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HIV and hepatitis pre- and post-test discussion in Victoria

Consultation report
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Blood Borne Virus
Sector Development Program

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Executive summary

Global, national and Victorian targets have been set for the elimination of HIV, hepatitis B and hepatitis C as public health concerns by 2030. In 2017, the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University initiated a consultation which aimed to describe best practice in HIV, hepatitis B and hepatitis C pre- and post-test discussion in the Victorian context. Building on existing evidence, and guided by the *National Testing Policies*, the purpose of this consultation was to better understand the components of a quality testing encounter in the era of elimination, with particular emphasis on the non-medical needs of people around the time of testing and diagnosis.

The practice of blood-borne virus (BBV) pre- and post-test discussion emerged from the HIV response, which saw the evolution of a HIV-specific approach to testing discussions and the delivery of test results. Over time, as HIV treatments improved, and HIV was reframed as a chronic manageable disease, this approach to HIV testing was superseded by a more streamlined process which aimed to normalise HIV testing as part of general healthcare. The HIV testing experience has informed the development of best practice in testing for hepatitis C, but has had limited influence on the practice of hepatitis B test discussions.

Rates of testing and diagnosis must increase in order to achieve the goal of the elimination of HIV, hepatitis B and hepatitis C. The burden of BBVs is largely borne by people who experience stigma and marginalisation, specifically men who have sex with other men, people with a history of injecting drugs, and culturally and linguistically diverse communities. To some extent, testing has been normalised among these communities and among the services that target them. However, rates of late diagnosis remain unacceptably high across all three BBVs. Normalising HIV, hepatitis B and hepatitis C testing among both healthcare providers and the general community is an important priority for the Victorian BBV response. BBV testing will be normalised when all healthcare providers feel comfortable initiating testing as part of general healthcare, when they feel able to provide basic information in a non-judgemental manner, and when they know when and where to refer. BBV testing will be normalised in the general community when people accessing primary and community health services, regardless of their degree of BBV vulnerability, either expect to be asked about BBV testing or are comfortable and safe when it happens.

The goal of elimination is also dependent on an increase in the proportion of people with HIV and viral hepatitis who are linked into treatment and care. To achieve this, it is essential to look at ways of reducing the impact of stigma on the test experience. Stigma-sensitive practice involves health practitioners acknowledging that stigma and shame may significantly impact on peoples' experiences of being tested for BBVs. Stigma-sensitive practice involves consciously creating an environment where clients feel safe, where cultural context and identity are respected, and where confidentiality and privacy is maintained and preserved to the highest possible degree.

An important shift from provider-led questioning about risk and prevention to optional patient-led disclosure is underway in some testing settings. This is an important driver for the normalisation of BBV testing. Discussions about risk factors and risk practices can be highly sensitive. For

hepatitis C and HIV, the practices associated with transmission are often subjected to negative social judgement. Provider-led questioning about risk practices, even if the providers are peers, can exacerbate stigma and shame for patients, as well as create discomfort for test providers.

Specific skills and knowledge are needed to conduct effective prevention discussions in HIV and hepatitis C. These include an understanding of sexual and gender diversity, cultures of injecting drug use, and the strategies for reducing harms arising from unprotected sex or injecting practices. The value and acceptability of these discussions depends on whether the test provider is competent at stigma-sensitive practice, and is able to adapt to the social and cultural context of the individual being tested. Hepatitis B is stigmatised in many communities, and hepatitis B transmission and risk are widely misunderstood. It is important for information about hepatitis B transmission to be delivered in a manner that does not overemphasise sexual and drug using practices. Discussions about hepatitis B prevention are complex because they involve conversations about natural history, and the testing and vaccination of family members.

The focus of this consultation was to identify best practice in pre- and post-test discussion for HIV, hepatitis B and hepatitis C. A range of health and community providers and researchers discussed the fundamentals of best practice at length and provided a great many insights into the components of quality testing services. Importantly, most participants acknowledged that while best practice is a valuable notion, it is not attainable in all healthcare settings. Best practice, therefore, needs to be flexible enough to be able to fit into any setting where HIV, hepatitis B or hepatitis C testing may occur.

Pre-test discussions for HIV, hepatitis B and hepatitis C ideally contain most of the following: information about confidentiality and notification; consideration of the patient's capacity to give their informed consent; enquiry about testing history; a brief assessment of health literacy; plain language information about the virus; stigma-sensitive description or patient-led discussion about risk and transmission; information or discussion about the availability of treatment and support services in the event of a positive result; and details of when and how the result will be delivered.

Additional considerations for HIV pre-test discussion include: the importance of explaining the implications of the test window period; and the importance of discussing strategies and supports for managing a positive result with people who may have significant risk factors or concerns about the result.

Additional considerations for hepatitis C pre-test discussion include: addressing patient concerns arising from notification requirements; the value of describing hepatitis C as curable; the importance of explaining the difference between the hepatitis C antibody and RNA tests; an awareness that some people who inject have difficulty to access veins, and that non-conventional methods of accessing blood may be required.

Additional considerations for hepatitis B pre-test discussion include: the essential role that interpreters play in hepatitis B testing; the ethics relating to the nature of gaining informed consent in settings where numerous other tests are taking place; the provision of individually tailored and culturally relevant information about hepatitis B, risk and transmission.

The delivery of negative results should ideally include: the immediate delivery of the result, and the opportunity for the person to respond; re-explanation of the window period and discussion about the need for further testing; and a reminder that individual results are not indicative of the BBV status of partners or contacts.

The delivery of positive results occurs over several appointments, and the following should be considered as essential in the process of linkage or referral into to treatment and care: preparation prior to delivery, including locating printed information and contact details for support services; focusing on the non-medical and psychosocial needs of newly diagnosed people; providing reassurance but minimising the amount of information given on the day of diagnosis; stigma-sensitive provision of information about transmission, prevention and vaccination; discussion about personal, community and peer supports; and discussion about privacy, disclosure and contact tracing.

Additional considerations for the delivery of HIV positive results include: preparation for the significant emotional impact of HIV diagnosis; avoiding any physical examinations or blood tests on the day of diagnosis; the importance of focusing on support needs and referral to community and peer support; the timing and stigma-sensitivity of discussions about risk, prevention of onward transmission and contact tracing.

Additional considerations for the delivery of hepatitis C positive results include: correct information about whether the result is hepatitis C antibody or RNA positive, and information about further testing as required; explanation of available cure and the implications of untreated hepatitis C; and avoiding the assumption that the availability of cure diminishes the shock, stigma or shame arising from the diagnosis.

Additional considerations for the delivery of hepatitis B positive results include: culturally appropriate information and discussions, as chronic disease management is significantly impacted by culture; plain language explanation of hepatitis B natural history, transmission and vaccination, and an awareness that misunderstandings about hepatitis B transmission are common; that patient engagement with regular monitoring for cancer prevention is underpinned by an understanding of asymptomatic disease; awareness that laws and implications around disclosure are different around the world; conversations about family testing and vaccination are highly important for hepatitis B case finding but they are not urgent and need to be approached in a gentle and patient-led manner.

Introduction

Global, national and Victorian targets have been set to eliminate HIV, hepatitis B and hepatitis C as a public health concern by 2030. These ambitious goals have been established in response to significant developments in prevention and treatment technologies. These include major policy and practice shifts to prioritise testing and treatment in preventing HIV and hepatitis C transmission, and preventing liver cancer associated with untreated hepatitis B.

The National Blood Borne Virus (BBV¹) Strategies articulate the principles of a strategic coordinated response in HIV, hepatitis B and hepatitis C. Elimination targets will only be met if rates of testing and linkage to care for HIV, hepatitis B and hepatitis C are improved. The National Testing Policies, which aim to align with the National BBV Strategies, have been developed to inform health professionals involved in ordering and performing HIV, hepatitis B and hepatitis C tests. In addition to outlining who to test, which tests to order, and how to interpret results, the National Testing Policies give an overview of the steps involved in gaining informed consent and delivering test results. Both the National Strategies and the National Testing Policies are updated every few years.²

In 2017, the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University initiated a consultation, which aimed to describe best practice in HIV, hepatitis B and hepatitis C pre- and post-test discussion in the Victorian context. Building on existing evidence and the guidance provided by the National Testing Policies, the purpose of this consultation was to better understand the components of a quality testing encounter in the era of BBV elimination.

Literature review

This section outlines the history of the provision of systematic pre- and post-test counselling in relation to BBVs, and how practices have changed over time. This section draws out aspects of the principles contained in the National Testing Policies to illuminate some of the considerations and nuances in articulating good practice in pre- and post-test discussion. It summarises recent published evidence to contextualise what constitutes ethical testing, and some considerations for the process of normalising testing initiated by GPs (referred to as provider-initiated testing).

The application and uptake of pre- and post-test discussion cannot be generalised across HIV, hepatitis C and hepatitis B. While the goal of elimination has been applied to all these BBVs, and there are many instances that these viruses have been conflated [1-3], there are important differences. The literature reporting on the acceptability and impact of pre- and post-test

¹ The term blood-borne virus refers to HIV, hepatitis B and hepatitis C.

² The first National HIV Strategy was written in 1989, and has been updated 7 times. The first National Hepatitis C Strategy in 1999 and has been updated 4 times. The first National Hepatitis B Strategy was not written until 2010, and has only been updated once. This highlights that a coordinated public health response to hepatitis B is relatively new in Australia. The first National HIV Testing Policy was written in 2011 and has been updated 4 times. The first National Testing Policies for hepatitis B and hepatitis C followed in 2012, and both have been updated twice.

discussion is predominately HIV-related, with significantly fewer peer-reviewed articles reporting on the experience and practice of testing for hepatitis B and hepatitis C.

Evolution of pre- and post-test discussion

The practice of pre-test counselling and discussion emerged from the HIV response, and it has undergone a number of iterations over the last three decades. What began as a behavioural change intervention has evolved into a practice that primarily aims to link people into treatment and care [4-6].

Initially delivered by members of the affected community, HIV pre- and post-test discussions aimed to encourage behavioural change through the provision of prevention education and information [4-8]. In the absence of effective treatment, people being tested for HIV were counselled through the decision to undertake a test, and the likelihood and possible implications of a positive result. This specialised approach to HIV testing has been referred to as *HIV exceptionalism* [5, 6, 9]. This included providing information about the window period and possible need for retesting; offering STI testing and prophylaxis; personal information gathering such as sexual history and HIV testing history; prevention and risk reduction information [7]. Over time, as testing technology and treatment have dramatically improved, there has been a shift in discourse from counselling to discussion and most recently to gaining informed consent and normalisation of testing [5, 6].

Normalisation involves the repositioning of these viruses alongside other diseases and/or conditions requiring early diagnosis. One approach that is commonly recommended and implemented is to offer routine HIV and viral hepatitis screening to all people who have or report any risk exposure [10-12]. In doing this, normalisation is associated with increased testing rates, reduced barriers to testing and reduced stigma associated with HIV and viral hepatitis [8, 13, 14]. It relies on clinicians being competent to test and diagnose [6], and on people expecting to be tested [8]. There are a number of concerns in the literature about normalising HIV testing, particularly in regard to the impact on essential aspects of the pre- and post-test process: most notably gaining informed consent and confidentiality [6, 13, 14], which is discussed in the following section.

