





Australian Healthcare and Hospitals Association

Shared planning towards common goals

Addressing systemic barriers and stigma and discrimination to increase access to the health system by people at risk of or with HIV, hepatitis B and hepatitis C

Attn: Levinia Crooks

Australasian Society for HIV, Viral Hepatitis and Sexual

Health Medicine (ASHM)

levinia.crooks@ashm.org.au

Australian Healthcare and Hospitals Association

Unit 8, 2 Phipps Close Deakin ACT 2600

PO Box 78

Deakin West ACT 2600

P: 02 6162 0780 F: 02 6162 0779

E: admin@ahha.asn.au

W: <u>ahha.asn.au</u>

@AusHealthcare

face book.com/Aus Health care

ABN: 49 008 528 470

Table of Contents

1.	Introduction 1
2.	Interventions that focus on the health workforce 3
	2.1 Front-line and reception staff
	Background to intervention3
	Overview of intervention3
	Recommendations4
	2.2 Primary health care nurses (with consideration of nurses caring for people with blood
	borne viruses in other health care settings) 5
	Background to intervention5
	Overview of intervention5
	Recommendations6
	2.3 Undergraduate medical and other health professional education 7
	Background to intervention
	Overview of intervention7
	Recommendations8
	2.4 Health service managers and executives
	Background to intervention9
	Overview of intervention9
	Recommendations9
3.	Interventions to support health care workers with a blood borne virus11
	Background to intervention
	Overview of intervention11
	Recommendations11
4.	Interventions to address the systemic barrier of data completeness 13
	Background to interventions
	Overview of interventions
	Recommendations13
	Interventions to address the cost of opioid substitution therapy as a
sy	stemic barrier to treatment for hepatitis C infection 14
	Background to interventions14
	Recommendations14
6.	Interventions to support patient resilience 16
	Background to interventions
	Recommendations
7.	Next steps

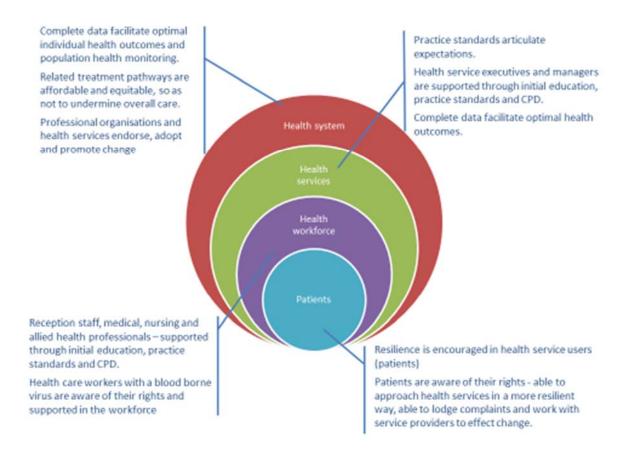
1. Introduction

The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) received funding from the Australian Government Department of Health to address systemic barriers and stigma and discrimination to increase access to the health system by people at risk of or with hepatitis B, hepatitis C or HIV.

The two-year project commenced in July 2016 with a review of existing health services that provide care to people diagnosed with HIV, hepatitis B and hepatitis C, to identify potential barriers to people at risk of or with HIV, hepatitis B and hepatitis C accessing the health system due to stigma and discrimination.

Through this review process, a number of priority areas were identified at various levels of the health system. These are depicted in Figure 1. Interventions in these priority areas were designed through working groups consisting of members of collaborating health services, health service implementation partners, research and communication partners, community collaborators, peer-led service organisations and additional subject-matter experts.

Figure 1. Priority areas



On 5 April 2017, representatives of collaborating health services, health service implementation partners, research and communication partners, and community collaborators came together to participate in a workshop facilitated by the Australian Healthcare and Hospitals Association (AHHA) to:

- Support increased awareness of the interventions being pursued within this project
- Workshop how they and their organisation or service could integrate these interventions in their own activities, systematically and sustainably, and to identify any further support required in order to achieve the greatest impact.

