in this report is anonymised, that is, any identifiable information, including names and places, has been replaced with pseudonyms. Key informant interviews and focus groups were electronically recorded, and transcribed, and individual transcripts organised and managed using NVivo qualitative software (QSR International, 2014). Extracts from interview transcripts were reviewed to derive themes and subthemes. The establishment of themes involved discussions between the research team to ensure research rigour, with final themes agreed upon by all authors, and disagreements resolved by consensus.

2.2 Policy analysis

A desk-based environmental scan and content analysis of Australian state and territory government legislation, strategies and action plans relating to the collection, storage and use of hepatitis C notification data was conducted between March and April 2020. In Australia, health policy[7] affecting the collection and use of hepatitis C-related notification data includes:

- Primary legislation, such as public health Acts, which establish the purpose, principles and requirements for the collection and use of notifiable diseases data
- Delegated or subordinate legislation such as regulations which support the implementation of the Acts
- Hepatitis C strategies and action plans.

All three components were reviewed for this report.

Notifiable disease legislation

National and state and territory legislation related to the purpose, collection and use of notifiable diseases was reviewed (see Table 1). Legislation was included in the review if it specifically mentioned notifiable diseases/conditions. For some states and territories, this required review of multiple pieces of legislation, including delegated legislation. The review did not include legislation that had been superseded, and focused on legislation current at the time of review. Sixteen acts and regulations were reviewed. Legislation was analysed according to how notifiable disease information is collected, how such information can be used, under what circumstances can it be used, and who has access to this information.

Privacy legislation and policies

Privacy legislation in each state and territory and at the federal level were reviewed to ensure there were no conflicts between provisions in the notifiable disease legislation and privacy legislation. Legislation and policies were analysed according to how health information about an individual can be collected, managed, used and disclosed.

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[7] In this report, we define health policy as “decisions, plans, and actions that are undertaken to achieve specific health care goals within a society” (World Health Organization, 2020). This can include treaties, agreements, legislation, guidelines, action plans or standards.

Government strategies and action plans

Government strategies and action plans relating to viral hepatitis, BBVs and hepatitis C were reviewed. This review included policy documents relating to hepatitis C amongst Aboriginal and Torres Strait Islander peoples and people in custodial settings, where available. The review of these documents focused on strategic action items relating to improving diagnosis or testing practices for hepatitis C, specific items related to the requirement to notify hepatitis C, and the use of the notification data to help facilitate appropriate care.

The results of analysis of this data are presented in the following chapter. The report concludes with a brief discussion of the implications of the analysis and recommendations for future studies and initiatives.

3. Research findings

3.1 Logistical considerations

All focus group participants and key informants were asked if an initiative in which notification data was used to locate people with hepatitis C, inform them of the availability of a cure and link them to treatment services were to be implemented, what logistical and practical issues should be considered. These logistical and practical issues included identifying the most appropriate person/agency to undertake this follow-up, who should be contacted (e.g., diagnosing clinician or patients), and how this process should be undertaken (e.g., telephone, text message or post). In addition, key informants were asked to consider the use of data linkage to locate people diagnosed with hepatitis C if insufficient contact information was available in notification data, and how far back retrospective notifications should be reviewed for follow-up.

Locating people with hepatitis C

There was consensus from interview and focus group participants that all hepatitis C surveillance data records should be considered when implementing any proposed initiative, so that every person who is at risk of hepatitis C-related liver disease and needs treatment has the potential to be cured.

Given individuals who were diagnosed with hepatitis C more than 20 years ago represent those at most imminent risk of developing severe liver disease and complications, all participants agreed that retrospective notification data searches should go as far back as possible. Indeed, because treatment can still be beneficial for people with advanced liver disease, some believed it would be unethical not to go back to when hepatitis C first became a notifiable condition to alert people of the availability of DAAs. One health department stakeholder emphasised that even notifications that occurred after the listing of DAAs on the PBS in 2016 should be followed up, because not all diagnosing clinicians were likely to be aware of DAAs at the time of diagnosis.

Notification data availability

One logistical challenge raised by key informants in using hepatitis C notification data to locate people diagnosed with hepatitis C was the potential unreliability and inaccuracy of contact information stored in state and territory notification systems. It was noted that many people will no longer be living at their original postal address, that phone numbers may have changed, and that many will have been diagnosed before the advent of the mobile phone. In addition, for people with histories of injecting drug use and incarceration—a key target group of a proposed initiative—contact details are more likely to be out of date because of transient and unstable accommodation.

Several key informants from health departments noted that whilst some notifications may include phone numbers, recording phone numbers is not routine, even for relatively recent hepatitis C notifications. Some representatives of health departments also noted that because notification data had previously been collected using paper-based forms rather than direct electronic transfer from laboratories, contact information may have been lost or details incorrectly transferred to electronic databases, and therefore health departments may no longer have the original form.

Using data linkage

Data linkage—a method for collating public health record information about the same person from multiple data sources—has gained increasing interest amongst policymakers, clinicians, and researchers for supporting individual patient and broader public health outcomes. Key informants were asked to consider whether using data linkage to identify people with hepatitis C would be reasonable given the potential challenges in accessing accurate contact information. The potential benefits and challenges of using such an approach were discussed, with some ideas for solving problems identified.

Informants saw several advantages in linking individual notification data to other sources of health and contact information. They highlighted that sourcing more accurate data could prevent unnecessary or inappropriate follow-up (e.g., letters to postal addresses where individuals no longer live, or telephone calls to mobile numbers that are now held by other individuals), and removing people who had cleared the virus or were treated since notifications were made could allow resources to be targeted to those most likely to benefit. For example, participants highlighted how laboratory data could help exclude those with subsequent RNA negative results, linkage to PBS data systems could identify people having already accessed treatment, and death registries could exclude people who had died.

An additional perspective for using PBS data was the potential to reach people who have become reinfected since they were treated. This was highlighted by one focus group participant who had been cured and then reinfected and was unaware that they could be re-treated; they saw the proposed initiative as an opportunity to provide accurate information to those who are unaware of their eligibility to be re-treated.

It was also highlighted that data linkage could identify current treating clinicians for people diagnosed with hepatitis C, who could then become the follow-up provider of treatment and care to their patient.

Despite the potential that data linkage could enhance the rate of successful follow-up, key informants raised concerns about using such an approach.

> People who've had bad experiences with government agencies or been in trouble with the law, or on the other hand have led a squeaky-clean life for the last twenty years but have a hidden secret from when they were younger – I think both those populations would freak out about data matching. I understand that's the most practical way to get contact details but that's also why we have reservations about the project. (KI 16, consumer organisation representative)

Some key informants were concerned about the potential intrusiveness of data linkage on people's privacy, believing the approach may not be considered acceptable by the targeted communities, and could raise suspicion of government overreach and inappropriate data sharing.

Concerns were also expressed about the resources required to undertake large-scale linking of notification data to other datasets. It was assumed that such an approach would be labour intensive and costly without automation. Furthermore, some participants were concerned that linking notification data to other health and contact data could involve regulatory and legal barriers that would create challenges for implementation.

There was consensus among key informants that if data linkage were used, that at a very minimum government departments from whom the contact details were sought should not be made aware that a person may have hepatitis C. Furthermore, it was suggested that reasonable attempts should be made to use notification data contact details already available for each case prior to any attempt to use data linkage for that person.

Contacting people with hepatitis C

When focus group participants and key informants were asked to consider the most appropriate person/organisation to make initial contact (e.g., GPs, specialist/consultant physicians, nurses and nurse practitioners, health department contact tracers, peer workers from non-government drug user and hepatitis organisations), diverse views were expressed. Considerations for choosing who should make initial contact with individuals included that the person was trustworthy, that they could maintain individual privacy and confidentiality, and that they had clinical expertise and knowledge about hepatitis C and treatments. Some participants expressed contradictory views, and there was significant variance in participant perspectives. Furthermore, some key informants acknowledged that decisions about who should or could make initial contact with individuals would likely be constrained by state and territory legislation and regulations.

Government health departments

Some participants felt it would be most appropriate for individuals to be contacted from within public health departments to avoid sharing notification data with third parties. For some key informants and people with lived experience of hepatitis C, a contact tracer within the health department was considered the best option and the most likely to be trusted, given their specific training to undertake this role (skilfully, respectfully and with the required hepatitis C-specific knowledge).

> [For] a lot of people who are using drugs … the assumption is that if the health department knows something, so do the police, so does [the justice department] and so does everyone who you don't want to know your business … Being contacted by the health department would be really challenging for a lot of those people […] My hunch is that when things are this highly criminalised and stigmatised, people will be highly frightened by what they see as the government trying to contact them. (KI 16, consumer organisation representative)

Alternatively, many focus group participants and some key informants shared their concern that for a person with a history of injecting drug use to be contacted by a government health agency could provoke anxiety, given the criminalised nature of drug use and associated stigma. Many participants with lived experience described how they had been continually exposed to discriminatory attitudes and practices of government, including through Centrelink[8] and law enforcement agencies, due to their injecting drug use, and as a result distrusted and feared government bodies. They described how, for this reason, they would not want to engage with any process they perceived as being related to government. Nonetheless, amongst focus group participants who said they would be concerned if they were contacted by their health department, most acknowledged that the benefits of being cured of hepatitis C outweighed these concerns.

There were other reasons, however, for preferring first contact be made by a clinician as opposed to someone from the health department, as described below.

Clinicians (GP, specialist/consultant physician, practice nurse, nurse practitioner)

Several key informants and focus group participants felt it would be preferable (where possible) for the first contact with individuals be made by clinicians (e.g., doctors or nurse practitioners that had ordered the original test or were currently managing the health of the individual involved), rather than public health departments. Many key informants pointed out that some clinicians (whether the diagnosing clinician or regular doctor) may consider it

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[8] Government provider of unemployment benefits and pensions.

a matter of professional courtesy for the health department to ask them to contact their patients themselves. Moreover, they suggested that some clinicians might be upset if their patient was contacted without their knowledge, as this may be perceived as interfering in the doctor–patient relationship, particularly if they had been the diagnosing clinician and were then expected to follow up with treatment and care. Anecdotal evidence suggests GPs in Australia have been faced with this same issue in relation to COVID-19, that is, some treating doctors have expressed concerns at having not received information from departments of health about their own patients' health status in relation to COVID-19. Thus, one health department representative highlighted that involving clinicians from the very beginning may increase patient confidence that health departments and clinicians are working in a coordinated way.

Some key informants highlighted that if clinicians were being asked to contact people, that those patients not requiring follow-up should be screened out as part of this process (i.e., people who have been treated and cured, spontaneously cleared the virus or were deceased). It was also noted that clinicians are likely to have more recent and/or additional contact details for affected patients, which could help increase follow-up success.

While many participants were supportive of clinicians undertaking follow-up of notified cases, practical barriers to using such an approach were also identified. For example, several key informants reported that involving the clinician who ordered the test or diagnosed the patient may prove difficult for older notifications, because the clinician may not have a current relationship with the person or may no longer be practising. Additionally, for some, clinicians' details may not have been recorded on the notification form or may have been lost in the transfer of information from paper-based forms to an electronic database. Additionally, some participants were concerned that expecting clinicians to locate and contact individuals could be too resource intensive for general practices, given many clinics already feel overburdened (and at present cannot bill for this activity).