Towards best practice in pre- and post-test discussion

In Australia, National Testing Policies outline key principles of testing that are consistent across HIV, hepatitis B and hepatitis C testing. These testing policies are developed to support targets established in the National BBV Strategies. They set out frameworks for providing quality testing and address real or perceived barriers to testing. The most recent Victorian strategies (2017), in addition to prevention, testing and treatment targets, also set a target of 100% stigma reduction.

While the National and Victorian BBV Strategies set ambitious targets to reduce the impact of stigma, the Testing Policies offer little to address the stigma associated with injecting drug use and sexual practices, and the documented impacts of these phenomena on testing and healthcare access. The World Health Organization's guidelines on HIV and hepatitis C testing [15, 16]

explicitly articulate the link between testing needs and stigma. These guidelines embed testing within a human rights approach. As Easterbrook et al. [11] explain, a human rights approach:

gives attention to such concerns as health-related rights (accessibility, availability, acceptability, and quality of services), gender equality, and universal health coverage so that *testing and care is provided in a supportive environment free of stigma and discrimination*; expanded testing and access is fair and equitable; and testing is prioritised for those most at risk (page 5; emphasis added).

In Victoria there is a lack of guidance for GPs and other test providers on how to engage and conduct testing for these highly stigmatised viruses. There are also reports suggesting that there are discrepancies between understandings of what is contained in the National Strategies and practice [17]. Given there are many reports detailing how attitudes, conduct and other structural and interpersonal factors create barriers to testing, care and treatment [19-21], testing guidelines and other related resources are well placed to define more explicitly what constitutes best practice for BBV testing.

The pre-test experience

The most recent HIV Testing Policy (2017) marks a policy shift towards normalising HIV testing in Australia.

It notes that a detailed risk assessment is no longer an essential component of the pre-test experience [22]. This reflects the literature in that for some people who test frequently for HIV and hepatitis C, risk assessments and lengthy pre-test discussions have been reported as repetitive, unnecessary, and ineffective prevention interventions [20, 23, 24], especially when delivered within a clinical setting [24]. Gaining informed verbal consent from a person prior to testing is identified as best practice in all of the National Testing Policies as well as in the literature, [7, 9, 14, 25, 26]. In accordance with the Ahpra codes and guidelines, gaining informed consent relies on 'good medical practice' and:

*is a person's voluntary decision about medical care that is made with knowledge and understanding of the benefits and risks involved.*³

³ Good medical practice involves:

1. Providing information to patients in a way that they can understand before asking for their consent.
2. Obtaining informed consent or other valid authority before you undertake any examination, investigation or provide treatment (except in an emergency), or before involving patients in teaching or research.
3. Ensuring that your patients are informed about your fees and charges.
4. When referring a patient for investigation or treatment, advising the patient that there may be additional costs, which patients may wish to clarify before proceeding.

Accessed: <https://www.medicalboard.gov.au/codes-guidelines-policies/code-of-conduct.aspx> (3rd October 2017).

This means that the person being tested agrees to be tested, that they understand the testing procedures and the reasons for testing and are able to assess the personal implications of the test. The testing policies outline that obtaining informed consent should be tailored to an individual's gender, culture, health literacy and intellectual level. The Testing Policies acknowledge that interpreters may be required to ensure that the person understands the processes and implications of testing. However, in practice, there are indications that informed consent is not systematically gained [14, 27, 28], and that efforts to scale up rates of testing may impact negatively on this essential aspect of pre-test discussions [4, 13, 29-31]. Bell et al. (2016) in their recent review of HIV pre-test information, discussion or counselling, found that while there is a minimum standard of information to be provided prior to testing, there are differences in these documents regarding how much to facilitate discussions to prepare people for the possible implications of a result [23].

The provision of HIV and hepatitis C prevention information and the conduct of risk assessments have historically been situated in the pre-test discussion. With the advent of new rapid testing technology, and other models of testing (such as opt-out), the timing of conversations have largely been omitted altogether, or identified as more appropriately placed within the post-test discussion [17]. The effectiveness of prevention discussions has increasingly been linked to peer models of service delivery [24, 32, 33]. Models and approaches that respond to the range of social, structural cultural and logistical factors (including vein access, turnaround time for test results and cost) are more acceptable to men who have sex with men (MSM) and people who inject drugs [19, 28, 34].

The National Testing Policies recommend the use of 'professional judgment' to assess a person's capacity to provide informed consent [26, 35]. What constitutes professional judgement is left to the test provider's discretion, however there is some brief recognition of other factors that may shape the testing experience. For example, the HIV testing policy acknowledges that the relationship between the GP and patient is

'complex' [9] and recommends that people performing the tests require appropriate training. The hepatitis C testing policy includes a section on 'people with complex needs'⁴, and the hepatitis B policy acknowledges the importance of health literacy. In light of the well documented power imbalance between GPs and patients, and the literature highlighting how pre-test discussions have been systematically experienced as missed opportunities for the provision of prevention information, and support to prepare for a possible positive test [36], further tools and skills are required.

The impact of negative and stigmatised medical encounters on health seeking behaviour is well documented in the literature [13, 37]. The pre-test experience plays a vital role in whether a person returns for the test result, and engagement in treatment and care for HIV, hepatitis C or hepatitis B.

⁴ People with complex needs identified are people who are unconvinced by their test result, people who do not return for positive test results and post-mortem testing.

The post-test experience

In Australia, the post-test experience is referred to as *conveying test results*. This is a shift away from post-test discussion and is in line with policy and practice shifts to normalise HIV and hepatitis C testing, and increase the screening rates for hepatitis B. All guidelines support the delivery of a positive test result in person, however a negative result can be delivered over the phone, text message or email [9, 15, 25, 26]. In their review of post-test discussions, Bell 2016 et al. [17] suggest that the assessment of peoples' psychosocial supports and needs could be strengthened. The hepatitis B literature clearly suggests that both the pre- and post-test experience needs to be systematically improved to better respond to the cultural, linguistic and clinical needs of affected people [38-41]. While there is some literature describing positive experiences in hepatitis C testing [36], there are reports that testing is a missed opportunity for the provision of prevention education [36]. There are a number of reports in the literature highlighting the need for several post-test appointments [19, 21, 38, 39, 42]. These follow-up appointments are important to ensure that newly diagnosed peoples' mental health and educational needs are addressed and allow for the initial appointment to focus on their immediate needs.

Receiving a positive diagnosis for HIV or viral hepatitis remains an exceptional experience for many people, and for them counselling is still an important element of the pre- and post-test process [19, 21, 30]. Counselling has been linked to an increased connection to care, support and treatment; the provision of appropriate information; and supporting people to integrate a positive diagnosis and support in notifying partners [7, 21, 41, 43, 44]. Despite assumptions that regular testers (especially for HIV) have higher levels of knowledge, positive results are often unexpected, and people often require further counselling and support to integrate what it means to live with HIV and/or viral hepatitis [41, 45]. However, of the three policies, only the National HIV Testing Policy identifies that counselling may be required following the delivery of a positive test result.

Linking people directly into treatment and care is one of the primary objectives following a positive test result and is associated with higher levels of treatment [7, 21]. While linkage to care aims to reduce the impact of BBVs as public health concerns, the impact of these shifts at an individual and ethical level has been noted by a number of researchers [3, 14]. They argue that mobilising people to engage with treatment should not be positioned as an imperative as, in most cases, a diagnosis is not a medical emergency. Further, some suggest that the social, economic and political circumstances of affected individuals are an important consideration when testing is being offered or encouraged [14, 21].

Method

In 2017, ARCSHS initiated a consultation that aimed to describe best practice in HIV, hepatitis B and hepatitis C pre- and post-test discussion in the Victorian context. Key informants were identified by the BBV Sector Development Program at ARCSHS and invited to participate. A total of 40 people participated in face-to-face interviews, telephone interviews and focus groups in the first half of 2017. Most participants (33) nominated one BBV as the focus of their participation in this consultation. A total of 16 participants worked predominately in HIV, with eight in hepatitis B and nine in hepatitis C. The remaining seven participants contributed their knowledge and expertise about more than one BBV. Key informant professions were: allied health and community-based testing providers (n=11); clinical testing providers (n=6); education and workforce capacity building (n=5); community-based BBV organisations (n=9); and research and policy (n=9). The sample included people with lived experience of HIV and hepatitis C. It is unknown whether any participants had lived experience of hepatitis B, however several participants came from cultural backgrounds that have a higher hepatitis B prevalence.

Interviews took between 30 and 60 minutes, and focus group discussions lasted for three hours. They were conducted using a semi-structured interview guide. The guide sought to define best practice in the encounter between the healthcare provider and the person being tested, and to identify barriers to effective pre- and post-test discussion. Interviews and focus groups were recorded with the consent of participants, and notes from the recordings were thematically analysed.

The method employed to conduct this consultation resulted in a participant group of health and community practitioners who were highly engaged with BBV testing. This project did not seek to include the perspectives of generalist health and community practitioners, nor did it seek to consider best practice in post-occupational exposure incident testing. These are important limitations to this project.

Results

The themes and discussions of key informants are presented in three sections. Part One offers a discussion of five key themes underpinning best practice in pre- and post-test discussion in the elimination era. Part Two offers annotated checklists to guide the encounter between testing provider and patient/client prior to BBV testing, and some initial considerations of the needs of newly diagnosed people. Part Three summarises additional considerations in the pre- and post-test discussion that are specific to HIV, hepatitis B or hepatitis C.

Part One | Defining best practice in the elimination era

This section draws out what participants identified as being the key aspects of best practice in pre- and post-test discussion, and the general approach required to conduct ethical pre- and post-test discussions with communities affected by HIV, hepatitis B and hepatitis C.

Normalisation: BBVs as chronic diseases

This consultation provides important evidence that normalisation of testing, as described in the literature, is identified as a priority in the Victorian response to HIV, hepatitis B and hepatitis C. Normalisation was understood as being the integration of BBV testing into general preventative healthcare, and the acceptability of provider-initiated testing among both healthcare providers and the general community. Participants described the importance of the process of testing for HIV, hepatitis B and hepatitis C being the same as for any other chronic disease or condition.

Participants identified stigma as the primary force that constrains the normalisation of BBV testing. The negative social meanings associated with HIV and hepatitis C transmission were identified as powerful sources of interpersonal, institutionalised and internalised stigma. Hepatitis B stigma was described as arising mainly from communicability and fear of transmission, rather than from negatively judged risk behaviours and practices. Nonetheless, the stigma associated with BBVs was recognised as having a profound impact on individual health and wellbeing. BBV stigma was also conceived as extending to peoples' partners, contacts and families in a way that is fundamentally different to non-communicable chronic diseases.

Normalisation of testing was also associated with the minimisation of invasive and confronting questions about personal risk practices. This type of questioning was seen as a barrier to testing not only because it exacerbates stigma and shame for patients, but because it creates discomfort for test providers. While it was recognised that many test providers are highly skilled at discussing risk and risk practices in a non-judgemental manner, provider-led risk assessment was seen as having a limited role in provider-initiated testing in generalist healthcare settings.