Shared planning towards common goals

The agenda for the workshop is included as Attachment 1. A list of services and organisations represented at the workshop is included as Attachment 2.

This report summarises discussions and recommendations from that workshop. They are grouped as follows:

- Interventions that focus on the health workforce
- Interventions to support health care workers with a blood borne virus
- Interventions to address the systemic barrier of data completeness
- Interventions to address the **cost of opioid substitution therapy** as a systemic barrier to treatment for hepatitis C infection
- Interventions to support patient resilience.

2. Interventions that focus on the health workforce

Australia's health workforce is 'large and diverse, ranging from highly qualified and specialised health professionals (about 43% of the health workforce) to workers with limited or no qualifications providing inhome care and support services'. As such, a range of interventions have been identified to address stigma and discrimination targeting different groups within the health workforce.

2.1 Front-line and reception staff

Background to intervention

While the project focuses on the health system, it was recognised that stigma in the community also impacts negatively on people's health seeking behaviour. Effort is therefore being devoted to providing front-line staff with strategies and resources to encourage resilience in their patients and service users and to encourage an open environment for consumer feedback about services.²

The qualification BSB31115 Certificate III in Business Administration (Medical) is available for those working in medical administration contexts. However there are no licensing, legislative or certification requirements applying to this qualification; any requirements for front-line or reception staff in health services are typically at the service level.

Experiences with training on stigma and discrimination that targeted front-line staff, e.g. in the Mid North Coast and Northern NSW Local Hospital Districts, showed there was significant interest and good attendance with such programs. Attendees in the program tended to lack awareness of their own stigmatising behaviours (i.e. they were not done intentionally), and so being able to watch scenarios in practice was identified as being useful for helping them to reflect on and address their own behaviour.

Overview of intervention

The intervention identified for this priority area is an online training program developed that will be relevant for all front-line or reception staff members, across all health services, including general practices, sexual health services, tertiary hospitals, community clinics, and pathology collection centres.

Participants in the workshop were provided a copy of a draft curriculum that identified the following training program objectives:

- A. Equipping health administrators working in reception and front of service positions with an understanding of:
 - the lived experience of hepatitis B, hepatitis C and HIV
 - the transmission of hepatitis B, hepatitis C and HIV
 - the management of hepatitis B, hepatitis C and HIV
 - key populations affected by hepatitis B and C and HIV
- B. Exploring how personal attitudes and preconceptions can influence how we interact with others, including patients, and providing insights into how these potentially discriminatory behaviours can be managed in the workplace through:
 - recognising issues
 - discussing issues with colleagues and supervisors, and
 - · trying to understand experience of the health system from the patients perspective, and

¹ Deeble Institute Issues Brief – Changing Health Professionals' Scope of Practice: How Do We Continue To Make Progress (2014)

² https://onthewards.org/systemic-barriers/

- from the perspective of the individual at risk of hepatitis B, hepatitis C and HIV, who will often experience similar stigma as that experienced by an individual with a diagnosis.
- C. Providing a refresher for existing reception staff, and providing new reception staff with an introduction to principles of:
 - · confidentiality, and
 - · respect in the health care setting, and
 - the supportive roles reception staff can play in improving the quality and completeness of data collected from patients.

The training program is being developed for online delivery including interactive and experiential components.

Recommendations

1. Health services to embed expectations of front-line and reception staff in their policies and procedures

Workshop participants discussed health services needing to recognise that many staff are untrained and have limited knowledge. They must ensure front-line and reception staff are clear about expectations, e.g.:

- Promotion of the Australian Charter of Healthcare Rights (or equivalent) in specifying the key rights of patients and consumers when seeking or receiving healthcare, and every staff member's role in upholding these rights
- Clear complaints/feedback mechanisms for patients and consumers, with staff aware of the importance of patients and consumers being able to express concerns, and an understanding of the value the service places on receiving feedback for quality improvement
- Addressing principles around stigma and discrimination through training more broadly, i.e. not limited to stigma and discrimination associated with blood borne viruses, but addressing stigma and discrimination more generally.
- Incorporating expectations relating to stigma and discrimination in the service's code of conduct.