Despite these practical barriers, most participants felt that a model in which individuals were contacted by health departments without any attempt to contact their clinicians would be unacceptable. If clinicians could not be involved, it was suggested that—at the very least—peak bodies representing health professionals approve the model and/or be informed (in advance) that such an initiative was being implemented.

While many participants believed it was preferable for clinicians to contact people directly, there was also concern that some people would not want their current clinician to be contacted. For example, one consumer organisation representative described how people who inject drugs often have two primary care doctors—one who knows about their injecting drug use and assists with related issues (e.g., drug rehabilitation, detox, pharmacotherapy), and another practitioner that they see for other health issues. Furthermore, a few participants with lived experience explained how they would be concerned if they were contacted by their current GP, because they had not disclosed their hepatitis C status to them for fear of discriminatory treatment. For example, one focus group participant said, “*I would definitely NOT want to be contacted by my GP—that would be an invasion of my privacy*”.

> There [was] no way known I’d tell [my GP] I had hep C, because … they’d discriminate against me […] If my GP phoned me, I’d say, “How did you get that information? Why are you ringing me?” Yeah, I’d be very, very disturbed by that. I’d feel that would be an invasion of my privacy. But if it came from the government, I’d think, “okay, so the government isn’t telling GPs about me, it’s just them”, so I can still go to my GP and keep my privacy. (focus group discussion #2)

Peer workers

Focus group participants were asked to consider whether individuals could be contacted by someone who identifies as a peer of people who inject drugs and/or who have hepatitis C—someone with lived experience who works for a non-government organisation providing services to people with or at risk of contracting hepatitis C. Most felt strongly that notification data must not be disclosed to peer workers given the risk of confidentiality breaches, especially if the peer worker already knew the person. Although it was acknowledged that some people might prefer to be contacted by a peer, given there is no way of knowing this in advance, this approach was generally not considered a viable option. Some focus group participants, however, suggested that after initial contact from a health department representative or clinician, people could opt to receive additional support from a peer worker.

> Like if the doctor said, “We have so and so that’s been through the treatment, and we can put them onto you”, I wouldn’t mind then [because] that’s someone who’s been in our shoes [and] like you know instead of getting called by some faceless people you don’t even know. (focus group discussion #1)

Potential methods of contact

When asked to consider how individuals should be contacted, most participants agreed that receiving a telephone call, as opposed to a text message or letter, would be the safest and most practical approach.

Telephone (voice call or text message)

For some focus group participants, the idea of receiving an unexpected phone call from someone they did not know was alarming. Some highlighted how an increase in *“cold calls”* to mobiles from *“scammers”* and marketing companies meant they would be unlikely to stay on the phone long enough to find out who was calling, and anecdotal evidence suggests people do not answer phone calls or texts from unknown numbers. It was also pointed out that most notification data do not include a mobile phone number (especially data that is older than five years).

Despite these concerns, telephone calls were unanimously the preferred mode of contact for any proposed initiative. One key informant noted that mobile numbers appear to be more stable over time than residential addresses or landline phone numbers. It was also highlighted by some focus group participants that a phone call may signal to people that the issue is important and warrants immediate attention.

A telephone call was universally preferred over receiving a text message, because it poses fewer potential risks to individual privacy and safety, by allowing the identity of the individual being contacted to be verified before any discussion of hepatitis C began, and thereby avoiding anyone other than the intended recipient receiving the message. One focus group participant, who had previously been in a violent relationship, said receiving a text message from the health department or their own GP would have alarmed their partner and could have placed them in danger.

It was highlighted that text messages usually require a response, and sometimes recipients lack phone credit to do this. A call allows explanation and reassurance, and an opportunity for the recipient to ask questions and receive immediate answers. Finally, as some participants highlighted, it is foreseeable that at least some people will want to know how their health information was accessed, and a telephone call would allow this concern to be addressed immediately.

Postal mail

Most participants agreed that receiving information from either the health department or a clinician by mail risked a breach of confidentiality, because an unintended recipient could open the letter. It was highlighted that even a non-specific letter asking the recipient to contact the health department may breach confidentiality and invite questions from others. Furthermore, there was broad acknowledgement that postal addresses for many people are likely to have changed since the time of notification.

> With mail, then somebody else could open it, like their partner, [because] I've opened other people's mail, and I know that they've opened my mail at times too. And what about if you change addresses? Like the mail gets sent to your previous address and then they could open up your mail? (focus group discussion #1)

One key informant highlighted, however, that a potential advantage of contacting individuals by mail was that undelivered letters could be returned to sender, indicating how many people were successfully reached. At a minimum, it was suggested that if letters or text messages were used to contact people, they must not mention hepatitis C. One key informant suggested that postal mail could include a unique code that the individuals would need to use as part of the identity verification process when they called a specified phone number. Furthermore, one participant recommended registered mail could work to protect confidentiality, because it would require recipients to sign for the letter, which would reduce the likelihood of information reaching unintended recipients.

> The trouble with a letter is that it's not very secure. If a letter is sent to my previous address and my mum or a previous flatmate opens it, that would undercut the project even more—if people thought their personal details were open to anyone that opened their mail. Text [message] is also an issue because you don't really know who's at the end of that either. (KI 16, consumer organisation representative) representative)

3.2 Ethical considerations

Participants raised several ethical considerations in using notification data to contact people previously diagnosed with hepatitis C. From one perspective, an ethical argument was made that if health departments are holding information with the potential to help an individual and have a broader public health benefit, then there is a moral obligation for this information to be used for such a purpose. From another perspective, ethical concerns were expressed about potentially breaching individuals' privacy and confidentiality, with the possibility that this could exacerbate stigma and discrimination.

Reducing harms is a purpose of notification data

Many key informants were of the view that, given the primary purpose of surveillance data is to protect the health and safety of the community by informing strategies to control communicable diseases and prevent transmission, not using notification data to inform people of DAA treatment would be unethical. The point was also made that even if it was not envisioned or understood that notification data could be used for purposes other than its original intention, using it to increase people's access to hepatitis C treatment and care was absolutely justified. For example, one health department representative said, *"The more health benefit we can get from the [notification] data the better—I think it should be a dynamic, interactive thing rather than just data coming in and nothing being done with it"*.

> Ethically you could argue that health departments are holding this information that can have a direct impact, not only on an individual's health and public health, which is what [health departments] are all about, so that's a strong argument for going forward with this work (KI 9, health department representative)

> There are people like me, who were infected thirty-five years ago, who knew about the interferon treatment but were too scared or unable to undergo that treatment, so they've left it. And now they'll be at severe risk of dying because of hep C. So, for those people, yes, this is a really important thing. (focus group discussion #2)

One participant noted that if diagnosing clinicians had routinely assessed and offered treatment for all people who had been diagnosed with hepatitis C in the past, then it would be unjustifiable for a third party (such as a health department) to get involved. However, because many clinicians' past practice did not involve such routine procedures, it was considered justifiable that health departments could use notification data to reach potential treatment recipients.

Testing and treatment regimes

Several key informants and focus group participants, when asked if they believed using hepatitis C notification data to inform people of the newer hepatitis C treatments was justifiable, raised the issue of the *"old treatment"* (interferon-based) and lingering negative perception of them, including low rates of cure and severe and sometimes long-lasting side effects. Many described their own or others' challenging experiences of receiving interferon-based treatment and how they believed this was a barrier that prevented them or others accessing DAA treatments. As a result, some participants supported the idea of using notification data to contact people with hepatitis C because they believed it would be an opportunity to provide accurate information about the newer treatment (including its improved efficacy and tolerability and shorter duration).

Most key informants knew that some people have been told they have chronic hepatitis C on the basis of a positive antibody test alone, and that a significant number of these people have not been followed up with RNA testing. Because notifications are largely based on positive antibody test results, this was considered further justification for the use of surveillance data—to ensure these individuals have follow-up RNA testing. Given around 30% (15–45%) of people infected with hepatitis C spontaneously clear the virus without treatment, the fact that many people believed they were chronically infected on the basis of an antibody-positive result was presented as further ethical justification for a proposed initiative, by providing an opportunity to promote RNA testing amongst these individuals.

> There's a database there and a new treatment is available… Do you think people would want to know if they had cancer, that a new treatment is available? You know, I think they would. (focus group discussion #2)

> This is not just about the individuals, it's also about the families, there's a large subset of the population that's impacted […] It's time. Use this opportunity. Throw it out in the open. Yes, it's an illness, and it's an illness that can be cured. (focus group discussion #2)

"We can prevent suffering and save lives"

An ethical rationale raised by some key informants for using surveillance data to locate people diagnosed with hepatitis C and link them to treatment services was that some people in the community have been unknowingly tested for hepatitis C, had never received a test result, and were potentially unaware they were living with hepatitis C. This is of particular significance given that people with hepatitis C can remain asymptomatic or have non-specific symptoms for decades after they acquire the infection, and as a consequence are less likely to seek out or be offered hepatitis C testing. As some participants highlighted, by the time someone becomes symptomatic it is likely that they already have chronic liver disease, a harm that could have been prevented with earlier treatment. Furthermore, it was noted that without treatment, some of these people will go on to develop serious liver damage including cirrhosis, liver failure and/or liver cancer. One key informant explained that historic notification data represents an opportunity to prevent liver cancer at a population level, and suggested that explaining the initiative as *"a liver cancer prevention program, no different to mammography, no different to bowel cancer screening"* may go some way towards alleviating stigma.

Some participants with lived experience of hepatitis C expressed their support for a proposed initiative based on its potential to prevent undue long-term suffering for individuals with hepatitis C and their families. Furthermore, as one participant who received interferon-based treatment two decades ago but was not cured (and had endured painful side effects in the process) said, "*it's not only a matter of like saving your life [but] what it's saving you from is potentially years of really horrible health*". This sentiment was shared by several participants who had been treated for hepatitis C, including one participant who had continued to experience long-term side effects of interferon-based treatment. They believed the use of hepatitis C notification data to increase people's access to DAA treatment was absolutely justified if it meant others would not have to experience the ill effects of chronic liver disease.

Amongst participants with lived experience of hepatitis C, the financial implications for governments of people living in the community with untreated hepatitis C (including the potential that some eventually need a liver transplant) was considered an important rationale for a proposed initiative. One participant who had acquired hepatitis C more than two decades previously, and had received two liver transplants, described how much government funding they believed could have been saved had he been treated when he was initially diagnosed. The few key informants that mentioned financial implications were more reserved, emphasising that retrospective case finding is expected to be resource intensive and therefore cost-effectiveness would need to be evaluated.

Stigma and discrimination

Although ethics were used as a basis to support using notification data to locate people with hepatitis C to inform them about DAAs and link them to treatment services, ethical concerns were also identified. Many participants were concerned about rights to privacy and confidentiality, and the potential that the initiative could expose individuals to stigma and discrimination.

> My hunch is that when things are this highly criminalised and stigmatised, people will be highly frightened by what they see as the government trying to contact them. (KI 16, consumer organisation representative)

All key informants and focus group participants shared their concern that because the proposed initiative targeted an already stigmatised group, there was potential for stigma to be exacerbated if particular care was not taken to minimise this risk.

In both focus groups, participants with lived experience were concerned about the commonly made association between hepatitis C and injecting drug use, and the assumptions that if a person has hepatitis C they inject drugs or have done so in the past, and that people who inject drugs necessarily have hepatitis C. Several participants stated that for people who inject drugs, the criminalised nature of injecting created fear and mistrust of government, which could affect how people felt about being contacted by government health departments. Some health department representatives also noted that for some, the potential of being contacted about an old hepatitis C diagnosis may trigger feelings of internalised stigma and shame associated with their hepatitis status.