Many participating clinicians perceived that recent biomedical advances in HIV and hepatitis C treatment and prevention have already changed the way the testing conversations are approached, adding significant momentum towards the normalisation of testing. Several participants expressed concern, however, that the public health momentum toward the virtual

elimination of BBVs may erode individual patient-centred care and standards of informed consent for testing.

Rapport and communication: 'Stigma-sensitive practice'

Throughout the interviews and focus groups, rapport and communication skills were described as the most important aspect of the testing encounter. Participants from clinical, community and research settings placed careful emphasis on aspects of rapport and communication which have the potential to increase engagement with testing and reduce the stigma and shame people may experience when being tested for BBVs, particularly HIV and hepatitis C. *Stigma-sensitive practice* has emerged as a key concept from this consultation.

Stigma-sensitive practice involves acknowledging that stigma and shame may significantly impact on peoples' experiences of being tested for BBVs. People being tested for BBVs often have experiences of marginalisation and they may face additional barriers in navigating services. Stigma-sensitive practice involves consciously creating an environment where clients feel safe and respected, and wherein confidentiality and privacy is maintained and preserved to the highest possible degree.

A range of clinical skills and approaches to stigma-sensitive practice were identified by participants. Stigma-sensitive practice involves acknowledging that testing can be a stressful experience and attending to any support needs that may arise. The use of open, reflective questioning when discussing risks was regarded as more valuable than the use of routine closed questions. Several participants described the value of test providers leaving gaps for patient questions, and of overcoming the discomfort of using silence to encourage patient insight or expression. Several participants reflected that good communication and rapport between the test provider and the patient often leads to family or network members presenting for testing.

Participants strongly emphasised the importance of patients being in control of the degree of disclosure. This could be achieved by ensuring that any discussion about individual risk history is patient-led, rather than led by the practitioner who is providing the test. Stigma-sensitive practice also demands an awareness of the importance of using neutral language that is free from judgement or suggestion that people are not taking responsibility for their health. For example, instead of asking, '*When did you last share injecting equipment?*' the test provider could ask, '*When was the last time you had to share?*'

It was generally acknowledged that the approach to testing, and the requisite communication and rapport-building skills differ depending on whether the test discussion is initiated by the patient or by the healthcare provider. Importantly, several participants also acknowledged the impact of stigma and shame on healthcare providers' willingness and ability to initiate testing, as well as their ability to effectively work with people requesting a test.

Increasing provider-initiated testing is central to reducing the proportion of people with BBVs that are undiagnosed. Participants identified a range of stigma-sensitive approaches to initiating testing as part of normal healthcare. These include respectful discussions about whether the test would be of value to the person, and plain language descriptions of the main risk factors. It was suggested that testing providers should be mindful about gauging patient reactions, and careful

about asking questions or using language that may be perceived as judgemental or punitive. Several participants highlighted the importance of building on peoples' motivations to protect their health and the health of others.

Models of service provision that incorporate peer workers, while not widespread, provide a ready example of stigma-sensitive practice. Peer workers are defined as health and community workers who openly share key characteristics, circumstances or life experiences with priority populations for BBVs [33]. Peer workers often work within innovative models of service delivery designed to meet the needs of target populations that aren't met by other services. Many participants, including peer workers, emphasised the importance of peer workers in HIV and hepatitis C testing services. Peer workers, and the services that employ them, were seen as being better able to build rapport, and to reduce the power imbalance between the service user and the service provider. Peer models were also associated with strengthening peer-to-peer communication about BBVs through social networks. Participants described the importance of peer workers in roles that may involve initiating testing, for example, primary health services for people who inject, or outreach HIV testing in sex on premises venues.

Best practice and best fit

The focus of this consultation was to identify best practice in pre- and post-test discussion for HIV, hepatitis B and hepatitis C. Participants clearly identified that there are some settings where best practice is both a realistic goal for service providers and a reasonable expectation of service users. These include settings that specialise in providing accessible services to priority populations, such as high lesbian, gay, bisexual, transgender and intersex (LGBTI) caseload GP clinics and sexual health services. These also include health and clinical services which incorporate peer workers in their model of care, or which actively seek to recruit people with lived experience related to BBVs. These services were described by many as having the capacity to develop and sustain models of care that meet the needs of priority populations, and the capacity to build a workforce that is highly competent and skilled at engaging those populations in testing, care, treatment and prevention.

Many participants felt very strongly that it is unrealistic to expect every healthcare provider in Victoria to deliver best practice BBV testing as standard of care. To increase access to testing among priority populations, and normalise testing among providers, the focus needs to shift beyond best practice. Several participants expressed concern that too much emphasis on best practice in BBV testing results in inadequate focus on mitigating, or working within, the real-world constraints across the healthcare sector.

It was recognised by participants that part of articulating *best practice* is acknowledging the role of *best fit* in normalising BBV testing in constrained environments. One of the key barriers identified during the consultation were time constraints. Participants reported a perception among providers that BBV testing discussions take more time than is available. Several participating GPs drew attention to the overwhelming time pressures that exist in primary care which can result in the omission of BBV testing from general practice. Other participants described constraints related to working with patients and clients that have multiple competing

health needs including: new migrants; refugees and asylum seekers; pregnant women; and people experiencing social isolation or marginalisation, substance use or mental ill-health. Clinicians working with these populations noted that the value of BBV testing was often measured against a range of other tests and processes, and time was allocated according to relative priority. A need was identified by several participants to convey to healthcare providers that any time allocated to discussing BBV testing is highly valuable, even if only a couple of minutes.

Testing in the margins

The burden of HIV, hepatitis B and hepatitis C is largely borne by people who experience many different forms of marginalisation. This section presents a summary of some of the considerations, as identified by participants, for best practice in testing among people and communities who are affected by BBVs.

People who inject drugs

People who inject drugs, or who have injected in the past, are the population most affected by hepatitis C in Australia. Injecting is also a risk factor for HIV and hepatitis B, although to a much lesser degree. Following the 2016 listing of curative hepatitis C treatments on the PBS, the emphasis in the current hepatitis C response is on the elimination of hepatitis C. Supporting current injectors to access and complete hepatitis C treatments is central to elimination.

Participants frequently talked about the need to support healthcare providers, particularly GPs, in building skills to work effectively with people who inject. While recognising that not all injecting is problematic, participants noted that hepatitis C testing may not always be a high priority for people who inject drugs. There may be other issues which require sensitivity or prioritisation including: experiences of trauma; refugee experiences; homelessness; mental illness; problematic substance use; a history of imprisonment; and lack of self-support skills.

Many articulated that GP education lacks the opportunity for GPs to explore the extent to which their views may impair their ability to provide care for people with a history of injecting. Most participants linked patient disclosure in healthcare settings of past or current injecting practices with patient experiences of being treated negatively or punitively. However, several participants were optimistic that the availability of curative hepatitis C treatments may mean that over time both patients and providers will be more comfortable with raising the issue of hepatitis C testing.

In contrast to the global picture of HIV, prevalence of HIV among people who inject is very low in Australia. Nonetheless, HIV transmissions resulting from non-sterile injecting do occur in Australia. One participant talked about the compounded stigma experienced by people with HIV who also use drugs, and the difficulty they often face integrating a positive test result with poor health literacy and a limited understanding of the importance of HIV treatment for staying well.

Gay, bisexual and other men who have sex with men

Gay, bisexual and other men who have sex with men are the main priority population in the HIV response, and their engagement in testing and treatment as prevention (TasP) is central to the goal of the elimination of HIV. Most participants recognised that HIV testing services are very accessible for gay and bisexually identifying men in, or with easy access to, Melbourne. It was acknowledged that there is scope for improvement, however, as there are sub-populations of gay and bisexually identifying men that have lower rates of testing. Participants identified that the main barriers to testing among these groups are location and convenience, as well as the time commitment and logistics of engaging in regular testing. Participants were optimistic that the continuing shift of testing models from primary care to community settings will increase testing rates over time.

Many men who have sex with men (MSM) do not identify as gay or bisexual and several participants discussed testing issues in relation to this group. MSM who did not identify as gay or bisexual were described as generally reluctant or unwilling to associate with the visible LGBTI community, and more likely to experience stigma in relation to their sexual practices and the experience of testing. They were seen as less likely to access HIV testing in LGBTI community clinics and high HIV caseload clinics.

Participants working in an HIV testing service staffed by gay-identifying peer workers noted that some non-gay/bisexually identifying MSM were uncomfortable in the service. They explained that when non-gay/ bisexually identifying MSM present for testing, staff change their approach to avoid any direct questions about sexual practices. Instead they focus on managing the client's questions and providing information about HIV and HIV risk.

People from culturally and linguistically diverse backgrounds

People born in high and intermediate prevalence countries are the communities most affected by hepatitis B, and comprise a significant proportion of people living with HIV and hepatitis C.

Participants identified a range of considerations for testing within culturally diverse communities. People from culturally diverse backgrounds may have a limited understanding of BBVs, and their understanding of health may differ from the Western medical model, particularly if they have recently arrived in Australia. Several participants also highlighted that migrant women may have had limited opportunities for education or for practising English, even if they have lived in Australia for many years. People being tested in refugee health services were seen as having limited health literacy and multiple competing health and life needs.

A strong emphasis was placed on the importance of assessing the need for an interpreter at the start of each testing consultation. This was seen as being integral to gaining informed consent. Many noted the importance of offering interpreters to people from non-English speaking backgrounds even if they have good conversational English. They also emphasised the importance of maintaining an awareness that some people have concerns about privacy and confidentiality and may prefer to use telephone interpreters. Several participants recommended briefing the

interpreter beforehand to agree on terminology, and to find out what other terms or concepts might be useful to support the understanding of the person being tested. Bilingual written information was regarded as invaluable.

Cross-cultural conversations between testing providers and patients about routes of transmission require cultural sensitivity. Participants noted that discussions about sexual practices and drug use could be highly sensitive and should be minimised where possible, or alternatively couched within a longer list of possible routes of transmission. This was seen as reducing the risk that people might not return for results or seek help because of stigma and embarrassment. One participant recommended the use of a global map to highlight the widespread nature of these viruses. It was also a useful way to point out that the features of the epidemic in the patient's country of origin, such as treatment availability and the legal requirements for disclosure, might be different here in Australia.

It was recognised by several participants that BBV testing conversations in culturally diverse communities need to occur within a socio-cultural context by recognising that individuals are culturally connected to family and community. Information about BBVs was seen as needing to be delivered in a way that focuses on both the individual and the community.

It is common for patients and their healthcare providers to be from different cultural backgrounds, and many participants highlighted some cultural considerations that can arise in this context. Participants noted that it is not appropriate for a male doctor to talk to women about sexual practices, and it was suggested that female nursing staff could be utilised here. Several participants highlighted the value of familiarity with the culture of the person being tested, as well as the value of a culturally diverse medical and community workforce.

Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander populations are disproportionately affected by hepatitis B and hepatitis C. While the actual numbers are low, rates of HIV among Aboriginal and Torres Strait Islanders have been steadily increasing over the last five years. Importantly, the proportion of recent HIV diagnoses in Aboriginal and Torres Strait Islander people attributed to male-to-male sex is lower (51%) than in the non-Indigenous population (74%) [46].