Action: Incorporate these recommendations into training programs for front-line and reception staff, and into the role/responsibilities for health service managers/executives.

2. Competencies that address stigma and discrimination to be embedded in training package for qualification BSB31115 Certificate III in Business Administration (Medical)

PwC's Skills for Australia is the Skills Service Organisation responsible for this qualification within the vocational education training sector, in particular researching what skills are needed in the relevant industries, identifying and understanding current and emerging trends and revising qualifications and training programs to better match what people learn with the skills needed by the relevant industries. Advice has been received that the training package for this qualification was approved for review in February 2017 and is expected to commence soon.

Action: Participate in the PwC's Skills for Australia review process to incorporate competencies in addressing stigma and discrimination.

3. Online training to address challenging scenarios encountered in practice

Workshop participants identified the following challenges encountered by those in front-line and reception roles:

- Maintaining privacy and confidentiality, e.g. having conversations where the physical layout of service areas is not supportive (hospital emergency departments, GP reception areas, pharmacies, needle and syringe programs, community health services)
- Zero tolerance policies, i.e. where people turned away then do not receive health services.
 Such policies have a significant effect on the client population and services must consider their responsibility to the client along with their right to a safe workplace. Being able to manage difficult situations and de-escalating conflict is important, but if services are actively pursuing sanctions, this must be done with a plan of how continued engagement with the client is achieved.
- Fear of infection, e.g. perceptions of transmission
- Staff turnover and the impact on maintaining relationships with clients/patients, particularly in rural/remote areas
- Personal beliefs and how they impact on the service they provide, e.g. how stigma and discrimination can arise through incidental behaviours (talk amongst staff, making people wait, etc) and how profiling and stereotyping can lead to inappropriate assumptions.

Action: Training should be real and relatable. It should incorporate narrative (real stories) and filmed scenarios that address the challenging scenarios identified by workshop participants and support self-reflection by those participating in training.

2.2 Primary health care nurses (with consideration of nurses caring for people with blood borne viruses in other health care settings)³

Background to intervention

A barrier to people with HIV, hepatitis B or hepatitis C accessing health services can originate from the stigmatising attitudes of staff within facilities. Nurses play a key role in primary health, and particularly in general practice. Effort is therefore being devoted to describing the expectations around what primary health care nurses can do in their role to limit the impact of stigma and discrimination and how they can address systems-level issues to improve access to care.

Overview of intervention

The intervention identified for this priority area is an online learning module developed for primary health care nurses, specifically those working in general practice. However, it would also be relevant to the broader nursing workforce.

Participants in the workshop were provided a copy of a draft overview that identified the following learning objectives:

- Reflect on hepatitis B, hepatitis C or HIV-related stigma and discrimination and related concepts;
- Articulate the negative consequences of stigma and discrimination on people and communities,
- Outline key strategies to reduce hepatitis B, hepatitis C or HIV related stigma and discrimination;

³ Initially the project was going to focus on primary health care nurses, but the working group thought initiatives should be open to a broader nursing workforce, through professional nursing organisations and through the online training being accessible to all nurses from the ASHM website

• Identify practical resources for further information or assistance on hepatitis B, hepatitis C or HIV-related stigma and discrimination.

Additional suggestions for inclusion in the objectives which were identified as currently being reviewed by the relevant working group included:

- Practical implementation in the workplace based on reflection
- Leading by example
- Consider, reflect on and clarify own values, assumptions and attitudes
- Self-stigmatisation

Recommendations

1. Stigma and discrimination to be addressed in the various pathways towards nurses becoming registered and practising

Workshop participants discussed the pathways towards nurses becoming registered and practising being varied, including overseas trained nurses and nurses returning to the workforce after being out of practice. With an advancing evidence base, the levels and currency of knowledge about blood borne viruses was noted as being varied — many are likely to have a 'redundant' understanding.