Many people with lived experiences of injecting drug use and/or hepatitis C described how they felt they had been treated differently by health professionals (including clinicians and methadone-provider pharmacy staff) once their hepatitis C status had been disclosed. This was identified as a perceived barrier that prevented others from accessing DAAs and encouraged people to keep their status hidden from friends, families and health service providers.

Privacy and confidentiality

Many focus group participants (especially those with more recent experience of injecting drug use) were surprised to hear about the longstanding requirement that any person receiving a hepatitis C diagnosis in Australia be told by their diagnosing clinician that their personal details will be provided to state or territory health authorities. In one focus group that included many people with a recent history of injecting, several participants reported that they would be outraged and angered if they received a phone call from a clinician (via a medical clinic or jurisdictional health department) about DAAs, because they were unaware that their personal details were held by jurisdictional health authorities.

Several described how they had "*opted out*" of sharing their health information online (My Health Record) due to a lack of confidence and trust that government would keep this data secure and confidential. For example, when one focus group participant discovered that the health department already had his personal details, he said, *"yeah, I'd be like, what the fuck! People know I've got hep C! What's going on?"* The fact that many focus group participants were unaware that hepatitis C was a notifiable disease (or indeed what this meant) was an issue raised by consumer organisation representatives. It was their concern that a potential negative outcome of this approach would be to deter people from presenting for

> The potential harms of contacting people are] anger and fear that governments have the ability to trace your whereabouts, cross with your doctor for sharing the information, won't go for further follow up because of the above reasons and less likely to access treatment in the future. (KI 15, consumer organisation representative)

hepatitis C testing if they were aware that health departments held an identified database of people who had tested positive for hepatitis C.

The risk of the wrong person being contacted because notifications data contact details are out of date or incorrect was seen to have the potential to undermine individual privacy. Similarly, there was a concern that even if the correct person was contacted, information could be intercepted by a family member, partner or friend, which could also place the individual at risk of stigma and discrimination.

A suggestion from some key informants for reducing at least some of these risks was to pilot an approach that targets more recent notifications where contact information is more reliable. This pilot could evaluate the yield as well as the demographic characteristics of those contacted, and if the yield was deemed to be acceptable, the project could proceed further back in time in a stepwise process until the yield diminished. As one key informant noted, however, whilst this approach makes sense, it does mean that those who are most at risk of the impact of chronic liver disease as a result of hepatitis C will be targeted last.

> If I got notified through the bloody health department I'd freak […] but I also think it needs to happen, like I know people might get angry, but isn't it more important that we save people's lives? (focus group discussion #2)

Nevertheless, all stakeholders agreed that the potential use of hepatitis C notification data to locate people diagnosed with hepatitis C, in order to inform them about DAAs and link them to treatment services and care, was justified. They agreed that even if it was not possible to differentiate people with chronic hepatitis C from those who had cleared the infection or were treated since the original notification was made, the harms to individual health by not attempting to contact people outweighed the potential harm of some people being contacted unnecessarily.

3.3 Policy analysis

In Australia, the surveillance of communicable diseases, including hepatitis C, is conducted at state and territory level through primary reporting and collation of notifications, and at national level to monitor trends in communicable diseases. Public health legislation enables the collection of personal information accompanying disease notification at the state and territory level and sharing of deidentified information to the Commonwealth for the purposes of national-level surveillance.

Australia publishes a national hepatitis C strategy every three to four years. Most states and territories develop an action plan or strategy for specific communicable diseases that are largely structured around the targets of the national strategies, with actions to reflect priorities within their jurisdiction.

Content analysis of both legislation and hepatitis C strategies sought to draw insights into the mandate of governments to implicitly or explicitly prioritise actions to achieve hepatitis C elimination targets. Analysis of legislation specifically focused on laws associated with the collection of health data and on the objectives and principles of each Act related to the collecting notification data and permitted purposes for the use and disclosure of personal information. In addition, where available[9], hepatitis C or BBV strategies and action plans were analysed according to stated priorities for the use of notification data.

Australia

Legislation: Notifiable diseases

At the federal level, the *National Health Security Act 2007 (Cwth)* mandates the establishment and maintenance of the *National Health Security (National Notifiable Disease List) Instrument 2018 (Cwth)* and the collection of notification data. All state and territory health ministers signed the *National Health Security Agreement* in 2008 (an instrument under the Act) which commits to a “robust surveillance and reporting system” (p. 1). This enables the sharing of information between the states and territories and the Commonwealth related to communicable diseases, and recognises that the primary responsibility for public health responses lies with the governments of the states and territories.

Division 5 of the *National Health Security Act 2007* enables the implementation and maintenance of the *National Notifiable Disease List*. One or more cases of any disease listed on the *National Notifiable Disease List* is considered to be a “public health event of national significance” for the purposes of the *National Health Security Act 2007.* Hepatitis C is one of 65 diseases on the *National Health Security* (*National Notifiable Disease List) Instrument 2018* (Cwth)[10].

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[9] Tasmania and South Australia did not have strategies at the time of review.

[10] For details of case definitions at a national level see Appendix 5.

Table 1: Australian legislation related to hepatitis C notification systems

Jurisdiction	Legislation
National	*National Health Security (National Notifiable Disease List) Instrument 2008* *National Health Security Act 2007* *National Health Security Agreement 2011* *Privacy Act 1988*
Australian Capital Territory	*Public Health Act 1997* *Public Health (Reporting of Notifiable Conditions) Code of Practice 2017 (No 1)*
New South Wales	*Public Health Act 2010* *Public Health Regulation 2012*
Northern Territory	*Notifiable Diseases Act 1981* *Public and Environmental Health Act 2011*
Queensland	*Public Health Act 2005* *Public Health Regulation 2018*
South Australia	*South Australian Public Health Act 2011* *South Australian Public Health (Notifiable and Controlled Notifiable Conditions) Regulations 2012*
Tasmania	*Public Health Act 1997* *Guidelines for Notifying Diseases and Food Contaminants (2016)*
Victoria	*Public Health & Wellbeing Act 2008* *Public Health and Wellbeing Regulations 2019*
Western Australia	*Public Health Act 2016* *Public Health Regulations 2017*

Legislation: Privacy and use of personal information

Information (including personal information[11]) may be disclosed under certain circumstances prescribed by the *National Health Security Act 2007 (Cwth)*. These prescribed circumstances are authorised for the purposes described in the Australian Privacy Principle 6 of the *Privacy Act 1988 (Cwth)*[12].

The *Privacy Act 1988 (Cwth)* seeks to protect and promote the privacy of Australians and regulates how Australian Government agencies and some private sector organisations use personal information. Under this Act, health information is sensitive information and is afforded greater protections as a result. This Act establishes 13 privacy principles which must be adhered to. The Australian Privacy Principle 6 (APP 6) is particularly noteworthy in relation to the use of diseases notification data. Under this principle, sensitive information cannot be used or disclosed for another (secondary) purpose that differs from the primary reason/purpose that such information was collected, except under certain circumstances, such as if consent has been obtained from the individual, the individual would reasonably expect their information to be used or disclosed in this way, or in other permitted circumstances.

Each state and territory, except for Western Australia and South Australia[13], has their own privacy legislation (see Tables 2 and 3). This legislation protects the privacy of personal information (this may include health information in some jurisdictions) held by state governments, agencies or Ministers. Similar to the Commonwealth Privacy Act, most allow for disclosure of personal information in circumstances that are directly related to the primary purpose of information collection, or when the disclosure is required to lessen a threat to someone's life or health, and in other prescribed circumstances. New South Wales, Victoria and the Australian Capital Territory also have separate legislation which covers the privacy of health records held by state governments, including health departments and public hospitals (see Table 2).

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[11] 'Personal' information is not the same as 'health' information. Under the *Privacy Act 1988* (Cwth) health information is considered sensitive information and is thus afforded greater protections.

[12] As cited in the legislation: "This subsection constitutes an authorisation for the purposes of other laws, such as paragraph 6.2(b) of Australian Privacy Principle 6."

[13] In WA some privacy principles are covered under the *Freedom of Information Act 1992* while in SA the privacy of personal information is protected under the Information Privacy Principles.

Table 2: Privacy legislation in Australia

Jurisdiction	Privacy Legislation
National	*Privacy Act 1988*
Australian Capital Territory	*Information Privacy Act 2014* *Health Records (Privacy and Access) Act 1997*
New South Wales	*Privacy and Personal Information Protection Act 1998* *Health Records and Information Privacy Act 2002*
Northern Territory	*Information Act 2002*
Queensland	*Information Privacy Act 2009*
South Australia	*No specific privacy legislation*
Tasmania	*Personal Information and Protection Act 2004*
Victoria	*Privacy and Data Protection Act 2014* *Health Records Act 2001*
Western Australia	*No specific privacy legislation*

Table 3: Mandate of Commonwealth and State Privacy Legislation

	Commonwealth	States and territories	
Legislation	Privacy Act 1988	Privacy legislation (except SA and WA)	State health record legislation (ACT, NSW, VIC)
Organisations and agencies subject to the legislation	Commonwealth agencies, private health organisations*	State government departments – may include other private organisations	State government departments and agencies, public and private health services
Type of information covered by the legislation	Personal and sensitive information including health information	Personal including health information in some jurisdictions	Health information

*Some private organisations will be subject to both the Commonwealth Privacy Act and Health Record legislation if it exists in that jurisdiction.

Frameworks and strategies

Australia's approach to communicable diseases, including hepatitis C, is underpinned by the *National Framework for Communicable Disease Control* (Commonwealth of Australia, 2014). The framework establishes broad principles to achieve a nationally coordinated and strategic approach to the management of communicable diseases. Aligned to this framework are discrete national strategies for HIV, hepatitis C, hepatitis B and sexually transmissible infections, with a strategy for blood-borne viruses and sexually transmissible infections amongst Aboriginal and Torres Strait Islanders.

The *Fifth National Hepatitis C Strategy 2018-2022* (hereafter *National Hepatitis C Strategy*) (Commonwealth of Australia, 2018) outlines key national actions to improve testing, diagnosis and treatment of people with hepatitis C and is used as a guide for states and territories for developing their own strategies or action plans. The *National Hepatitis C Strategy* offers implicit support for the use of notification data to identify people with hepatitis C, by stating the importance of "finding everyone who is currently undiagnosed, partially diagnosed (no confirmatory test) and/or not engaged in active management of their hepatitis C" (p. 24), through a range of approaches, including active case-finding strategies. In addition, this strategy supports approaches to complete confirmatory testing, increase the number of people who are diagnosed and ensure appropriate treatment uptake, especially amongst priority populations. The *National Hepatitis C Strategy* also identifies opportunities to improve patient management systems to support the prompt identification and treatment of people with hepatitis C.

Recognising Aboriginal and Torres Strait Islanders as a priority population and over-represented amongst people with hepatitis C, a separate strategy guides national action in this population in a culturally aware manner. The *Fifth National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2018-2022* (Australian Government, 2018) (including an associated Action Plan) recognises the need for culturally respectful testing and treatment and data collection to ensure more complete data on patients' Aboriginal and Torres Strait Islander status and that systems enable "active patient management… to reduce 'loss to follow up'" (p. 21). In addition, the Strategy considers the importance of collaborative approaches to respond to data collection and surveillance of BBVs.