Testing for BBVs urgently needs to be normalised in general health checks or sexual health checks in order to increase the rates of diagnosis and destigmatise these viruses. One Aboriginal participant noted that while hepatitis C was relatively well understood, hepatitis B suffered from stigma by association with hepatitis C and was not well understood. HIV was described as highly stigmatised, and still seen as a terminal illness rather than a chronic manageable condition. Confidentiality was described as complex in Aboriginal community-controlled settings, and it was acknowledged that a significant proportion of Aboriginal people use non-Aboriginal health services.

Health literacy was raised by one participant, specifically in relation to Aboriginal gay men's understandings of safe sex or non-condom-based methods of HIV prevention. It was noted that many Aboriginal gay/ bisexually identifying men are not connected to the LGBTI community.

Several participants talked about how being too direct was not culturally appropriate or effective when working and communicating with Aboriginal communities. Non-Aboriginal healthcare workers should have an awareness that direct body contact like handshakes and eye contact are often culturally inappropriate. It was also suggested that healthcare providers avoid using imperatives like, *'you should'* or *'you need'*, instead using terms like, *'how would it be if you...'* and *'you might consider...'*. Gender and age concordance was seen as important in Aboriginal health, and it was noted that gender or age difference could create additional barriers between health worker and patient.

Women and HIV

At the end of 2014, an estimated 8.7% of people living with HIV in Australia were women. While most HIV infections are attributed to unprotected sex between men, the proportion of heterosexually acquired HIV has increased in recent years [46]. This is the case among both Australian-born and overseas-born people.

Access to quality testing and timely HIV diagnosis was seen as a significant issue for women. Outside of provider-initiated testing settings such as antenatal and migration testing, participants perceived that women are only tested for HIV if they become unwell. Normalisation of testing for women outside of pregnancy and migration services was described as being critical to the reduction of late HIV diagnosis among women.

HIV testing is recommended for all pregnant women. A focus group discussion highlighted that antenatal testing settings are highly time constrained. HIV testing occurs alongside a range of other antenatal tests and an overwhelming amount of information. Participants identified that the key points that must be conveyed to all pregnant women are: that HIV is transmitted through unprotected sex; that HIV can be passed from mother to baby, and that recent HIV infections may not be detected by the test. The importance of mentioning partner testing was also noted.

Several participants expressed concern about women's safety in relation to testing positive for HIV. It was recognised that if women are diagnosed before their partners, for example at migration or during pregnancy, they may be held responsible if their partner subsequently tests positive. One community-based worker talked about the importance of ensuring that women testing positive for HIV receive targeted information around safety, self-care and disclosure.

Transgender and gender diverse communities

Several participants had specific experience of BBV testing and prevention among transgender and gender diverse communities. Best practice in working with gender diversity involves the creation of a safe environment for people to disclose that they or their partner have a transgender experience.

Participants also talked about the importance of inclusive language and practice. Inclusive practice begins at intake and assessment by ensuring that data collection systems can capture diverse gender identity. One testing provider reported that a significant hidden population of trans-

identifying men within their existing client group was revealed when their data collection practices were improved.

Another participant emphasised that not all transgender and gender diverse people will want or need to disclose their gender identity at the point of testing. It was also seen as important to ensure that any information or questions about risk are not fixed to particular assumptions about bodies or practices such as, for example, that all men have a penis. It was seen as important to explain that different levels of risk could relate to different body parts. In the event that detailed discussions about risk practices arise, questions such as *'What kind of sex do you have?'* and *'What language do you use to describe sex/ body parts?'* were seen as important.

HIV exists within the transgender and gender diverse community, but participants emphasised that there is no evidence to suggest that gender diverse bodies themselves are at increased risk of HIV. HIV risk was associated with poor health literacy and lack of inclusive practices. One participant described how HIV health promotion campaigns in Australia targeting gay and bisexual men have not been inclusive of transgender men who have sex with other men. As a result, transgender and gender diverse men were seen as having inadequate levels of knowledge about HIV risk reduction that was specific to their experience.

Testing and prevention

Discussions about prevention and risk reduction are central in the delivery of a positive result. The findings from this consultation echo the literature in suggesting that discussions about prevention and risk reduction are no longer positioned as a core element of pre-test discussion or in the delivery of a negative result.

It was widely acknowledged, particularly in HIV and hepatitis C contexts, that providers need to have specific skills and knowledge to conduct effective prevention discussions. Further, the value and acceptability of these discussions was seen as being dependent on whether the testing provider was competent at stigma-sensitive practice, and able to adapt to the social and cultural context of the individual being tested. Written information about prevention was seen as ideal for patients and providers alike.

Expert HIV prevention conversations were seen as needing to incorporate the changing social meaning of HIV risk reduction. While new prevention technologies have provided welcome alternatives to condom use and post-exposure prophylaxis (PEP), there is more confusion than ever about HIV risk reduction. The emergence of non-condom-based strategies of HIV prevention were seen as being quite specific to gay and other homosexually-active men, and there is a need for these to be more effectively tailored to other HIV-affected communities.

Participants highlighted that meaningful conversations about hepatitis C prevention and injecting can only occur in stigma-sensitive environments. Participants in the consultation with lived experience of injecting drugs emphasised the importance of test providers understanding that people do not want to share injecting equipment, rather that they do so because sterile equipment is not always available when needed. However, peers were cautious about the value of

test providers encouraging people with hepatitis C to promote testing and treatment among their networks. They pointed out that positive experiences were often shared among networks, but an overt focus on reaching out to networks could place too much emphasis on public health imperatives and undermine the experience of individual care.

For hepatitis B, prevention discussions were described as complex because they involve conversations about natural history, the testing of family members and the possibility of other family members testing positive. They also overlap with conversations about transmission and vaccination of family members. Participants overwhelmingly emphasised the importance of providing accurate information about transmission, because people with hepatitis B and their families frequently misunderstand household hepatitis B transmission and the protective effect of the vaccine.

Part Two | Checklists for best practice in pre- and post-test discussion

The following three checklists offer an outline of best practice in pre-test discussion, the delivery of negative test results and the delivery of positive test results. These checklists are applicable across all three BBVs, and expand on what is already in the National Testing Policies.

In Part Three of this report, additional considerations for HIV, hepatitis B and hepatitis C are discussed.

Checklist: pre-test discussion

- ☒ Confidentiality and notification
- ☒ Informed consent
- ☒ Testing history
- ☒ Health literacy
- ☒ Basic information about BBVs
- ☒ Stigma-sensitive discussion about risk and transmission
- ☒ Implications of positive result and supports
- ☒ Process of delivering the result

☒ Confidentiality and notification

It is essential to provide information about privacy and confidentiality before every test.

Notifications should also be briefly mentioned. HIV, hepatitis B and hepatitis C are included on the list of more than 60 communicable diseases where positive results must be notified to the Victorian Department of Health and Human Services (DHHS). This information is securely held and only used for statistical purposes and in managing outbreaks. At the time of writing, this information is not shared with other government departments or made public in any way. Identifying details are required for hepatitis B and C notifications, while HIV notifications are coded.

☒ Informed consent

Healthcare providers are legally and ethically required to gain informed consent prior to any medical procedure or test. In the context of HIV, hepatitis B or hepatitis C testing, informed consent means that the person agrees to be tested on the basis of understanding the testing procedures and the reasons for testing, and is able to assess the personal implications [9, 25, 26]. The aim of the pre-test discussion is to enable the patient to give their informed consent.

The extent to which a patient is 'informed' when they consent may vary according to the constraints in the testing environment, including the time available, competing healthcare

priorities, and provider skill. It may not always be possible to ensure that a patient understands the full implications of the test, given the complexity of these chronic viral conditions. Health literacy assessments and awareness of cultural context are important.

In settings where multiple tests are indicated, test providers need to use their clinical skills to determine how much of the available time will be spent discussing each test.

Some patients will readily identify that they understand the virus and indicate that they want to proceed with the test. Others will ask if the test provider recommends that they have the test and consent on that basis. While not best practice, this may be best fit in settings where patients have many concurrent health and social priorities.

Testing guidelines identify that the pre-test discussion and the gaining of informed consent may occur face-to-face, by video or by other visual mediums. Information can also be conveyed in pamphlets and other written materials, and be presented individually or in groups [15, 16].

☑ Testing history

Have you been tested before? How was that for you?

One of the most important and useful questions to ask at the start of the discussion relates to a person's testing history. This is a means of introducing the topic of testing, to determine whether they have been tested before, and to begin to gauge health literacy. Asking about the impact of this experience may assist in assessing the person's level of understanding and their level of comfort with the topic.

Considerations for first time testers may include: complex reasons for not having been tested; fear and shame about disclosing personal risk factors; outdated ideas about the medical consequences of infection; fears of social marginalisation, particularly when people have come from countries where marginalisation of people with BBVs is common.

Enquiries about previous hepatitis B testing should specifically include vaccination history, or of a family history of liver disease.

When the patient initiates the test, it is important for test providers to respectfully acknowledge people for the effort they have made to seek a test.

People who test regularly for HIV and hepatitis C may be more relaxed in the testing experience, more knowledgeable about the viruses, and often appreciative of a brief and friendly encounter. A shortened pre-test discussion might involve the test provider saying:

It's great that you make the effort to get tested regularly. How are you going, anything changed since your last test? Do you have any questions about the changes in treatment and prevention?

Or

'Your last few test results have been negative, has there been anything since the last test that concerns you? Any new questions?'

☑ **Health Literacy**

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [47]. Clinicians routinely overestimate the health literacy of their patients [40].

A brief assessment of patient health literacy can support test providers to build patient understanding and informed consent for testing. Test providers can enquire about their patients' existing knowledge about medical conditions, and tailor their approach accordingly. Using communication skills and plain language to assess and improve health literacy will support the patient to gain a clear understanding of transmission and risk factors, and also to decide whether regular testing might be beneficial.

A health literacy assessment will identify any patients who are already adequately informed, which can lead to a streamlined testing experience. This is often preferred by people who engage in regular testing.

A secondary purpose of assessing health literacy is to build rapport. Consciously working at understanding the patient's point of view, and seeking to learn from and about the patient, builds empathy, which is key to rapport.

If the test provider is from a different cultural background to their patient, it may be useful to enquire about the patient's background, paying particular attention to their social and educational history. These discussions can provide insight into whether the person being tested will understand the concept of the virus, transmission, and even how they might manage a positive result.

Information needs, health literacy and even informed consent can be culturally defined. For example, high levels of cultural deference to doctors can mean that some patients will accept their doctor's recommendations and ask very few questions. It is important for test providers to adjust for this.

☑ **Basic information about BBVs**

Patients need to have a basic understanding about the virus for which they are being tested to be able to give their informed consent. Brief and succinct information should be provided in plain language, which includes information about the window period (particularly for HIV and hepatitis C), transmission and the availability of highly effective treatments for all three viruses.

Hepatitis C is an infection in the liver. It can be passed on when blood containing hepatitis C enters another person's bloodstream. Hepatitis C is mostly transmitted from unsterile injecting of drugs including steroids. It can also be passed on through unsterile medical and tattoo procedures. Excellent treatments mean that more than 95% of people can be cured, but without treatment, hepatitis C can cause serious liver problems and sometimes cancer.