Action: Pursue discussions with the Australia Health Practitioner Regulation Agency (AHPRA), the Nursing and Midwifery Board of Australia (NMBA), the Australian Nursing and Midwifery Accreditation Council (ANMAC), the Australian College of Nursing (ACN), Australian Primary Health Care Nurses Association (APNA), Royal District Nursing Association (RDNA) and Australian Nursing and Midwifery Federation (ANMF) about expectations regarding stigma and discrimination for nurses and midwives through undergraduate education, registration, re-registration and continuing professional development (CPD), as well as options to strengthen requirements.

2. Online learning module to reflect the leadership role that nurses can have

Workshop participants identified that nurses could have a leadership role in addressing stigma and discrimination, including:

- Nurses being in a position to identify when colleagues are being discriminatory, and so need to know how to support these colleagues (e.g. reference to code of conduct and ethics) as well as how to elevate concerns to senior staff
- Nurses being hypervigilant to stigma when patients and consumers are transferring from one service to the next, and so need to know their role in managing this
- Nurses providing orientation programs for new staff within services, and recognising the
 varying levels of knowledge, they need to be provided accurate information about such things
 as blood borne viruses, transmission, treatment as prevention (TasP) and staff with blood
 borne viruses.

Action: Online learning module should address the leadership role nurses can have in addressing stigma and discrimination.

3. Online learning module to address challenging scenarios encountered in practice

Workshop participants identified the following challenges encountered by those in front-line and reception roles:

Idiosyncrasies of the population with blood borne viruses (history vs present)

- Redundant understandings of blood borne viruses
- Personal beliefs and how they impact on the service they provide, e.g. how stigma and discrimination can arise through incidental behaviours (talk amongst staff, making people wait, etc) and how profiling and stereotyping can lead to inappropriate assumptions
- Zero tolerance policies, i.e. where people turned away then do not receive health services, and therefore the importance of managing difficult situations and de-escalating conflict
- Patients who continue substance use with serious physical and mental impacts.

Action: Training should be real and relatable. It should incorporate narrative (real stories) and filmed scenarios that address the challenging scenarios identified by workshop participants and support self-reflection by those participating in training. There should be positive stories, not just negative ones.

4. Health services to embed expectations of nursing staff in their policies and procedures

Workshop participants discussed health services needing to ensure nursing staff have clarity about expectations in relation to stigma and discrimination, but also be aware of the challenges staff face, e.g. through:

- Orientation programs for new staff
- Senior leaders spending time in clinical roles.

Action: Incorporate these recommendations into interventions for health service managers/executives

2.3 Undergraduate medical and other health professional education

Background to intervention

Research in Malaysia shows worrying attitudes of medical, dental and other health professional students towards people with a blood borne virus.⁴ Intentions to discriminate can be identified early in education programs, and so addressing and assessing stigma and discrimination should be included early in training pathways for all health professionals.

Resources have been developed outside this project to provide guidance on inclusive language in respecting people of intersex, trans and gender diverse experience.⁵,⁶

The respective working group is considering such things as how to influence the standards and curricula of the many education and training programs, as well as the development of a package (including training and tools/resources/checklists) that could be implementable across disciplines with options for tailoring to specific settings.

Overview of intervention

The intervention identified for this priority area is the development of a package (including training and tools/resources/checklists) that could be implementable across professions/disciplines with options for tailoring to specific settings.

⁴ Earnshaw V, et al. Exploring intentions to discriminate against patients living with HIV/AIDS among future healthcare providers in Malaysia. Trop Med Int Health 2014;19(6):672-9.

⁵ The Genderbread Person. University of Tasmania

⁶ Inclusive Language Guide: Respecting people of intersex, trans and gender diverse experience. Sydney: National LGBTI Health Alliance; 2013.

Recommendations

1. Stigma and discrimination to be addressed in the various education and training programs towards medical practitioners and other health professionals becoming registered and practising Workshop participants discussed the pathways towards nurses becoming registered and practising were varied, including overseas trained nurses, nurses returning to the workforce after being out of practice. With an advancing evidence base, the levels and currency of knowledge about blood born viruses varies – many are likely to have a 'redundant' understanding.