State and territory governments are responsible for the operation of custodial settings. There is no national strategy for addressing hepatitis C in prisons in Australia. However, in 2005, the Australian Government, via the then Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis, developed guidelines for custodial settings (*Hepatitis C*

Prevention, Treatment and Care: Guidelines for Australian Custodial Settings [Department of Health, 2014][14]), that recommend offering voluntary testing of hepatitis C to all people in custodial settings.

States and territories

Public health legislation

The collection of information about people with notifiable diseases and the maintenance of notifiable disease registers is mandated under public health legislation in each state and territory, or in the case of the Northern Territory (NT), under a specific Act for notifiable diseases (*Notifiable Disease Act 1981).* Public health legislation also includes more general issues that relate to notifiable diseases, such as establishing the authority of the Chief Health Officer in each jurisdiction, needle and syringe programs and the licensing or regulation of premises that provide services that involve invasive procedures such as acupuncture, tattooing and piercing. Stated objectives of public health legislation in each state and territory are to protect, promote and improve public health, including facilitating ways to detect, manage and control of infectious diseases.

Hepatitis C is a notifiable disease in each state and territory under the relevant legislation. However, state and territory legislation does not distinguish between antibody-positive and RNA-positive diagnoses. All positive diagnoses, regardless of whether a person has an active hepatitis C infection, must be reported.

Most of the reviewed Acts include guiding principles which follow on from the objectives of each Act and are important in their “application and interpretation”[15] (Australian Law Reform Commission, 2020). In addition, the Victorian Law Reform Commission states that guiding principles “provide guidance not only to decision makers, but also speak to community expectations and standards, and provide a picture of the broader policy context underpinning the relevant legislation” (Victorian Law Reform Commission, 2020).

For the Acts which do state guiding principles, the most common principle is the precautionary principle, that is, “a lack of full scientific certainty should not be used as a reason for postponing measures to prevent, control or abate” a public health risk[16]. In addition, most Acts provide specific guiding principles in relation to notifiable diseases. Commonly, these principles establish both the rights (or entitlements) and responsibilities of a person who has or may have a notifiable disease. In SA, Victoria (VIC), Western

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[14] The webpage for this reference was last updated in 2014.

[15] Although this reference is in the context of sexual offences, the meaning is the same.

[16] Other common principles include proportionality, equity, participation and collaboration.

Australia (WA), Queensland (QLD) and the Australian Capital Territory (ACT) these rights include the right to privacy, dignity and the right to receive information about the disease and any associated treatment (*South Australian Public Health Act 2011 s14; Public Health & Wellbeing Act 2008 [VIC] s111; Public Health Act 2016 [WA] s88; Public Health Act 2005 [QLD] s66; Public Health Act 1997 [ACT] s99*).

While not all legislation explicitly states the purpose of disease notification or maintaining disease registers, public health legislation in New South Wales (NSW) and Queensland state their purpose as enabling follow-up, care and treatment, while in Victoria the purpose is to support "monitoring, surveillance, investigation or intervention"[17] of a person with a notifiable disease (*Public Health Act 2010 (NSW)* s97:1a; *Public Health Act 2005 (QLD)* s68; *Public Health & Wellbeing Regulation 2019 (VIC) s90b*).

All states and territories describe in their public health Act, or associated regulations, who is required to submit a notification if they reasonably believe that someone has or may have a notifiable disease. Most require either a medical practitioner, laboratory or hospital CEO to submit a notification to the Chief Health Officer in the relevant jurisdiction. However, the ACT requires notifications from a broader range of professionals, including counsellors, nurse counsellors, social workers or a person responsible for the care, support or education of a person (*Public Health Act 1997 (ACT) s105*).

The information required with the notification and the timeframe in which the notification must be submitted are frequently described in regulations under the relevant Act and often determined by the classification of the notifiable disease under the Act or associated regulations. For example, in Victoria, hepatitis C is classified as a notifiable condition that requires written notification within five business days, as opposed to other notifiable conditions that require notification as soon as practicable (*Public Health and Wellbeing Regulations 2019 (VIC)*.

Notifications of hepatitis C commonly require identifiable information to be collected as part of the notification. This often includes the patient's name, date of birth and address. This identifiable information may differ based on the classification of the disease under the regulations. For example, in NSW category 5 diseases of which only HIV is listed, must not include identifiable information, whereas hepatitis C is considered either a category 2 or 3 disease, and as such identifiable information about the patient must be collected.

In terms of disclosure of identifiable information, various circumstances are detailed across the Acts, with a consistent theme that the disclosure must relate to a purpose prescribed

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[17] This is for notifications that require a timely rather than an urgent response.

under the Act or relate to a matter in the public's interest and adhere to guiding principles (if any). Jurisdictions including the ACT, SA, Tasmania and WA state that disclosure may be permitted for the purposes of disease prevention and control such as investigation, follow-up and/or treatment (*Public Health Act 1997 (ACT)* s109*; South Australian Public Health Act 2011* s99; *Public Health Act 1997 (Tas) s147; Public Health Act 2016 (WA) s298)*.

Hepatitis C strategies and action plans

At the state and territory level, current strategies and policy documents are publicly available in all jurisdictions except for Tasmania and SA (see Table 4). As these states do not have current strategies or action plans, it is difficult to determine their priorities regarding the use of notification data.

All available strategies and policy documents recognise the importance of robust testing procedures and ensuring people are diagnosed and treated to reduce hepatitis C transmission and incidence. The level of detail differs substantially, with some, such as the ACT and NT strategies, focusing on setting targets for hepatitis C testing, diagnosis and treatment, while others set out more comprehensive approaches and strategies for these outcomes.

The *NSW Hepatitis C Strategy 2014-2020* (NSW Ministry of Health, 2014) and *Victorian Hepatitis C Strategy 2016-2020* (Victorian Government, 2016) both state the importance of the respective Ministry/Department of Health contacting the diagnosing clinician following a notification of hepatitis C to ensure appropriate assessment, treatment, follow-up and referral of that patient. Similarly, the *Queensland Hepatitis C Action Plan 2019-2022* (Queensland Health, 2019b) notes the need for contact following a notification, and is the only jurisdiction that specifically considers the importance of re-engagement with people notified with hepatitis C prior to July 2016 to enhance uptake of DAA treatment.

Within the ACT and WA strategy documents, it is less clear whether the use of notification data for follow-up is supported. However, the *Western Australia Hepatitis C Strategy 2019-2023* (Department of Health, 2019) notes opportunities to identify and lower barriers at the institutional, regulatory and system level to testing and treatment of hepatitis C and considers the potential to improve "patient management systems [and] conducting patient recall". No further detail is provided about the objective of patient recall and the time period in which such recall could occur. Similarly, the ACT's *Hepatitis B, Hepatitis C, HIV, and Sexually Transmissible Infections ACT Statement of Priorities 2016-2020* (ACT Governmment, 2016) makes no mention of the use of notification data to locate and contact with people with hepatitis C. It does, however, note that hepatitis C clinical and treatment data are limited in their scope, and identifies an opportunity to assess such data “to better inform and evaluate policy and activities in this area”.

Table 4: Australian strategies and action plans relating to hepatitis C notification systems

Jurisdiction	Strategies and action plans
National	*National Hepatitis C Testing Policy (2012)* *National Framework for Communicable Disease Control (2014)* *Fifth National Hepatitis C Strategy 2018-2022 (2018)* *Fifth National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2018-2022 (2018)* *Hepatitis C Prevention, Treatment and Care: Guidelines for Australian Custodial Settings (2014)*
Australian Capital Territory	*Hepatitis B, Hepatitis C, HIV, and Sexually Transmissible Infections ACT Statement of Priorities 2016-2020 (2016)* *Strategic Framework for the Management of Blood-Borne Viruses in the Alexander Maconochie Centre 2013-2017 (2013)*
New South Wales	*NSW Hepatitis C Strategy 2014-2020 (2014)*
Northern Territory	*Northern Territory Sexually Transmissible Infections and Blood Borne Viruses Strategic and Operational Plan 2019-2023 (no date)*
Queensland	*Queensland Hepatitis C Action Plan 2019-2022 (2019)* *Queensland Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Action Plan 2019–2022 (2019)*
South Australia	*South Australian Prisoner Blood Borne Virus Prevention Action Plan 2017-2020 (2017)*
Victoria	*Victorian Hepatitis C Strategy 2016-2020 (2016)* *Justice Health Communicable Disease Framework (2017)* *Korin Korin Balit-Djak Aboriginal Health, Wellbeing and Safety Strategic Plan 2017-2027 (2017)*
Western Australia	*Western Australia Hepatitis C Strategy 2019-2023 2(019)* *Western Australia Prisons Drug Strategy 2018-2020 (2018)*

Aboriginal and Torres Strait Islander people

Queensland is the only jurisdiction that has a specific strategy or action plan that addresses hepatitis C amongst Aboriginal and Torres Strait Islanders, although the planning/development of a Victorian strategy/plan is currently underway. The *Queensland Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Action Plan 2019–2022* (Queensland Health, 2019a) addresses the importance of improving the collection of Aboriginal and Torres Strait Islander status to support surveillance of BBVs and sexually transmissible infections and achieving testing, diagnosis and hepatitis C treatment targets amongst this population.

Health and wellbeing strategies and frameworks relating to Aboriginal and Torres Strait Islanders were also reviewed to identify any linkages with hepatitis C. The *Victorian Korin Korin Balit-Djak Aboriginal Health, Wellbeing and Safety Strategic Plan 2017-2027* (Department of Health and Human Services, 2017) was the only framework or plan to specifically set targets for “hepatitis C treatment and other prevention, screening, testing and treatment options” (p. 70) of Aboriginal and Torres Strait Islander people. Other plans are either under development (SA) or only address general key principles for improving Aboriginal and Torres Strait Islander health and wellbeing and make no mention of viral hepatitis or BBVs (WA, NT, and NSW).

People in custodial settings

Policy documents relating specifically to BBVs or hepatitis C in prison populations differ greatly between jurisdictions. Publicly available documents relating to BBVs or hepatitis C in custodial settings could only be found for SA, Victoria, WA or the ACT.

The South Australian Prisoner Blood Borne Virus Prevention Action Plan 2017-2020 (Department of Correctional Services & Department of Health and Ageing, 2017) sets clear proposed actions such as the implementation of an opt-out approach to hepatitis C testing, enhanced recording of all tests conducted, exploring opportunities for rapid testing, and ensuring treatment uptake of inmates with hepatitis C. In addition, this Strategy notes an opportunity to participate in the strengthening of the national surveillance system and reporting procedures. In Western Australia, the *Prisons Drug Strategy 2018-2020* (Department of Justice, 2018) has established targets to increase the number of optional screening tests of BBVs and provide DAAs, thus seeking to reduce the incidence of hepatitis C in the prison population. Similarly, in Victoria, the *Justice Health Communicable Disease Framework* (Department of Justice and Regulation, 2017) includes actions to promote screening for BBVs for all prisoners upon entry and when transferring to a new prison site. The framework also recognises the value of an electronic health record in supporting policy development and conducting clinical audits. In the ACT, the *Strategic Framework for the Management of Blood-Borne Viruses in the Alexander Maconochie Centre 2013-2017* (ACT Government, 2013) covers the only prison in the territory. This framework seeks to achieve increases to screening, testing, diagnosis, and treatment of prisoners to reduce morbidity and mortality associated with BBVs.