HIV is a virus that affects the immune system. It is mainly passed on through unprotected sex (vaginal and anal), unsterile injecting, and from mother to baby during birth and breastfeeding. It

can also be passed on if blood, semen, pre-ejaculate, vaginal fluids or breast milk blood containing HIV enter another person's body. Treatments are very effective and mean that people can live until old age. Treatments can also stop a person from passing on HIV.

Hepatitis B is an infection in the liver. It is common in many parts of the world, and most people with chronic (lifelong) hepatitis B were infected at birth or in early childhood, and often several people in the family have it. Vaccination is available to protect people who don't have it. Hepatitis B is mainly passed on from mother to baby but can also be passed on sexually and through blood. People with hepatitis B can stay healthy with regular tests and sometimes treatment. Without care, hepatitis B can cause liver problems including cancer in about 25% of people who are infected.

The window period is the time between infection with a virus and the markers of that virus showing up on the test. The window period for hepatitis B and hepatitis C is 3 months. The window period for HIV is 6 weeks. Very recent exposure may not show up on the test.

Stigma-sensitive discussion about risk and transmission

It is important for people being tested to understand the ways that these viruses are transmitted and the risk factors of having and transmitting a BBV. This assists people to understand their own risks, as well as to help them prepare for a possible positive result.

As part of the normalisation of BBV testing, direct questioning about individual risk factors, including the use of a checklist of questions, is not routinely recommended.

Direct questioning is not a prerequisite for identifying risk factors or case-finding initiatives. Test providers can specifically name the practices associated with transmission, for example unprotected sex (between anyone, not just men) or unsterile injecting, in order to convey how viruses are transmitted. Test providers can then encourage patient-led disclosure by asking if patients have any questions, or if there are any events or incidents that they would like to discuss.

When talking about risk and transmission, it may also be helpful to mention other less stigmatised routes of BBV transmission such as unsterile medical and cosmetic procedures. This may be particularly useful when working cross-culturally, with young people or in any situations where the test provider wishes to reinforce cultural safety or reduce the power differential between them and the patient.

Providing information about risk factors in a stigma-sensitive manner supports the person being tested to assess their own degree of risk in order to prepare for a possible positive result. There will be times patients will not disclose any information about their personal risks, however an absence of disclosure does not indicate an absence of risk.

If direct questions about risk practices for BBVs are deemed appropriate in the testing context, it is important to use language that is inclusive of all genders and bodies, sexualities, relationship types and licit and illicit drugs. Test providers should be comfortable with providing further information in a stigma-sensitive manner about each question they ask. This may include

information about safe injecting, such as where to access sterile injecting equipment locally, sources of information and support, or methods of non-condom-based HIV prevention.

Patients presenting for testing will often have contemplated their own risk factors, however they may not wish to answer questions prior to testing. Test providers might say:

We can either discuss your reason for testing and any specific concerns you have, or I can just go through the basic information about HIV and the testing process without needing to talk about your personal situation.

People who are anxious about their risk factors may need a more in-depth discussion about risk. This is also an indication that information, support and referral may be needed for people to manage their anxiety while waiting for the result.

It is important for test providers to mention during pre-test discussion that the patient's result may not be the same as those of their partners or contacts. The only way for a person to know their status is to have a test.

☑ Implications of positive result including supports

It is useful for people being tested to know that in the event of a positive result, and in addition to medical services, that there are many community-based and peer support services that can support people with a new diagnosis.

It may be helpful, particularly if significant risk factors have been disclosed, for the test provider to initiate a discussion about the implications of a positive result. A more in-depth discussion may be required if the person being tested is very anxious about the result. Possible approaches to questioning include: how a person might manage the possible repercussions of a positive result; how much support a person has; or whether the timing of the test is right in relation to other background stressors.

In the absence of any disclosure of risk factors, or in instances when the test provider considers there to be a low risk of a positive result, it is still important to consider the psychosocial⁵ context of the person being tested.

☑ Timeframe and method for delivering the result

People being tested need to understand before they consent how and when they will receive their results, and if relevant what the process is if they do not return for their results.

Some busy testing centres offer patients the choice of receiving negative results by text message, phone or email. This assists in freeing up clinical time for other people seeking a test. Negative results by text message may be appreciated by people who are regular testers, who initiate their own testing, or who value not having to return for results. Where the option to send results by

⁵ Psychosocial context refers to the impact of individual psychology and the surrounding environment on health and wellbeing.

text message exists, it is important that patients are given the choice to receive their results in this manner.

In settings where negative results may be delivered by text, additional detail needs to be covered in the pre-test discussion. Emphasis should be placed on ensuring that the patient understands the window period and the limitations of a negative result in relation to recent exposures. It should also be emphasised that a negative result does not mean that their partners or contacts are also negative.

Providers should be aware that delivery of negative test results by text message may not always be appropriate or beneficial. This is discussed further in the HIV section of Part Three.

Checklist: post-test discussion | delivering a negative result

- ☒ Give result and allow response
- ☒ Window period and need for further testing
- ☒ Partners and contacts

☒ **Give result, explain result and allow response**

The result should be given immediately, as people may be feeling very anxious.

Test providers should check the patient's understanding of the result, including their understanding that the term negative means that the virus is not present in the blood sample. Asking the patient whether they were expecting a negative result could open up a discussion about the testing experience or allow them to raise concerns that weren't shared prior to testing.

For people who have had an anxious wait, or who indicate verbally or nonverbally that they are relieved, it may be helpful to allow some time to debrief the result.

When discussing negative results with people with current risks, attending to support needs and ways of minimising stigma and judgement will increase the likelihood that they will engage in ongoing testing.

It may be appropriate to engage in a patient-led discussion about prevention, or to provide written information about risk reduction that is appropriate to the person's context, identity and culture.

☒ **Window period and need for further testing**

It is essential to reiterate the window period for everyone, regardless of whether or what risks were disclosed. Explicitly state that any possible exposures that have happened during the window period may not have shown up on this test. Patients should understand that if there have been any recent risks another test will be needed after the window period has lapsed. Regular testing is recommended for people with ongoing risks for HIV and hepatitis C, and vaccination is recommended for people at risk of hepatitis B.

☒ **Partners and contacts**

It is important to convey to the person that their negative test result is not indicative of the test results of partners or contacts, and that individuals need to seek their own tests.

Checklist: Post-test discussion | delivering a positive result

- ☒ In person or over the phone?
- ☒ Prepare
- ☒ Immediate needs on the day of diagnosis
- ☒ Information about transmission and prevention
- ☒ Support, disclosure and contact tracing
- ☒ Follow-up appointment

☒ **In person or over the phone?**

While there is no legal requirement in Victoria, the National Testing Policies recommend that positive results for HIV, hepatitis B and hepatitis C be delivered in person wherever possible. Patient understanding, responses and needs are more difficult to assess over the phone, and it is harder to develop the rapport needed to link people effectively to care.

Positive results should only be delivered by phone when it is not possible to organise a face-to-face meeting in a timely manner, which may be more likely in the rural and regional context. Results by SMS or in writing are rarely appropriate.

☒ **Prepare**

Testing providers should prepare themselves for delivering bad news and ensure that they have read all available notes and sought any clarification about the next steps as needed.

Discussing positive results can result in longer appointments. It is important to avoid interruptions during these discussions.

Always offer interpreter services to people with limited English, even if they have declined previously. Be aware that patients may prefer telephone interpreter service due to concerns about confidentiality within their community and language groups.

Test providers should consider preparing the wording they will use to deliver the result, which should include clarification that the word 'positive' means that the person has the virus.

It is also important to locate culturally and linguistically appropriate written information, which is suited to the literacy level and socio-cultural context of the person being diagnosed.

It is possible that a positive result, particularly for HIV and hepatitis, could be delivered to a person who had not disclosed any risk factors. In these circumstances test providers should be prepared to be sensitive to the stigmas surrounding risk practices and allow the newly diagnosed person to be in control of when and how much they disclose about their risk history. Positive HIV, hepatitis B and hepatitis C results must be notified to the Victorian DHHS within 5 days, and this involves providing information about exposure categories. Be aware of the sensitivities here and prioritise supporting the patient over completing the notification form during the consultation.

Immediate needs on the day of diagnosis

People being diagnosed often want to know about the immediate implications for their health, including their future health. Patients need reassurance that there are things that can be done to keep them well. People also are greatly concerned about passing on the virus to family and loved ones, and whether others need to be tested.

It is essential to avoid overloading people with information about prognosis and prevention. Test providers should focus on immediate needs and emotional reactions and save detailed information and discussion for the follow-up appointment. Diagnosis can still be shocking, despite the availability of excellent treatments and prevention technologies, and people will not remember much of what is discussed.

Discussions about further tests and treatments may need to be prioritised if the person being diagnosed has symptoms of (or risk factors for) more advanced disease. However, in the absence of such indicators there is no urgency to medically respond to the diagnosis. If possible, conduct further testing at a follow-up appointment rather than on the day of diagnosis. People's needs at the time of diagnosis may be predominantly psychosocial. Nonetheless, if patients are keen to act, and don't appear to be distressed, it may be useful to capture the momentum at the point of diagnosis and discuss a referral to a relevant specialist service.

Regardless of background, people may have specific cultural understandings of illness and disease transmission. It may be useful to explore the meaning and cultural context of the diagnosis for the person and ask what they think they may need to do to manage it. This information can then be incorporated into building health literacy and familiarising the person with the biomedical model of management and treatment.

When working with people who were born overseas, test providers may wish to familiarise themselves with the epidemic in the person's country of origin to inform discussions about the differences between the viruses in each country. Likewise, patients may have limited understanding of the implications for testing positive in Australia and may have fears and misconceptions based on the meaning of diagnosis in their country of origin.

☑ **Information about transmission and prevention**

An essential role for the diagnosing healthcare provider is to clarify people's understanding of transmission and risk practices. Many patients will have significant immediate concerns about the risk they pose to others, but it is important that this conversation be patient-led as far as possible.

If the person being tested has not disclosed any risk factors, it may be useful for the test provider to acknowledge this, reiterate confidentiality, and to ask whether they would like to go over the basics of transmission or discuss risk factors.

If prevention of transmission doesn't appear to be a primary concern for the patient, there is no urgency that this be covered in depth during the initial consultation. It is essential that people feel safe and supported to return for a follow-up appointment, and in many cases the best way to achieve this will be to focus on support rather than infectiousness. Written information containing further information about transmission and prevention can be provided.

Most people will be experiencing shock at the time of diagnosis, and focusing on infectiousness, transmission, behaviour change and risk to others can impact negatively on people's subsequent ability to cope with their diagnosis and engage with care.

If the newly diagnosed person has disclosed any injecting practices or unprotected sex, be aware that conversations at the time of diagnosis are long remembered and can compound stigma and shame. Testing providers who don't feel confident discussing risk reduction in a supportive and non-punitive way may wish to simply provide basic information about transmission and refer the patient to community or peer support agencies.

☑ **Support, disclosure and contact tracing**

Diagnosis is as much a psychosocial event as it is a medical event. Testing providers should utilise communication skills to gain an understanding of the meaning of the diagnosis, and of what is happening for the person in the moment. Many people will be in shock.