Action: Pursue discussions with the Australia Health Practitioner Regulation Agency (AHPRA), the Medical Board of Australia (MBA), the Australian Medical Council (AMC) and relevant professional colleges (e.g. Royal Australian College of General Practitioners) about expectations regarding stigma and discrimination for medical practitioners through undergraduate education, postgraduate training, registration, re-registration and continuing professional development (CPD), as well as options to embed/strengthen requirements. Equivalent discussions with the regulatory and accreditation bodies for the other health professionals.

Action: Continue discussions with Sydney University to develop pilot for inclusion in Medical, Nursing and Allied Health training curricula (consider pan-professional training, in new school). This could act as a model for uptake by other institutions.

Action: Pursue discussions with Heads of medical and other health professional programs about expectations regarding stigma and discrimination for medical practitioners and other health professionals, and options for embedding/strengthening its inclusion in curricula of programs leading to registration (e.g. desired inclusion/format of a package if developed and likely uptake).

Action: Pursue discussions with state educational bodies (e.g. Health Education and Training Institute NSW; HETI) and Colleges and Societies about expectations regarding stigma and discrimination for medical practitioners, and options for embedding/strengthening its inclusion in curricula of postgraduate and CPD programs (e.g. desired inclusion/format of a package if developed and likely uptake).

Action: Explore the opportunity of a collaborative workshop bringing together representatives of the regulated health professions' national boards, accreditation authorities, AHPRA, self-regulating health professions, education providers, government health departments, health service executive to improve how stigma and discrimination is addressed in the education of health professions in Australia (e.g. modelled on the workshop *Collaborating for Patient Care – Interprofessional Learning for Interprofessional Practice*, held in June 2015).

2. Undergraduate training, intern training and continuing professional development (CPD) to address challenging scenarios encountered in practice

Workshop participants identified the following challenges encountered by those in medical roles:

- Breaking down stereotypes
- The consequences of 'stigmatised people'

⁷ Workshop report: Collaborating for patient care. At: www.healthprofessionscouncils.org.au/files/7c4d0b610f2d2161ec0828fcd57372350ef0f6f0_original.pdf

- How much detail to seek in clinical histories
- Rural confidentiality
- Referral letters and information provided in transitions of care
- Injecting drug use
- Behaviours with continued substance use.

Students through to practising health professionals need exposure to people with lived experience, including exposure to patients who can explain the consequences of not addressing stigma and discrimination. They need exercises in managing the consequences of stigma and discrimination.

Action: Training should be real and relatable. It should incorporate people with lived experience. It should address the challenging scenarios identified by workshop participants and support self-reflection by those participating in training. There should be positive stories, not just negative ones.

2.4 Health service managers and executives

Background to intervention

While attitudes may be ingrained in the health workforce outside of the workplace, behaviour inside the workplace needs to be modulated and acceptable. CEOs and senior staff may or may not be aware of the problems associated with stigma and discrimination, but even those who are, may not have the capacity to have changes in these areas prioritised above other demands on funds, for example waiting lists, emergency wait times. The challenge then becomes how to give executive and senior management staff the evidence, resources and tools to be able to make meaningful change, recognising these are generally unregulated professional groups.

Overview of intervention

Opportunities identified for this priority area included the development of content for incorporation into the programs of the Australasian College of Health Service Management (ACHSM), including their Congress, CPD offering, internship program, Fellowship program, mentoring, and University accreditation requirements. Requirements around stigma and discrimination can be embedded in the global competency standards ACHSM is working on with the International Hospital Federation.

Recommendations

1. Executives and managers to set the culture

Workshop participants discussed that there is an absence of supportive policies for employees about expectations and responding to stigma and discrimination, which can lead to a lack of compliance with existing legislation, which then impacts on patients/clients.

There should be an expectation that executives and managers model appropriate behaviour and language.

Action: The need for executives and managers to set the culture of the service/organisation and embed stigma and discrimination reduction in all policies, procedures and their own behaviour should be incorporated into ACHSM programs.