4. Summary of findings

This formative research aimed to explore the potential for using Australian notification systems to increase access to hepatitis C treatment and accelerate hepatitis C elimination in Australia. The perspectives of people affected by hepatitis C and other sector stakeholders were sought to assess acceptability and understand the logistical and ethical issues associated with following up people recorded on hepatitis C notifications databases. A policy analysis was undertaken to better understand how public health legislation and policies relating to disease notification and the use of notification data may support or impede the use of these data to enhance hepatitis C treatment uptake. This involved a review of national and jurisdictional strategic documents to identify content supporting the use of notifications data for this purpose.

Members of affected communities and key informants who participated in this study indicated strong support for using notifications data to follow up people diagnosed with hepatitis C to ensure their awareness of and enhance access to hepatitis C treatment, and that retrospective case finding should go as far back as possible. Key informants perceived such activities as aligned with the primary purpose for which notification data was collected (i.e., to protect the health and safety of the community). Although all participants acknowledged people’s right to access information that had the potential to reduce their risk of serious disease or even death, there was also recognition that this must be balanced against people’s right to privacy and confidentiality. To protect these rights and minimise individuals’ exposure to stigma and discrimination, the findings therefore suggest every attempt must be made to avoid information reaching unintended recipients, and that wherever possible, unnecessarily contacting people (including those who have since been treated for hepatitis C, have spontaneously cleared the virus, are terminally ill or have died since a notification was made) should be avoided.

Key informants and affected community participants raised a range of practical considerations for achieving these ends. The likelihood that notification data contact information stored by state and territory health departments is incomplete or inaccurate, particularly for older notifications, was a concern. In addition, although data linkage was generally considered an appropriate means to rectify this problem, concerns were raised about it being labour intensive, costly and perceived by the community as intrusive. Our findings, therefore, suggest that if data linkage processes are used, at a very minimum, government departments from whom contact details are sought should not be made aware that a person may have hepatitis C. Despite participants sharing diverse views about the most appropriate person/organisation to contact individuals (e.g., health department staff, diagnosing clinicians or clinician currently providing care), their unanimous view was that contact via telephone call would protect people's privacy and confidentiality better than text message or postal mail. Importantly, there was also consensus that those contacting individuals must have the knowledge and expertise to conduct this role skilfully, respectfully and with specific hepatitis C knowledge (including an understanding of the sensitivity of health information related to hepatitis C and the importance of privacy and confidentiality in this context), and that all persons contacted should be given the opportunity for prompt follow-up for RNA testing, treatment and care.

Our policy analysis found that in accordance with the guiding principles of public health legislation in the ACT, Victoria, WA, SA and QLD, a person with a notifiable disease has the right to receive information or be supported to make an informed decision about the disease and receive any associated treatment. Our findings, although highlighting that Queensland is the only jurisdiction (to date) to identify as a priority re-engagement with people who had a notification made before 2016 to support linkage to care (within the state hepatitis C action plan), show that other jurisdictions and the Commonwealth, via their strategies and action plans, have demonstrated broad sport for active case-finding strategies and other approaches that improve hepatitis C testing and treatment uptake. That three states explicitly state that one of the purposes of maintaining disease registers or requiring notifications is to support follow-up, care and treatment (QLD and NSW) and investigation and intervention (VIC) provides evidence that the use of notification data for patient and community benefit is justified and consistent with public health legislation. Indeed, our findings suggest that the use of notification data for the purpose of increasing people's access to DAA treatment does not conflict with privacy legislation or principles in any state or territory, provided that its use relates directly to the primary purpose of data collection and adheres to the permitted reasons for disclosure prescribed within the legislation.

5. Implications and actions

Our findings highlight the potentially significant individual, community and health systems benefits that could be achieved by following up notifications to inform and enhance access to hepatitis C treatment for people diagnosed with hepatitis C. We recommend the following actions in order to progress policy and practice to better utilise hepatitis C notifications to enhance treatment access and help achieve Australia's hepatitis C elimination targets:

- Undertake further national community and stakeholder consultations to establish agreement on acceptable approaches to using HCV notification data for follow-up
- Implement a national consultation process with Aboriginal and Torres Strait Islander organisations and communities to determine acceptable and effective approaches to using HCV notification data to follow up Aboriginal and Torres Strait Islanders diagnosed with hepatitis C, including notifications emerging from Aboriginal Community Controlled Health Services
- Use the findings from this review of Australian legislation and policies related to the use of notifications data as the basis for further consultation with state and territory health departments, with the aim of reaching consensus on the permissible use of hepatitis C notifications data for follow-up
- Work with state and territory governments to identify and address operational and technical challenges to undertaking effective hepatitis C notification follow-up
- Implement and evaluate hepatitis C follow-up projects that align with existing state and territory activities and operating environments to identify optimal strategies for using HCV notifications data to enhance treatment uptake
- Establish systems that use hepatitis C notifications and other related data to create sustainable national evaluation and reporting frameworks to monitor and guide Australia's progress towards hepatitis C elimination.

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Appendix 1: Detailed focus group participant information

In March 2016, the Australian Government provided unrestricted access to direct-acting antivirals (DAA), through the Pharmaceutical Benefits Scheme (PBS), to all people with hepatitis C over the age of 18 years. This treatment has significantly improved cure rates, patients are experiencing few side effects, hepatitis C transmission is being reduced, and deaths from liver cancer/other liver diseases are being prevented. When access to DAAs was obtained in Australia, it was estimated 220,000 Australians were infected with chronic hepatitis C. Between 2016-2018 it is estimated that 74,600 people have received DAA therapy, which is over one third of the total of those infected. Of concern is that the number of people accessing treatment has fallen from an average of 3,400 treatment initiations per month in March to November 2016, to an average of 1,300 initiations during 2018. While various interventions have been implemented to reduce structural barriers to accessing the newer hepatitis C treatment, and promote treatment to people with hepatitis C (e.g., testing/treating people in prisons and at pharmacies administering OST, and skilling up health care professionals in the community, to screen/treat people), the use of jurisdictional notification systems has been mostly unexplored. Hepatitis C is a notifiable infection in all Australian states/territories with medical practitioners &/or pathology services required by law to notify the local health department of a patient's hepatitis C diagnosis. Of specific relevance to this project, the data collected through the notification process includes name, date of birth, residential address, and phone contact details.

Project objectives

This project aims to determine the potential of increasing peoples accessing to the DAA treatment in Australia, by using notification data (held by state/territory governments) to inform people previously diagnosed with hepatitis C, who have not accessed treatment, that a cure is available, and how to access it. We acknowledge the potential for hepatitis C notifications data to accelerate hepatitis C elimination, and the perceived concerns of using identifiable data by state and territory health departments to contact people diagnosed with hepatitis C. Thus, we are seeking to understand perceptions of people with hepatitis C and other public health sector stakeholders about balancing individual privacy versus the right to be informed about treatments that can reduce risk of serious disease, including liver cancer. In particular we aim to:

- Examine whether people with hep C likely to find it acceptable to be contacted by third party (to be determined) to promote access to hep C treatment, using info. provided to health department notification systems
- Review the regulation, systems and processes used by state and territory health departments to collect and store notification data, including the implications of privacy legislation within each jurisdiction; and
- Identify potential legislative/procedural barriers to contacting people previously notified with hepatitis C infection

Project components

Key informant interviews: with key informants (incl. representatives of organisations whose constituents include people with hepatitis C and/or people who inject drugs, and professionals with public health and blood borne virus expertise working in public health services, government and/or research sectors.

Focus groups: with staff, volunteers and peer workers of Harm Reduction Victoria and volunteers of Hepatitis Victoria to explore the issues related to the potential of using notification data to contact people about the newer hepatitis C treatment and how they can access it. Focus groups will explore the ethical/practical issues of such an approach, including:

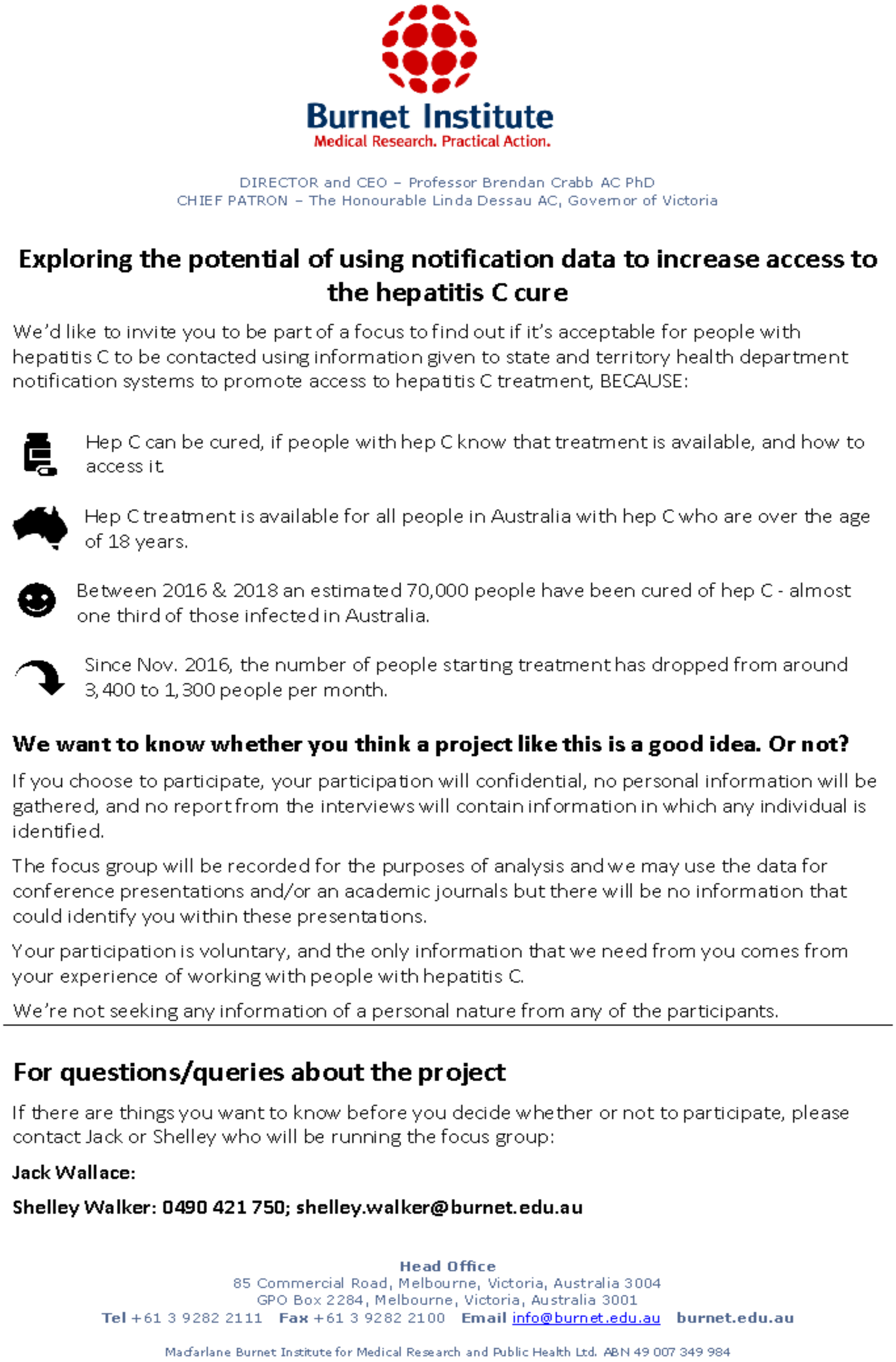
- Impact of stigma, discrimination, shame, and privacy related to hepatitis C notification and/or injecting drug use.
- The impact of these issues on people's willingness to be contacted (i. e. confidentiality), and if there are ways of reducing the potential harms associated with this contact.
- What would be the most acceptable method/s for being contacted? (e.g., postal mail, phone, email), and by whom? (e.g., researcher, peer, government worker, medical professional)

Environmental scan: of Australian state/territory governments to identify individual methods used to collect/store/use hepatitis C notification data, privacy legislation affecting storage of and access to such data, any legal implications related to accessing this data, and the completeness of the data, particularly in relation to accessing collected contact information.