When discussing the person's immediate support needs, testing providers should include information about community and peer support services, and consider whether an active referral would be helpful. BBV-specific support and information services are available to Aboriginal people, people from culturally diverse backgrounds, women, heterosexual people and families, gay and other men who have sex with men, trans and gender diverse people and people who inject. Not everyone has a support person or network, and those that do may not be able to disclose their BBV test result. A Mental Health Care Plan may assist people with any challenges or traumas that they encounter in coming to terms with their diagnosis.

Newly diagnosed people should exercise caution in relation to telling others about their results. Disclosure is essential for accessing support, but it frequently leaves people vulnerable and open to judgement. Newly diagnosed people should ideally be able to assess the health literacy of their potential supports and their social networks before making the decision to disclose. It may be important for people to be able to confidently explain transmission and vaccination before disclosing to others. Written or web-based information may also be helpful. People with HIV,

hepatitis B or hepatitis C are not obliged to tell their employer (except in some healthcare roles), school or childcare centres.

Generally, diagnosing clinicians have a role in contact tracing but with the exception of HIV this is poorly-defined and understood. The index patient may be asked to consider whether they wish to notify their contacts, but there is no specific legal obligation to do so. Contact tracing considerations for each BBV are further discussed in Part Three.

It is worth noting that the Victorian *Public Health and Wellbeing Act 2008* articulates the principle that people should take all reasonable precautions to prevent the transmission of an infectious disease. It also states that people should take reasonable precautions to avoid contracting the infectious disease [48].

Follow-up appointment

Follow-up consultations provide an opportunity for more extended discussion once the newly diagnosed person has begun to process the test result. Whether in days or weeks, testing providers should schedule a follow-up appointment to discuss any questions arising, to organise further tests, to discuss community and peer support, and to engage the person in the process of managing their chronic disease. Health information needs are very high at the time of diagnosis, and for a significant time afterwards.

Wherever possible, and always with the utmost concern for confidentiality, test providers should utilise available resources to contact patients and support and encourage them to return. People should be given written information and details of community supports at the initial consult in the event that they do not return for their follow-up appointment.

Part Three | Additional considerations for HIV, hepatitis B and hepatitis C

In this section we provide additional details of HIV-, hepatitis B- and hepatitis C- specific issues in pre- and post-test discussion that were identified during the consultation.

HIV

HIV pre-test discussion

Late HIV diagnosis

Approximately one-third of new HIV diagnoses in Australia in 2016 were classified as late, and this proportion has not changed in recent years [46]. Late diagnoses are more common among people who inject, women, people from Aboriginal and Torres Strait Islander backgrounds, and people from South East Asia. It is important to recognise that the indications for testing in the National HIV Testing Policy include people who are widely understood to be at increased risk of HIV (men who have sex with men and people who inject), as well as groups who aren't readily associated with HIV testing (people with recent partner change and people with multiple sex partners) [9].

The window period for HIV testing

All HIV blood tests undertaken in Victoria have a window period of 6 weeks. Rapid tests have a window period of 6 to 12 weeks, depending on the test.

Participants universally identified that that an understanding of the window period is an essential component of informed consent for HIV testing. The test provider should wherever possible calculate and explain the timeframe around possible retesting.

Discussing HIV risk

The majority of participants shared the view that:

- People seeking a HIV test have probably engaged in a process of considering their own level of risk, and a discussion about specific risk factors may be useful. Where possible, this discussion should be led by the client rather than by direct questioning, and be useful and safe for the person being tested.

- HIV pre-exposure prophylaxis (PrEP) is a new technology and it may be useful to mention during the pre-test discussion that there is a now daily tablet which is highly effective at protecting people from HIV. People who disclose significant risks for HIV would benefit from being given detailed information about accessing PrEP.

Discussion about implications of a HIV positive result

A key question for participants was the extent to which discussion about the implications of a positive result were still important prior to testing for HIV. There were three main themes to the interview and focus group discussions:

- It is still important to contemplate the possibility of a positive result during the pre-test discussion, particularly if people have substantial risk factors. Receiving a HIV diagnosis is a significant and difficult event for many people. Despite the shift away from detailed pre-test discussion, a discussion about strategies for managing a positive result may be valuable for the person being tested and for their relationship with their provider.
- Discussion about the potential impact of a positive result is not helpful for everyone. It can create unnecessary psychological stress, especially among regular testers and the 'worried well'. Further, the impact of this interaction could diminish after multiple negative test results.
- In the era of normalised testing, where HIV testing is part of general preventative healthcare, discussions about the implications of a positive result may have a limited role.

Delivering a negative HIV test result

Participants highlighted that:

- Many regular testers, despite their anxiety, expect to get a negative result. It can be useful for test providers to remind regular testers that positive results are often unexpected, and they often follow many, many negative results. Providers may ask:

What is it like for you to repeatedly test negative?

- It is important for people to understand the window period in specific relation to the high viral load that may be present during early infection. A person with a recent negative test result and recent risk factors is more likely to pass on HIV than someone with HIV and an undetectable viral load.

The delivery of negative HIV results by text message or other electronic means was deemed acceptable by participants. Considerations include:

- Patients should opt-in to receive results by text message, this should not occur automatically. Results by text message may not be suitable for people with high-risk profiles, or if there are indications that the person may not understand or cope with a text. If people don't disclose any risk practices, it is difficult to know whether a text message is appropriate.

- When results are to be delivered by text message, the window period needs to be heavily emphasised during pre-test discussion.
- People expecting to receive negative results by text message may, when called in for an appointment, be delivered a positive result by proxy.

The actual wording of the negative result text message was discussed during a focus group.

- Messages should include the test result and date, and a reminder about the window period and the timeline for follow-up tests, and a link to further online information.
- Confidentiality is a concern, particularly as text messages which began with, *'Your HIV test result on 21/6 is negative...'* may be partially visible on a locked screen.

Delivering a positive HIV test result

Prepare

People delivering HIV positive test results need time to prepare. Participants talked about:

- The importance of locating and printing suitable resources for the patient.
- Testing providers can prepare to listen to the person's emotional response, however difficult that may be, and resist defaulting to a medical response.
- Some HIV testing agencies have a policy of not giving any HIV positive test results on a Friday due to the scarcity of support services over the weekend.
- If the result has come back as inconclusive (formerly indeterminate) testing providers should seek further advice from the testing laboratory (VIDRL) or an infectious diseases specialist about interpretation of serology before inviting the patient into the room. Indeterminate results are difficult to give as they usually mean the person will subsequently test positive, but not always.

Immediate needs at the time of HIV diagnosis

There was consensus among participants that advances in medication and prevention haven't altered the fact that being diagnosed with HIV is still a very significant, life changing moment.

- Use clear wording, with compassion and without preamble. For example, *'Your HIV test has come back positive'*. People often need clarification about the meaning of the result, so it may be helpful to say: *'The test showed that HIV was found in your blood'*. The distress from this moment can stay with people for a long time. The gentle use of silence may be a useful way of allowing the patient to respond to the information.

When asked about meeting the needs of people newly diagnosed with HIV, participants identified a range of approaches:

- People need some brief reassurance that excellent treatments are available to them, and that by starting treatment soon they are likely to live as long as people who do not have HIV.
- It is essential to avoid overloading people with information or providing too much detail when answering the person's questions.
- It may be valuable to state the result, provide space for the emotional response, provide information in written format and focus on setting up support for immediate period.
- The consultation could focus on the significance of the test to the individual, including their immediate concerns about their health and transmission to others.
- Physical examinations are unnecessary and potentially harmful. Similarly, blood tests are generally unnecessary on the day of HIV diagnosis.
- This initial encounter should be brief. A follow-up appointment is essential within a few days of the initial HIV diagnosis. This is the most appropriate time to do further HIV-related blood tests, or to act to commence treatment. However, this appointment needs to be culturally safe and guided by the participant's questions, concerns and emotional state.

Accessing support and disclosure of HIV

The diagnosing healthcare provider was universally seen by participants as having a key role in assessing and adapting to the person's psychosocial situation. This includes:

- Identifying support people, as well as other external stressors in relation to things like relationships, housing, employment and mental health.
- Some newly diagnosed people struggle to make sense of their own fear and devastation in an era where HIV is framed as a chronic manageable infection.
- Those providing the HIV diagnosis should be aware of the risk of suicide. This risk is significantly lower than in the early years of the epidemic, however it is still a possibility.
- Assisted referral to community and peer support agencies will enable newly diagnosed people to ask questions and learn from other people living with HIV, in a non-clinical environment.
- The meaning of a HIV diagnosis for an openly gay or bisexual man is very different than for a person from a community where HIV is relatively uncommon and poorly understood.
- People from culturally diverse backgrounds, women, Aboriginal people and people who inject are more likely to be diagnosed late [49], so linkage to care is highly beneficial. While there are peer support options for many of these groups, the stigma and shame about disclosure of HIV status may be a barrier to access.
- Newly diagnosed people should carefully consider whether they disclose their result to anyone in the immediate timeframe while they are still in shock.
- Phone services, with the anonymity they offer, have an important role to play in supporting people through the initial shock and fear.
- People testing positive for HIV may be at risk of intimate partner violence, and may benefit from receiving targeted information around safety, self-care and disclosure.

Information about transmission, prevention and contact tracing

The timing of discussions about HIV transmission and prevention was seen by participants as very sensitive and largely determined by individual professional judgement. Two key points emerged:

- It is important to give people basic information about HIV treatments on the day of diagnosis, specifically mentioning that treatments keep people well and significantly reduce the risk of passing on HIV to others.
- Too much emphasis on infectiousness, prevention and behaviour change on the day of diagnosis could escalate the experience of stigma and impact people's ability to cope with their diagnosis and engage in care.

There was some variation among respondents about the timing of discussions about partner testing and contact tracing. Often the discussion occurs naturally due to patient concerns about transmission, but these conversations were seen as difficult to initiate. Some considerations include:

- While some people will be prepared to contact partners, many will not.
- Gentle, non-directive enquiries about current sexual partners is an ideal starting point:

How would you feel about talking to your partner about testing?

- It may be useful to explain the available support systems that assist people with anonymous contact tracing. It can also help to point out that most HIV transmissions in Australia occur when the HIV positive partner doesn't know their HIV status.
- Given the 72-hour window for HIV PEP, on the day of diagnosis it is important to sensitively ask the patient whether they may have been in contact with anyone in the previous 3 days.
- People with very recently acquired HIV have a greater likelihood of having a higher viral load and therefore more likely to pass on HIV. This may inform partner testing and contact tracing discussions.
- Linkage to Victorian DHHS Partner Notification Officers is important but is most effective when patients feel safe and supported in their relationship with their doctor. Newly diagnosed people may be cautious about identifying their partners to the health department and may only nominate partners perceived to be at higher risk.