Project investigators

Prof. Margaret Hellard, Burnet Institute, Principal Investigator; Prof Mark Stoové, Burnet Institute; Dr Joe Doyle, Burnet Institute; Dr Peter Higgs, La Trobe University; Dr Jack Wallace, Burnet Institute; Dr Alisa Pedrana, Burnet Institute; Prof Carla Treloar, University of New South Wales (UNSW); Melanie Walker & Jude Byrne, Australian Injecting & Illicit Drug Users League (AIVL); Helen Tyrrell, Hepatitis Australia; Prof Rebecca Guy, Kirby Institute, UNSW; Shelley Walker, Burnet Institute; Ned Latham, Burnet Institute.

Appendix 2: Summarised focus group participant info.



Burnet Institute
Medical Research. Practical Action.

DIRECTOR and CEO – Professor Brendan Crabb AC PhD
CHIEF PATRON – The Honourable Linda Dessau AC, Governor of Victoria

Exploring the potential of using notification data to increase access to the hepatitis C cure

We'd like to invite you to be part of a focus to find out if it's acceptable for people with hepatitis C to be contacted using information given to state and territory health department notification systems to promote access to hepatitis C treatment, BECAUSE:

Hep C can be cured, if people with hep C know that treatment is available, and how to access it.

Hep C treatment is available for all people in Australia with hep C who are over the age of 18 years.

Between 2016 & 2018 an estimated 70,000 people have been cured of hep C - almost one third of those infected in Australia.

Since Nov. 2016, the number of people starting treatment has dropped from around 3,400 to 1,300 people per month.

We want to know whether you think a project like this is a good idea. Or not?

If you choose to participate, your participation will confidential, no personal information will be gathered, and no report from the interviews will contain information in which any individual is identified.

The focus group will be recorded for the purposes of analysis and we may use the data for conference presentations and/or an academic journals but there will be no information that could identify you within these presentations.

Your participation is voluntary, and the only information that we need from you comes from your experience of working with people with hepatitis C.

We're not seeking any information of a personal nature from any of the participants.

For questions/queries about the project

If there are things you want to know before you decide whether or not to participate, please contact Jack or Shelley who will be running the focus group:

Jack Wallace:

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Macfarlane Burnet Institute for Medical Research and Public Health Ltd. ABN 49 007 349 984

Appendix 3: Key informant interview guide

Opening rapport. Confirm has had opportunity to read letter including key points:

- Participation is voluntary
- Request that interview be recorded for later note taking
- Aggregate interview data may be used in conference presentations/academic

turn on recorder

Background

Work currently being done in UK and NYC, using historical notification data to contact people.

The potential to conduct a health systems study aiming to use hepatitis C notification data stored by state and territory governments to identify and inform people diagnosed with hepatitis C that a cure is available, and how to access this cure

Relates specifically to historical/existing notification data, not enhanced surveillance re new cases

Ethical implications

For this first question, I'd like you to set aside any legal considerations and assume that it is possible to contact people using hepatitis C notification data.

When, if ever, do you think it is justified to contact people who have been notified as having hepatitis C sometime in the past?

What are some of the negative possible effects of contacting people? How could these be addressed? Does it matter how long-ago notifications were made? How far back is it reasonable to go? Why?

If it were not possible to accurately differentiate between people who still have chronic hep C from those who had cleared the infection or were treated since original notifications were made, should contact still proceed?

Practicalities

What are the practical barriers that you foresee to the overall concept of contacting people using historical notification data?

If a trial of contacting people using notification data was to proceed, how do you think these barriers could be overcome?

Who should be contacted? (The case themselves, the person that ordered the original hepatitis C test, a clinician that saw the person recently [assuming this could be ascertained])

Who would be the best person to make contact with the case?

- Someone from the health department?
- The clinician that ordered the test.
- Someone from one of the hepatitis NGOs; e.g. a nurse from hepatitis AU

Assuming cases were to be contacted directly, at one point does this become unjustifiably intrusive? How intensive should efforts contact people be?

- Letter? Phone call? Text message?
- Do you think it would be reasonable to use data matching for the most up to date contact details?

Regulatory and legal implications (for relevant stakeholders only)

- the methods used to collect and store hepatitis C notification data
- the legislation affecting the storage of, access to and use of hepatitis C notification data
- the completeness of the data, particularly in relation to accessing collected contact information

Anything else?

Appendix 4: Focus group interview guide

Introduction

- Brief information about the Hepatitis C Notification Data Project
- Introductions by workers and about the Burnet Institute
- Confirm participants understand the purpose of the focus group
- Request that interview be recorded for later note taking
- All data will be de-identified
- Invite verbal consent
- Time frame (expect will run for 45-60 minutes)
- Data may be used in conference presentations/reports

  turn on recorder

Background

More detailed information about the Project:

- Explain the notification system (what data is collected and by whom, where the data is stored and for what purpose) – what happens when someone receives a positive diagnosis.
- About the newer treatment (DAAs) – PBS funded, 95-98% effective, few side-effects.
- In Australia, b/w 2016 & 2018, estimated 70,000 people cured (1/3 of those infected). Since Nov 2016 the number of people starting treatment has dropped from around 3,400 to 1,300 people per month. In order to increase the rate of people treated, one idea is to use the notification data system to follow-up with people (diagnosed in the past) to let them know about the newer treatment and how they can access it.
- We'd like to hear your views/perspectives on this idea.

Prompts

If you (or your friend) had hepatitis C, had been diagnosed a number of years ago, and had not been treated (or had unsuccessfully received Interferon treatment), how do you think you/they would feel about being contacted by someone, to let them know about the DAA treatment available via Medicare, had few side effects, and was 95-98% effective in curing the infection?

If so, what would be the best way to be contacted? (e.g. letter, phone call, text)?

- Who would you most like to receive this information from? (e.g. medical practitioner [GP, medical clinic nurse, government organisation, contact tracing nurse, harm reduction/hep C positive peer worker)?
- What things need consideration? (e.g. privacy, confidentiality, stigma)

If not, why not?

- What are the biggest concerns, and are there things that would convince you otherwise?
- Impact of stigma, discrimination, shame (injecting drug use/hep C diagnosis)
- Are there ways of reducing the potential harms associated with this contact?

Anything else?

Appendix 5: State & territory policy document summaries

AUSTRALIAN CAPITAL TERRITORY

In the ACT the *Public Health Act 1997* and the *Public Health (Reporting of Notifiable Conditions) Code of Practice 2017 (No 1)* enable the notification of notifiable diseases. Section 99 details specific principles in relation to notifiable conditions such as reducing the public health effects of a notifiable disease. In addition, a person who has a notifiable disease under this Act has the right to privacy and the right to receive information about the notifiable disease and any treatments provided that these rights do not "infringe unduly on the wellbeing of others". Under this Act doctors and nurse practitioners are responsible for providing the patient with information about the disease, how it is transmitted, arrange for counselling to occur (if applicable) and provide the patient with anything else that is required by the Chief Health Officer.

Section 209 of the *Public Health Act 1997* covers the circumstances in which the use of notification information can occur. Such circumstances include: the prevention and control of notifiable conditions in the Territory and elsewhere; the prevention and control of risks to public health generally in the Territory and elsewhere; research related to public health in the Territory and elsewhere. The use of notification data must be used in accordance with the principles of section 99 and the objectives of the Act as stated in section 4. *The Code of Practice* provides further information for the use of notification information and states that "unless authorised, a person may not disclose personal information to any person not involved with the investigation or follow-up of a disease notification."

Strategy documents

In terms of the Territory's stated priorities, the *Hepatitis B, Hepatitis C, HIV, and Sexually Transmissible Infections ACT Statement of Priorities 2016-2020* articulates a number of specific targets relating to testing and treatment to reduce the incidence of hepatitis C. While the Strategy makes no mention of using notification data to make contact with people with hepatitis C, it does note that clinical and treatment hepatitis C data are limited in their scope and identifies an opportunity to assess such data "to better inform and evaluate policy and activities in this area". While this statement is somewhat vague it may provide implicit support for the use of historical notification data to follow up patients.

In the ACT, the *Strategic Framework for the Management of Blood-Borne Viruses in the Alexander Maconochie Centre 2013-2017* covers the only prison in the territory. While this framework is now outdated, it seeks to achieve increases to screening, testing, diagnosis and treatment of prisoners to reduce morbidity and mortality associated with blood-borne viruses.

NEW SOUTH WALES

Under Schedule 1 of the *Public Health Act 2010* hepatitis C is classified as a category 3 condition in the state of New South Wales. The health and safety of the public is 'to be the paramount consideration in the exercise of functions under this Act'. This legislation allows for a public health or disease register to be established and maintained for the care, treatment and the follow up of a person who has or may have been exposed to a notifiable disease (s97 (1a)). Identifiable information may be disclosed in certain circumstances (s130) including if consent from the person has been obtained, if the disclosure is related to this Act and any associated regulations, if approval has been granted by the Chief Health Officer (for epidemiological data) or in ‘other prescribed circumstances’ (130e).

Strategy documents

The *NSW Hepatitis C Strategy 2014-2020* notes an opportunity to “implement strategies to reduce undiagnosed hepatitis C infections.” The Strategy also considers opportunities to “prompt appropriate education, care, referral, testing and contract tracing by diagnosing clinicians” and support general practitioners, nurses and primary care providers to identify people with hepatitis C and promote linkage to care. No mention is made of using notification data to promote uptake of DAA treatment, although it is noted that the strategy was written before the broad access of DAAs.

NORTHERN TERRITORY

Legislation differs in the Northern Territory with notifiable diseases legislated under the *Notifiable Disease Act 1981* rather than specific public health legislation. The *Public and Environmental Health Act 2011* does not address notifiable diseases; however, it does establish objectives to protect and promote the health of people in the Territory and enable special action to protect people from public health risks. The only principle that this Act requires regard to is the precautionary principle, that is, that a ‘lack of full scientific certainty should not be used as a reason for postponing measures to prevent, control or abate the risk’.

Under the *Notifiable Disease Act 1981*, hepatitis C is considered a transmittable disease. Section 10 requires a medical practitioner to advise the person about the notifiable disease, measures to prevent the spread of disease and information about the treatment. A medical officer can direct the person (in writing) to carry out measures required to treat or prevent the spread of the disease (s11). The Chief Health Officer (by notice in the Gazette) may also require that specific people attend for medical examination or may be required to answer questions to determine if they have an infectious disease (s14).