Hepatitis B

Hepatitis B pre-test discussion

Initiating the discussion about hepatitis B testing

Chronic hepatitis B is usually asymptomatic but is a leading cause of liver disease and liver cancer. While campaigns to promote screening and raise community awareness may prompt people to request a hepatitis B test, participants generally indicated that most hepatitis B testing is provider-initiated. Participants said:

- A script or set of prompts to support providers to initiate hepatitis B testing may be beneficial for those who are unsure where to begin or are concerned about offending people. *'Have you heard of hepatitis B? What do you know about hepatitis B? Have you ever been tested for hepatitis B? Have you ever been vaccinated? Have you ever thought about getting tested for hepatitis B?'*
- Most GPs have very limited knowledge of chronic hepatitis B, the risk factors related to country of birth and Aboriginal and Torres Strait Islander background, and general prevalence rates in affected communities.⁶
- While some basic information about hepatitis B is needed prior to testing, this may be less important than building rapport and engagement.

Informed consent and the implications of hepatitis B testing

Assessing the need for and providing interpreters is an important part of informed consent.

There was consensus among participants that gaining consent is an essential part of ethical practice. Participants described the challenges of gaining *informed* consent in the real-world context of hepatitis B testing. Some considerations:

- Testing for hepatitis B commonly occurs alongside other tests, and in the context of competing individual health and social needs. The threshold for informed consent can vary for each test. It also varies according to the context or health literacy of the patient, and the time available.
- A lack of informed consent prior to testing is likely to increase the shock and distress of receiving a positive result, as well as the risk that the person will not return to engage in hepatitis B care.
- Ethical practice is complex. Providers need to weigh the importance of gaining informed consent from every individual tested against the need to reduce the high proportion of people with hepatitis B who are undiagnosed and at high risk of liver cancer or death. A lower threshold for informed consent may be ethically balanced with the delivery of comprehensive high-quality post-test discussion in the event of a positive result.
- There may be visa implications for people who test positive for chronic hepatitis B, particularly if their visa category does not include Medicare rights. It may be important for people to understand this prior to testing.

Explaining hepatitis B

Those who provided hepatitis B testing emphasised the importance of using plain language and simple concepts when describing hepatitis B. Most participants noted that:

⁶ Estimates of hepatitis B prevalence in Victoria by country of birth in community prevalence can be found here: 53. MacLachlan, J.H., et al., The burden of chronic hepatitis B virus infection in Australia, 2011. *Australian and New Zealand journal of Public Health*, 2013. **37**(5): p. 416-422.

- It may be helpful to provide some information about hepatitis B prevalence in the patient's country of origin. For example, *'In many Asia Pacific countries more than 1 in 10 people have hepatitis B'*.
- Health literacy assessments are particularly important in hepatitis B testing.
- Some people will not know the term 'hepatitis B' but may be familiar with other terms such as 'liver sickness' or 'yellow disease'.
- It is helpful to mention the availability of an effective vaccine prior to testing, particularly if the patient has risk factors for hepatitis B.
- Hepatitis B transmission primarily occurs from mother to child, and for people with hepatitis B, their understanding of the infection may include a cross-generational experience of the infection.

Discussing hepatitis B risk and transmission

Unlike HIV and hepatitis C, which have behavioural risk factors, the main risk factors for chronic hepatitis B relate to country of birth and Aboriginal and Torres Strait Islander origin. Participants emphasised the following considerations when discussing risk and transmission:

- Misinformation about transmission is very common. Being tested for hepatitis B is an opportunity to address and dispel common myths about transmission, such as that hepatitis B is transmitted through hugging and sharing eating utensils.
- Sensitivity regarding the interpersonal and familial nature of hepatitis B, particularly in relation to sexual transmission, is needed. Translated printed information may be helpful.
- Chronic hepatitis B isn't strongly associated with stigmatised behaviours, however discussions about hepatitis B transmission require stigma-sensitivity. Stigma is a powerful force among some individuals and communities due to general fear of transmission as well as some specific cultural beliefs related to hepatitis B. This can result in people diagnosed with hepatitis B being socially marginalised.

Information about the hepatitis B test

This consultation highlighted several key considerations about hepatitis B serological testing:

- The National Hepatitis B Testing Guidelines provide detailed information about which hepatitis B tests to order, and how to interpret the results. Despite this, testing practices and protocols vary widely according to setting.
- Test providers need to know their agency's protocols, but patients need only know what the test will tell them. For example, that the test will tell them whether or not they have hepatitis B, and whether or not they have protection from past infection or vaccination.
- The window period is generally not discussed, unless there is a risk of acute infection following a known exposure.

Delivering a negative hepatitis B result

Participants frequently drew attention to the impact of the wide variation in testing practices on the way that results could be delivered. In relation to negative results:

- A full hepatitis B testing panel reveals whether the person has been successfully vaccinated, or whether they have immunity from a past infection.
- For people whose results indicate that they have no immune protection, the test provider should discuss whether vaccination might be relevant.
- Vaccination is Medicare-funded for many groups at increased risk of hepatitis B. Engaging susceptible patients around the reasons for and benefits of vaccination often results in better completion rates.

Delivering a positive hepatitis B result

Participants working in hepatitis B identified that many healthcare providers were unsure about how to interpret hepatitis B results, particularly positive results. It was noted that in most cases further testing will be needed, however this is rarely urgent.

Immediate needs at the time of hepatitis B diagnosis

Delivering a diagnosis of chronic hepatitis B was described by many participants as an ongoing process. Several participants noted that there was an overwhelming amount of information to cover, and it was important to do this in an unhurried manner in order to engage with the person and their family. Most participants told us that:

- People need culturally appropriate information and discussions, as chronic disease management is significantly impacted by culture. Test providers need to work toward an understanding of the cultural and individual meaning of the hepatitis B diagnosis.
- Some people may be devastated by their hepatitis B diagnosis. Others may have a mild response, particularly if they are from a community in which hepatitis B has been normalised, or where the community has a limited understanding of hepatitis B. It is important for test providers to be aware of and work within these responses.
- People newly diagnosed with hepatitis B require several follow-up appointments.

Information about transmission and vaccination

A universal theme of discussions with participants was the importance of providing clear information about hepatitis B transmission in written and verbal formats. Three main aspects of transmission information were articulated:

- Most people with chronic hepatitis B acquire it at birth, and usually other people in the family will also have chronic hepatitis B.

- There are other ways that hepatitis B can be transmitted, and a safe and effective vaccine is available to prevent hepatitis B transmission. Conversations about vaccination may be more effective if they focus on the positive protective aspects of vaccination, and the potential for vaccination to end hepatitis B transmission within the family.
- Myths and misconceptions about transmission need to be addressed. People may overestimate the risk of household transmission of hepatitis B, and unnecessarily separate or ostracise people with hepatitis B.

Understanding chronic hepatitis B

Participants emphasised that understanding of hepatitis B as a chronic disease is often limited. Most participants noted that:

- It is important that people with chronic hepatitis B understand the importance of seeing their doctor regularly regardless of how well they may look or feel. The concept of asymptomatic disease generally underpins a good understanding of hepatitis B as a chronic disease. People also need to understand that treatment is available but is only needed by some people.
- Approaches to building understanding of hepatitis B as a chronic and often asymptomatic disease, especially among communities dealing with many chronic diseases, need to be individualised.
- The *Hepatitis B Story* is a health information resource which contains hepatitis B information in plain language and engaging graphics, and which has been translated into a range of community languages [54]. This resource was highly valued by participants, both in the context of building health literacy and supporting newly diagnosed people to understand hepatitis B. It is simple, pictorial, easy to use, non-judgemental, and effectively challenges stigma by normalising hepatitis B across all cultures and nationalities.

Other points include:

- People may become overwhelmed with the barrage of information and disengage from the process. Follow-up tests and results may offer additional incentive for the patient to attend follow-up appointments.
- Experienced GPs can manage people's hepatitis B virus in primary care settings from the point of diagnosis, however many GPs choose to refer to tertiary clinics. If GPs decide to refer newly diagnosed patients they should carefully explain the concept and role of referral, and the expected timeframe.

Disclosure and support

It was suggested by several participants that it might be useful for healthcare providers to have some specific knowledge about the legal implications of hepatitis B in the newly diagnosed person's country of origin. Disclosure laws and restrictions relating to hepatitis B, as well as social meanings and levels of stigma, are different around the world. While these will influence the way

that hepatitis B is understood within different migrant communities in Australia, it is important for people to understand that in most cases there are far fewer employment restrictions and disclosure requirements in Australia than there are in other countries.

Of the clinicians who worked in high hepatitis B caseload roles, several described the importance of providing some caution around disclosure. This was seen as particularly important for people who were not especially worried about their hepatitis B diagnosis, as they were often unaware that casual disclosure could result in stigma and discrimination.

Family testing and contact tracing

Most participants noted that newly diagnosed people were concerned about the risk to others, and the meaning of this diagnosis for their family. However, participants were careful to note that conversations about family testing and vaccination were often very sensitive and complex.

Participants identified considerations for effective discussions:

- They are highly dependent on the person's relationships with their partners and family, as well as on the cultural meanings and stigmas associated with hepatitis B within their community.
- It is better to proceed with the conversation about family testing and contact tracing in a gentle and patient-led manner, rather than in a system-led and threatening manner. The timeline is not urgent because most newly diagnosed patients have been living with hepatitis B since birth.
- This conversation was seen as closely linked with, and dependent on, the patient's understanding of hepatitis B transmission and the likelihood that several people in the family might also have hepatitis B. *'Are you in contact with your family? What would it be like to talk to your partner or family about testing? How might it affect your relationship?'*
- Healthcare providers can offer to speak to the parents, partners or children of newly diagnosed patients. They may also consider talking with patients about whether to contact any overseas family, keeping in mind that there may be different legal implications for positive people living overseas.
- The most effective approach is to support people to proceed in their preferred way. It is important to accept that people are not always in contact with their families, or able to discuss hepatitis B testing with their families. In these instances, it is more valuable to focus on building the relationship between the newly diagnosed person and their healthcare provider. Contact tracing discussions can be revisited at a later date.
- Contact tracing usually focuses on families and partners, rather than all household contacts. It is generally sufficient to give information about household prevention and the availability of free vaccine to contacts.

This consultation has highlighted that there is a lack of clarity about responsibility for contact tracing. The National Contact Tracing Guidelines [52] focus on sexual partners and are not applicable to chronic hepatitis B. Some key considerations:

- Doctors may be unclear about the extent to which they are responsible in the contact tracing process.
- Additional resources are needed to engage undiagnosed family members in care.
- The DHHS Partner Notification Officers do not work in chronic hepatitis B. An enhanced role in hepatitis B contact tracing would be welcome, as well as additional resources, but there are challenges and sensitivities associated with this in relation to marginalised or refugee communities.
- It is important to consider the impact on the individual of effectively being given responsibility for their own contact tracing.

Hepatitis C

Hepatitis C pre-test discussion

Initiating testing and curing hepatitis C

Curative treatments have fundamentally shifted hepatitis C from a chronic disease to a curable condition, and for most participants this has also significantly shifted their approach to pre- and post-test discussion. These shifts include:

- Cure represents a significant step towards normalising provider-initiated testing among providers who don't see themselves as working with populations at risk.
- Providing basic information about the availability of a cure prior to testing can mitigate the seriousness of any positive result.
- The advent of a more effective and tolerable cure for hepatitis C may mean condensed pre-test discussion, a reduced threshold for informed consent, and more active case finding for hepatitis C (including a wider interpretation of any guidelines that require risk factors to be present for testing).
- Patients may experience less anxiety and apprehension when testing, and it may contribute to destigmatising the testing experience for both patient and the provider.
- It is important to keep in mind that cure is not accessible or appropriate for everyone. People's anxieties about hepatitis C testing and diagnosis may persist despite their knowledge of curative treatments.