Section 27 of the *Notifiable Diseases Act 1981* enables a register to be kept by the Chief Health Officer. No further detail is provided about the use of information collected as part of this register other than secrecy should be preserved when a person is carrying out duties under this Act.

Under the *Public and Environmental Health Act 2011* health information may be used for monitoring, protecting or promoting public health. Section 112 allows disclosure of information as part of administration of the Act, if consent from the person has been obtained or for statistical purposes that does not identify individuals. In addition, the Chief Health Officer may authorise the disclosure of health information for a stated purpose, if efforts are taken to protect the privacy of individuals. Examples include for research purposes or ensuring the accuracy of the health information register (s112 (3)).

Strategy documents

The *Northern Territory Sexually Transmissible Infections and Blood Borne Viruses Strategic and Operational Plan 2019-2023* is not as comprehensive as other states. The document is primarily focused on setting targets for testing, diagnosis and treatment with a priority focus on people in prison, outpatient clinics and rehabilitation centres. The document uses the number of people diagnosed, number on treatment, number engaged in care, number cured as performance measures to achieve these goals. No mention is made about the use of notification data to make contact or follow up with people with a hepatitis C diagnosis.

QUEENSLAND

The *Public Health Act 2005* mandates the notification of certain diseases and enables a register of notifiable diseases to be stored in the state of Queensland. The *Public Health Regulation 2018* classifies hepatitis C as a controlled notifiable condition for the purposes of the *Public Health Act 2005*. As stated in section 65 'an appropriate balance between the health of the public and the right of individuals to liberty and privacy' should be considered in relation to notifiable conditions. Section 66 establishes the rights of people who are at risk, who may have or currently have a notifiable condition such as the right to be protected from discrimination, the right to have privacy respected and be supported to make informed decisions about medical treatment. It is also noteworthy that one of the purposes of a notifiable disease register established under this Act is to enable a person to undergo examination or treatment for a disease (s68).

In terms of disclosure and use of personal information, section 77(1) states that a person must not disclose confidential information, however, information may be disclosed if it is to the person whom the information relates (section 79c) or for the purposes of case finding (section 80). In addition, under section 81 confidential information may be disclosed if it is in the public interests. In this circumstance the Chief Executive must authorise the disclosure in writing and it must be detailed in an Annual Financial Report (without such providing confidential information). Section 84 allows information to be provided to the Commonwealth, or a State entity provided it is in the public's interest and the information provided is only used in the way it was agreed.

Action Plans

The *Queensland Hepatitis C Action Plan 2019-2022* explicitly states the need for contact following a notification to the Notifiable Conditions System of a newly acquired or unspecified hepatitis C infection to ensure linkage to care and treatment. In addition, this is the only state or territory policy document that explicitly states the need to develop protocols to re-engage with people notified with hepatitis C prior to July 2016 to enhance linkage to care and uptake of effective DAA treatment. The Action Plan also notes an opportunity to change notification criteria to focus on diagnoses based on positive RNA rather than prior exposure.

Queensland has also published the *Queensland Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Action Plan 2019–2022.* However, this document is primarily focused on the collection of information regarding Aboriginal and Torres Strait Islander status and achieving targets in terms of diagnosis and treatment amongst this population.

SOUTH AUSTRALIA

Hepatitis C is classified as a controlled notifiable condition under the *South Australian Public Health (Notifiable and Controlled Notifiable Conditions) Regulations 2012* for the purposes of the *(2011).* The *South Australian Public Health Act 2011* provides the legislative framework for the notification of specific diseases and contaminants. This Act does not describe the purpose of a notifiable disease register however it provides a comprehensive list of the rights and responsibilities of a person who has a notifiable disease including the right to privacy, confidentiality, and dignity, to be free of any discrimination (other than what is 'reasonably necessary' for public health) as well as the opportunity participate in decision-making processes and be able to make an informed decision about their medical treatment.[1]

In terms of disclosure of medical and personal information, under section 99 a person is authorised to disclose personal information as part of official duties in a number of circumstances. Disclosure can occur if it is at the request or with consent of the person who the information relates. Information can also be provided to a health service provider if it is required for the treatment, care or recovery of the person. Other circumstances involve the disclosure of information if it is required "to lessen or prevent a serious threat to the life, health or safety of a person or a serious threat to public health".

Strategies, frameworks and action plans

South Australia does not have a current hepatitis C strategy with the last implementation plan expiring in 2018. It is therefore difficult to determine South Australia's explicit priorities in regard to the use of notification data for follow up of people with hepatitis C. However, the South Australian Communicable Disease Control Branch does reference the *National Blood Borne Viruses and Sexually Transmissible Infection Strategies* in coordinating policy and programs across the state.

South Australia does not have a blood borne virus or hepatitis C strategy specific to Aboriginal and Torres Strait Islanders, and South Australia's Aboriginal and Torres Strait Islander health framework or plan is currently under development. However, South Australia has developed the *South Australian Prisoner Blood Borne Virus Prevention Action Plan 2017-2020* which may provide some implicit support for this project. This comprehensive action plan includes objectives such as the implementation of an opt-out approach to hepatitis C testing, enhanced record keeping of all tests conducted, exploring opportunities for rapid-testing and ensuring treatment uptake of inmates with hepatitis C. In addition, the Action Plan notes an opportunity to participate in the strengthening of the national surveillance system and reporting procedures.

TASMANIA

The *Public Health Act 1997* mandates disease notification and surveillance in Tasmania. There are no guiding principles stated under this Act. However, under section 50 a medical practitioner must provide a person who has or may have a notifiable disease with information about the transmission and prevention of that disease and other relevant information.

Section 147 details a number of circumstances in which disclosure of identifiable information about a person can occur. Of those relevant to the use of notification data includes; disclosure to a person involved in the diagnosis, clinical assessment, treatment or counselling to which the information relates (3b), a person in charge of any institution or facility which is involved in the clinical assessment, treatment or counselling of the person to which the information relates (3c), if it is required in the management, detection, notification, treatment or prevention of the spread of a notifiable disease (3ei) or for managing a threat to public health or a likely threat to public health (3eii).

Strategy documents

Tasmania does not have a publicly available hepatitis C strategy or action plan. The *Healthy Tasmania Five Year Strategic Plan* also makes no mention of blood-borne viruses or hepatitis C. It is therefore unclear what Tasmania's stated priorities are in regard to hepatitis C and the use of notification data.

VICTORIA

In Victoria the *Public Health & Wellbeing Act 2008 and Public Health and Wellbeing Regulations 2019* legislate the notification of certain diseases. Section 111 establishes a number of principles in relation to the management of infectious diseases. Of note is that 'the spread of an infectious disease should be prevented or minimised with the minimum restriction on the rights of any person' and a person who has or may have an infectious disease is entitled to receive information about the infectious disease and any available treatment and receive such treatment. Under this Act notifications for specified notifiable conditions requiring written notification (e.g. hepatitis C) are required for the purposes of 'monitoring, surveillance, investigation and intervention' (s90 b).

The *Public Health and Wellbeing Act 2008* allows for a person to disclose information to the Secretary, the Chief Health Officer or an authorised officer of the Department if the disclosure is required under the Act or associated regulations (s55). Disclosure of information is allowable to the Commonwealth or another State or Territory if it occurs under an agreement for the purpose of promoting and protecting public health.

Strategy documents and frameworks

The *Victorian Hepatitis C Strategy 2016-2020* states the importance of the respective Ministry/Department of Health contacting the diagnosing clinician following a notification of hepatitis C to ensure appropriate assessment, treatment, follow up and referral of that patient.

The Victorian *Korin Korin Balit-Djak Aboriginal health, wellbeing and safety strategic plan 2017-2027* was the only Aboriginal and Torres Strait Islander framework or plan reviewed which specifically set targets for hepatitis C screening, testing and treatment of Aboriginal people. The *Justice Health Communicable Disease Framework* also includes actions to promote screening for blood borne viruses to all prisoners upon entry and when transferring to a new prison site. The framework also recognises the opportunity of the electronic health record to support policy development and when conducting clinical audits but does not make mention of using notification data.

WESTERN AUSTRALIA

According to the *Public Health Regulations 2017* hepatitis C is classified as a notifiable infectious disease in Western Australia for the purposes of the *Public Health Act 2016*. This Act details a number of principles which should be adhered to when acting in accordance with this legislation. In particular, a person who has or may have a notifiable disease has the right to be provided with information about the disease and any medical treatment as well as the right to examination and treatment provided free of charge, if certain criteria are met. The *Public Health Regulations 2017* also enable authorised officers to request further information to *"*to assist in preventing, controlling or abating a public health risk that might foreseeably arise from the disease or condition".

Under section 298(2), 'specified information' collected in relation to a notifiable disease may be disclosed; for monitoring, preventing, controlling or abating a public health risk; for general protection, promotion or improvement of public health; for reporting purposes to the Commonwealth or States or for any other purpose relating to public health prescribed by the regulations.

Strategy documents

The *Western Australia Hepatitis C Strategy 2019-2023* primarily sets targets regarding hepatitis C testing, diagnosis and treatment. The strategy considers potential opportunities to identify and address barriers at the institutional, regulatory and system level to testing and treatment of hepatitis C. The Strategy also states the opportunity to engage with health care workers to identify and engage people with hepatitis C in treatment through "improving patient management systems [and] conducting patient recall". No further detail is provided about the objective of patient recall and the time period in which such recall could occur. Nevertheless, it appears to offer implicit support for the follow up of people with hepatitis C.

In addition, the Western Australia *Prisons Drug Strategy 2018-2020* has established targets to increase the number of optional screening tests of blood-borne viruses and provide DAAs thus seeking to reduce the incidence of hepatitis C in the prison population.

Appendix 6: Comparison of legislation relation to notifiable diseases in Australia

	Australian Capital Territory	New South Wales	Northern Territory		South Australia	Tasmania	Queensland	Victoria	Western Australia
LEGISLATION	Public Health Act 1997; and Public Health (Reporting of Notifiable Conditions) Code of Practice 2017 (No 1).	Public Health Act 2010; and Public Health Regulation 2012.	Notifiable Disease Act 1981.	Public and Environmental Health Act 2011	SA Public Health Act 2011; and SA Public Health (Notifiable & Controlled Notifiable Conditions) Regulations 2012.	Public Health Act 1997; and Guidelines for Notifying Diseases & Food Contaminants.	Public Health Act 2005; and Public Health Regulation 2018.	Public Health & Wellbeing Act 2008; and Public Health Wellbeing Regulations 2019.	Public Health Act 2016; and Public Health Regulations 2017.
OBJECTIVE OF ACT	Protect public from public health risks, monitor health indicators to generate information about health of population, to support design and implementation of public health policies and programs and ensure rapid response to public health risks (s4).	Promote, protect and improve public health; Control & prevent spread of infectious diseases and risks to public health & monitor diseases of public health importance; The health & safety of the public 'is to be the paramount consideration in the exercise of functions under this Act' (s3).	An Act to consolidate and amend the law relating to notifiable, infectious and other diseases, and for related purposes.	To protect and promote the health of people in the Territory and enable special action to protect people from public health risks.	Promote health and wellbeing of individuals and communities, to provide for prevention, or early detection, management and control of diseases and allow monitoring of a disease to support prevention and early detection (s4).	Protect and promote the health of communities in the State and reduce the incidence of preventable illnesses.	Protect and promote the health of the QLD public (Act).	Recognise State's role in protecting and promoting public health and wellbeing of the public; Aims to achieve the highest attainable standard of public health and wellbeing.	Protect, promote and improve the health and wellbeing of the public of WA and reduce the incidence of preventable illness, and for related purposes (s3).
GUIDING PRINCIPLES OF ACT	Any actions that occur under this Act must be conducted in a professional and responsible way, with respect to a person's liberty and privacy (s4).	None stated.	None stated.	Precautionary principle, that is, that a 'lack of full scientific certainty should not be used as a reason for postponing measures to prevent, control or abate the risk'.	Precautionary principle, proportionate regulation (economic and social impacts are minimised in efforts to promote public health), sustainability, prevention, population focus, participation, partnership and equity (s6-13).	None stated.	Preventing, controlling and reducing risks to public health; providing for identification of, and response to, notifiable conditions; collecting and managing particular health information, and establishing mechanisms for health information held by health agency to be accessed for appropriate research (s7 of Act).	Evidence-based decision-making, precautionary principle, primacy of prevention, accountability, proportionality collaboration.	Sustainability, the precautionary principle, proportionality, intergenerational equity and a principle for Local Government (s3).