Explaining notification

Several participants who worked as testing providers noted that people being tested for hepatitis C often had a lot of questions about notifications.

- Some patients may benefit from further explanation that notifications are about population health rather than individual surveillance, and that their privacy is guaranteed. It may help to show the full list of notifiable infections, or to point out that notifications data helped influence the government decision to fund the hepatitis C cure for everyone.

- The hepatitis C notification form collects identifying data such as the newly diagnosed person's name, address and date of birth. This may be an issue for some people who inject drugs. The National Hepatitis C Testing Policy states that if notification is likely to be a barrier to testing, anonymised notification should take place [26].

Explaining the tests: Hepatitis C antibody, hepatitis C RNA (PCR)

Participants universally acknowledged the importance of both providers and patients understanding the tests required to diagnose hepatitis C. Two tests are required to confirm a hepatitis C diagnosis.

In Australia, the first line screening test for hepatitis C is an antibody test, however antibodies cannot confirm current infection as 25% of people who acquire hepatitis C will spontaneously clear the virus in the first 6 months. The HCV RNA test, also referred to as the PCR test, is the only test that can determine whether a person has current active hepatitis C. It is estimated that 81% of people living with hepatitis C in Australia have been diagnosed with an antibody test, but only 47% of those have had an RNA test to confirm their chronic hepatitis C infection [46].

Test providers need to explain the limitations of the hepatitis C antibody test as part of informed consent. Many participants talked about people who had been diagnosed based on the presence of hepatitis C antibodies, and who had lived for many years with the shame and stigma of hepatitis C, only to discover that they had been incorrectly diagnosed.

Window period

Participants' views differed as to whether information about the window period for the hepatitis C antibody test was essential in hepatitis C pre-test discussion. Some participants felt it should always be mentioned, and some would only mention it to people who disclosed risk factors. Others considered it sufficient to explain the window period when delivering and explaining a negative result.

Risk assessment for hepatitis C

Key testing guidelines recommend testing for hepatitis C only in the presence of risk [26, 50, 51], which informs the testing approach in many settings. Hepatitis C case finding initiatives often rely on asking direct questions about injecting history. Despite this, participants in this consultation generally took the position that direct pre-test questioning about the patient's history of injecting was of limited value for the patient and for their healthcare. Concern was expressed that it only added to stigma and judgement and extended the power imbalance between patient and provider.

Several participants suggested that services and testing providers should to carefully consider the purpose of hepatitis C risk assessment questioning. Many felt that direct questioning about risk factors was sometimes more for the purposes of surveillance, or to support the clinician, than to identify undiagnosed hepatitis C or to support people to reduce their risks.

Testing and venous access

A number of participants who work with people who inject talked about inaccessible veins and the implications for testing. Key points from these discussions include:

- Inaccessible veins may be a significant barrier to upscaling testing, as well as treatment, among people who inject due to the number of blood tests involved.
- Testing providers can acknowledge in a non-judgemental way that vein access and taking blood may be an issue for some people. Patients often have expert knowledge in accessing their veins.
- In some settings, nurses support people to access their own veins to draw blood for testing.
- Participants identified a need to improve access to testing for people with damaged veins. This could involve the development specialised phlebotomy skills, the use of butterflies or the utilisation of nonconventional veins.

Delivering a negative hepatitis C test result

The key consideration identified during this consultation is whether the negative result was from a hepatitis C antibody test or a hepatitis C RNA (PCR) test, as the meaning and window period is different for each of these tests. Specifically:

- A hepatitis C antibody negative result means that up until 3 months prior to the test there was no evidence of hepatitis C. A negative PCR result also indicates no evidence of hepatitis C.
- People who test antibody positive and PCR negative do not have hepatitis C. However, they are not immune to hepatitis C and reinfection is possible.
- People with hepatitis C antibodies will always be positive, and when being tested in future only a PCR test will be able to indicate a new infection.

Delivering a positive hepatitis C result

Immediate needs at the time of hepatitis C diagnosis

Participants identified several important considerations for discussions on the day of diagnosis, as well as the follow-up appointment(s). These include:

- The importance of clear and correct information, which, if needed, clarifies the difference between a positive antibody result and a positive HCV RNA (PCR) result. Because some people clear the virus naturally, only a positive PCR result is indicative of current infection.

- Many people experience shock and grief when diagnosed with hepatitis C, even in the era of hepatitis C cure. People may need to take time to make sense of their emotional response to the diagnosis before engaging with treatment services.
- A brief discussion about next steps is valuable, but it may be more important to attend to the person's response before going into detail about treatment. This could include asking people what they need, what the result means to them, and what's most important to them right at the moment.
- Many people with a history of injecting may experience shame and stigma at the time of diagnosis.
- They may prefer to follow up with a different service provider or find their own supports. Information about phone services and peer support services may be valuable.

Treatment

Common themes from discussions about treatment and cure:

- 95% of people with hepatitis C can be cured, and the path from diagnosis to cure is becoming more straightforward each year. However, people experiencing marginalisation, people who inject drugs and people with secondary needs requiring more complex levels of care may experience additional barriers to cure. An assessment of broader health and psychosocial care needs will provide important insight into where hepatitis C treatment might fit into a person's life.
- While there is usually no urgency to commence treatment, it may be helpful to begin the process of making a plan.
- All newly diagnosed people, including those that aren't ready for treatment, should understand the link between long-term untreated hepatitis C and liver cancer.

Disclosure and Contact Tracing

Test providers were seen as having a role in talking with newly diagnosed people about disclosure, as disclosure was associated with increased vulnerability to stigma. Participants recommended that these discussions include:

- Discussion about who people might tell, why, and what impact it might have.
- Information about the right to privacy, including that there is no requirement to disclose to partners, family or other contacts.

The National Contact Tracing Guidelines indicate that the diagnosing clinician has a role in supporting people newly diagnosed with hepatitis C to inform their contacts [52]. However, these guidelines, which focus primarily on sexual contacts, do not offer any consideration of the specific issues that arise in relation to contacting and notifying injecting networks. In Victoria, the Department of Health and Human Services does not provide any specific resources to support patients or healthcare providers to notify hepatitis C contacts. Interview and focus group

participants were asked about the extent to which they thought hepatitis C contact tracing was feasible. Participant views included:

- Clinicians rarely engage with clients about notifying their contacts about hepatitis C.
- Contact tracing initiatives that are used in HIV and STIs, such as anonymous SMS notification systems or the use of Victorian DHHS Partner Notification Officers, are not appropriate in the context of hepatitis C. Because of the illicit nature of drug use these would not be acceptable to people who inject, and their introduction would likely be a deterrent for testing.
- There are no guidelines or resources to support newly diagnosed people wishing to do contact tracing within their own networks, and the risk of harm outweighs any potential public health or individual benefit.

Conclusion and recommendations

Quality testing is central to linking people with BBVs into treatment and care, and it underpins the public health goal of the virtual elimination of HIV, hepatitis B and hepatitis C. This study set out to identify the components of quality HIV, hepatitis B and hepatitis C testing encounters, with emphasis on the non-medical needs of people around the time of testing and diagnosis.

It is important to understand and continually build on best practice in BBV pre- and post-test discussion in order to facilitate regular testing among people at increased risk, and to increase the rate of diagnosis among BBV-affected communities. This consultation highlighted that best practice also means finding strategies to adapt BBV test discussions to accommodate the many constraints that exist in generalist primary and community health services across Victoria. Healthcare providers need to be supported to understand that even a couple of moments spent discussing BBV testing with patients can be extremely valuable.

Risk factors and indicators for testing, particularly for chronic hepatitis B and HIV, are poorly understood by healthcare providers. BBV testing urgently needs to be normalised as part of general health and preventative care. Normalisation is pivotal to increasing BBV testing and rates of diagnosis and reducing late diagnosis among affected populations. Normalisation represents a shift away from the idea that testing is only offered to or needed by people at high risk of acquiring BBVs. In the context of HIV and hepatitis C, it is also a shift away from the outdated notion that conversations about testing require expert knowledge in management, or specialist skills in counselling and behaviour change.

Discussions about risk factors during the pre-test discussion require careful consideration. Direct questioning about risk practices, such as taking a risk history of drug use and sexual practices, may be a deterrent for testing. This approach is often experienced by patients as stigmatising, confronting and unnecessary. It can also be uncomfortable and difficult for healthcare providers, and may deter some providers from initiating testing discussions with their patients. Conversations about risk, prevention and contact tracing need to be patient-led and sensitive to the patient's cultural and community context.

HIV and hepatitis C testing will not be normalised until the impact of stigma is significantly diminished. The adoption of stigma-sensitive practice by test providers may help to minimise stigma for people being tested for BBVs. Stigma-sensitive practice involves the conscious application of basic communication skills to convey the practitioner's awareness that stigma exists and can be exacerbated in healthcare settings. Stigma-sensitive practice also involves the recognition that communities affected by BBVs experience many forms of marginalisation, and that the whole experience of testing is, for many people, not at all easy.

Recommendation: Adaption of workforce education initiatives to incorporate the concept of stigma-sensitive practice. In addition to medical and clinical information, GP education could include an overview of the published evidence relating to BBVs and stigma. Existing education initiatives may be enhanced by providing the opportunity for GPs to explore how values and belief systems impact on practice and identify and address any conflicts of value that may arise when

working with communities affected by BBVs, particularly people who inject and men who have sex with men.

Recommendation: Inclusion of enhanced information about the documented impact of BBV-related stigma on testing and engagement with care in future iterations of the National Testing Policies. In addition, further detail is needed about what constitutes ‘professional judgement’ and ‘ethical conduct’ in the context of BBV testing.

Recommendation: Service level evaluation of the approach to discussion and assessment of HIV and hepatitis C risk. In normalising provider-initiated HIV and hepatitis C testing, the use of direct questions about risk practices should be carefully weighed against the potential for direct questions to increase stigma, deter people from engaging with services, and deter healthcare providers from initiating testing.

Recommendation: Consideration of the role of peers and peer models in normalising testing. The value of expanding peer testing models, including peer-initiated testing in outreach settings, group testing and network testing, should be investigated.

Recommendation: Development or adaptation of a BBV health literacy assessment tool that can support healthcare providers to build patient health literacy and increase engagement with and understanding of patients’ individual health needs.

Recommendation: Exploration of methods for improving access to testing for people with damaged veins. This could involve the development of specialised phlebotomy skills, the use of butterflies, the utilisation of non-conventional veins, and improved policy and practice support for self-drawn blood.

Recommendation: Development of accessible written information about risk and prevention that healthcare providers can give to patients during testing. Resources need to be stigma-sensitive, culturally specific and produced in partnership with peer and community organisations.

Recommendation: The displaying of information leaflets and posters in waiting rooms and other testing environments, which indicate to service users that discussions about HIV and viral hepatitis are welcome.

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