Appendix 6: continued

	Australian Capital Territory	New South Wales	Northern Territory		South Australia	Tasmania	Queensland	Victoria	Western Australia
Guiding principles regarding notification	Reducing the public health effects of a notifiable disease. A person who has or may have contracted a notifiable condition has responsibilities under the Act. A person who has a notifiable disease under this Act has the right to privacy and the right to receive information about the notifiable disease and any treatments provided that these rights do not “infringe unduly on the wellbeing of others” (s99).	None stated.	None stated.	None stated.	A person with a controlled notifiable condition has the right to privacy, confidentiality, and dignity, to be free of any discrimination (other than what is ‘reasonably necessary’ for public health), the opportunity participate in decision-making processes and be able to make an informed decision about their medical treatment (s14).	None stated.	Spread of notifiable conditions should be prevented/ minimised without infringing on a person’s liberty or privacy. People at risk of contracting or who may have a notifiable condition has responsibility to reduce spread and confirm diagnosis (if applicable). Anyone at risk of, or has a notifiable condition also has right to be protected from discrimination, have privacy respected and be supported to make informed decisions about medical treatment (s66).	The spread of an infectious disease should be prevented or minimised with the minimum restriction on the rights of any person A person who has or may have an infectious disease is entitled to receive information about the infectious disease and any available treatment and receive such treatment (s111).	Personal liberty and privacy should not be unnecessarily restricted, and regard should be had in relation to principle of proportionality a person who has or may have a notifiable disease or is at risk of contracting a notifiable disease has the right to privacy, to be protected from discrimination, to be provided with information about the disease and any medical treatment as well as right to examination and treatment provided free of charge, if certain criteria met.
Classification of hepatitis C under legislation	Group B of notifiable conditions (Code of Practice).	Hepatitis C is a category 3 condition although all forms of acute viral hepatitis are considered category 2 (Act).	Transmittable disease.	None stated.	Controlled notifiable condition (Reg).	Notifiable disease (Guidelines).	Controlled notifiable condition (Reg).	Notifiable condition that requires written notification within 5 business days (compared to notifiable conditions requiring notification as soon as practicable).	Notifiable infectious disease.

Appendix 6: continued

	Australian Capital Territory	New South Wales	Northern Territory		South Australia	Tasmania	Queensland	Victoria	Western Australia
Purpose of notification or register	None stated.	A register may be established and maintained for the purposes of care, treatment and the follow up to people who have or have been exposed to notifiable disease (s97(1a).	A register may be kept by the Chief Health Officer (s27).	A health information register may be kept by the Chief Health Officer (s65).	None stated.	None stated.	Supply data to support monitoring and surveillance; identify people who have contracted a notifiable condition and enable Cwth, State or local govt to take action to prevent & minimise spread of disease or enable a person to undergo examination or treatment (s68).	Notifications are required for the purposes of 'monitoring, surveillance, investigation and intervention' (s90 b).	None stated.
Notifying professionals and mode of notification	Doctor, nurse practitioner, pathologist, hospital CEO (if in-patient). Counsellors, nurse counsellors, social workers or a person responsible for care, support or education of person if they believe a person has or may have a notifiable disease to the Health Protection Service within 5 days (s102-105).	Medical practitioners if it is a category 2 condition, laboratories if category 3 (Reg).	Medical practitioner or person in charge of a laboratory (s8 and s16).	None stated.	Notification to the Communicable Disease Control Branch by medical practitioners, pathology services or another responsible person described under the Regulations.	Medical practitioners, laboratories, and hospitals. The notification must be submitted by the end of the next working day via telephone or facsimile to notify the Director of Public Health or a Public Health Officer.	Doctor, person in charge of a hospital, director of a pathology laboratory (Act s70-73).	Medical practitioners and pathology services must provide the notification to the Department of Health and Human Services.	Medical practitioner, nurse practitioner or responsible pathologist must notify the Chief Health Officer if they believe that a person has or may have a notifiable disease via the Communicable Disease Control Directorate if in the Perth Metropolitan area, or regional Public Health Units in regional areas within 72 hours.

Appendix 6: continued

	Australian Capital Territory	New South Wales	Northern Territory		South Australia	Tasmania	Queensland	Victoria	Western Australia
Personal information required for notification	Preference to receive the person's full name. The Report of Notifiable Condition or Related Death Form contains fields for further information about patient including Aboriginal and Torres Strait Islander status and information about the diagnosis and other relevant information for the notifiable disease.	Patient's name, date of birth, address, diagnosing doctor, a mobile phone contact, medical condition, mode of transmission and risk factors (Reg).	Patient's full name, date of birth, address, telephone number, Aboriginal and Torres Strait Islander status, clinical details and information about the treating doctor or hospital (Gazette).	None stated.	The patient's name, age, gender, address and contact details, Aboriginal and Torres Strait Islander status, mode of (suspected) transmission, details around the diagnosis of hepatitis C as well as the doctor's name and contact details.	Notification of hepatitis C requires the person's full name, gender, date of birth, telephone number, usual residential address and Aboriginal and Torres Strait Islander status, information about disease and diagnosis and contact details about the laboratory and treating medical practitioner.	None stated.	The patient's name, date of birth, sex, Medicare number, address, Aboriginal and Torres Strait Islander status, clinical information, risk factors and information about the reporting medical practitioner.	Name of notifiable disease as well as patient's name, residential address, telephone numbers, email address, date of birth, country of birth and gender, mode of transmission and the basis for diagnosis (Act and Regulations).
Other relevant information	Doctors and nurse practitioners responsible for providing patient with information about the disease and how transmitted, arrange for counselling (if applicable) and provide patient with anything else required by Chief Health Officer.	Medical practitioners must keep records for seven years (Reg).	Medical practitioner must advise person about notifiable disease, measures to prevent spread of disease and information about treatment (s10); A person can be required to undergo treatment to prevent spread of disease (s11); Chief Health Officer (by notice in Gazette) may require people attend for medical examination or answer questions to determine if they have an infectious disease (s14).	None stated.	Chief Public Health Officer under Act can require a person to undergo a medical examination, tests, counselling, education or another action deemed necessary to control spread of a notifiable disease.	Medical practitioner must provide information about transmission and prevention of that disease and other relevant information (s50). Director of Public Health may serve a notice requiring a person to 'submit to clinical assessment, medical treatment or counselling'(42(d).	Notification must be provided within 48 hours to Chief Executive by fax, email or other electronic means following a pathological diagnosis.	Disclosure of information can occur to the Secretary, the Chief Health Officer or an authorised officer of the Department if the disclosure is required to exercise a power, or perform a duty or function, under the Act or the associated regulations (s55). Information can be disclosed to the Commonwealth or another State or Territory if it occurs under an agreement for the purpose of promoting and protecting public (s56).	Authorised officers to request further information "to assist in preventing, controlling or abating a public health risk that might foreseeably arise from the disease or condition"; Chief Health Officer can make orders for tests, medical examination and counselling to a person with a notifiable infectious disease.

Appendix 6: continued

	Australian Capital Territory	New South Wales	Northern Territory		South Australia	Tasmania	Queensland	Victoria	Western Australia
Allowable circumstances for use and disclosure of notification information	For prevention and control of notifiable conditions in the Territory and elsewhere; for prevention/control of risks to public health generally in the Territory and elsewhere; For research related to public health in the Territory and elsewhere. Information must be used in accordance with principles of section 99 and objectives in section 4 (s109). The Code of Practice states, “unless authorised, a person may not disclose personal information to any person not involved with the investigation or follow-up of a disease notification.”	If consent from the person has been obtained; If the disclosure is related to this Act and any associated regulations. If approval has been granted by the Chief Health Officer (for epidemiological data) or in ‘other prescribed circumstances’ (Act s130e).	A public sector employee must maintain secrecy in relation to information obtained under this Act (s29).	Health information may be used for monitoring, protecting or promoting public health. Disclosure of information as part of administration of the Act, if consent from the person has been obtained or for statistical purposes that does not identify individuals. The Chief Health Officer may authorise the disclosure of health information for a stated purpose, if efforts are taken to protect the privacy of individuals examples include for research purposes or ensuring the accuracy of the health information register (s112[3]).	If at the request or with consent of the person who the information relates. Information can be provided to a health service provider if it is required for the treatment, care or recovery of the person. If it is required “to lessen or prevent a serious threat to the life, health or safety of a person or a serious threat to public health” (s99).	To a person involved in the diagnosis, clinical assessment, treatment or counselling to which the information relates (s147 3b). A person in charge of any institution or facility which is involved in the clinical assessment, treatment or counselling of the person to which the information relates (s147 3c). If it is required in the management, detection, notification, treatment or prevention of the spread of a notifiable disease (s147 3e,i.) For managing a threat to public health or a likely threat to public health (s147 3e.ii.).	Information can be disclosed if it is to the person that the information relates. For the purposes of contract tracing. If it is in the public’s interests (this must be in writing and disclosed in an Annual Financial Report). Information can be provided to the Commonwealth, or a State entity provided it is in the public’s interest and the information provided is only used in the way it was agreed (Act s77-84).	To the Secretary, the Chief Health Officer or an authorised officer of the Department if the disclosure is required to exercise a power, or perform a duty or function, under the Act or the associated regulations (s55). To the Commonwealth or another State or Territory if it occurs under an agreement for the purpose of promoting and protecting public health.	For monitoring, preventing, controlling, abating a public health risk; for general protection, promotion or improvement of public health; for monitoring/evaluating effectiveness of measures taken to prevent, control or abate a public health risk; for medical or epidemiological research, whether conducted by persons who are public health officials or other persons; for funding, managing, planning, monitoring or evaluating public health services; any purpose relating to reporting, at State or Cwth level, on public health services; For any other purpose relating to public health prescribed by the regulations.

ABOUT EC AUSTRALIA

Eliminating hepatitis C as a public health threat in Australia by 2030 is the long-term goal of EC Australia.

By bringing together researchers and implementation scientists, government, health services and community organisations, EC Australia will support services to increase hepatitis C testing and treatment among key affected populations.

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