2. Induction and orientation processes support employees with varied backgrounds and experience

Workshop participants discussed that employees will have different levels of experience working with different patient/client groups, and will bring their own stigma with them. Induction and orientation processes need to raise an individual's consciousness of their own stigma; set an expectation of a zero tolerance environment; and link stigma and discrimination to poor outcomes for patients (e.g. sub-optimal treatment, low patient satisfaction).

Action: Designing induction and orientation processes to address stigma and discrimination should be incorporated into ACHSM programs.

3. Co-design of services

Workshop participants discussed that genuine (not tokenistic) engagement with consumer representatives is important in the design, implementation and evaluation of services intended for them. There should be clear reasons for engaging with them, and they should be supported and trained to understand how to contribute most effectively.

Action: The need for executives/managers to engage genuinely with consumer representatives in addressing stigma and discrimination, and how to do this most effectively, should be incorporated into ACHSM programs.

4. Quality improvement processes

Workshop participants discussed that complaints processes are too often default processes that put the onus on patients to advocate for themselves, which patients/clients may believe leads to (real or perceived) worse care.

It was discussed that both formal and informal feedback mechanisms should be available to patients/clients. Patient and employee satisfaction processes may be avenues to explore for engaging with the management system. There should also be transparency about complaints, with all feedback to be built into quality improvement processes.

Action: The need for executives/managers to ensure feedback and complaints process are supportive, transparent and used in quality improvement processes, and how to do this most effectively, should be incorporated into ACSHM programs.

5. Funding to drive change

Workshop participants discussed whether funding could be tied to measurable outcomes around stigma and discrimination.

Action: To explore the opportunities for funding of health services to be linked to measurable outcomes around stigma and discrimination.

3. Interventions to support health care workers with a blood borne virus

Background to intervention

The Communicable Diseases Network Australia (CDNA) was established in 1989 as the Communicable Diseases Control Network, as a joint initiative of the National Health and Medical Research Council and Australian Health Ministers' Advisory Council. Its goal is to provide national public health co-ordination and leadership, and support best practice for the prevention and control of communicable diseases.

CDNA has been revising the *Australian National Guidelines for the Management of Health Care Workers known to be infected with Blood Borne Viruses*. These were last published in 2012, and do not allow health care workers known to be with a blood borne virus to perform exposure prone procedures (EPPs), even if achieving an undetectable viral load on effective antiretroviral therapy. In 2014, guidelines in the United Kingdom were updated to allow health care workers with a HIV to perform EPPs. The UK approach includes registering those health care workers known to have HIV.

With the Australian review, the focus is on balancing tensions between meeting the needs of health care workers and public health risks. It was reported that allowing health care workers on HIV treatment with low viral loads to perform EPPs was not contentious and had good level of agreement. However, it is the type and frequency of testing required by these workers that is still being considered. A register of those with a BBV is unlikely in Australia, with the approach more likely to be focussed on professional standards. The goal will be to support health care workers to return to performing EPPs when this can be done safely.

Overview of intervention

Once the revised version is endorsed, there will be an opportunity to:

- Promulgate existing provisions and changes to the guidelines through the health service so that health care workers with a BBV are not stigmatised and/or discriminated against
- Promulgate this information to health care workers with a BBV so that they might reconsider past decisions about employment.

Recommendations

1. Communication strategy for the health workforce

Workshop participants discussed that once endorsed, the revised version of the policy would need to be promulgated to the health workforce broadly, e.g. through:

- Registration bodies
- Professional bodies
- University education bodies (for prospective health care workers)
- Conferences and professional development activities (e.g ACHSM conference).

Communication of key messages needs to be done with:

- Consistency across all audiences, yet adapted for the different audiences by the organisations that communicate with the particular constituencies, e.g. through position statements, articles in journals.
- Clarity around definitions, e.g. what constitutes an EPP
- Non-stigmatising language, e.g. health care worker with BBV not 'infected HCW'

Action: To develop a broad communication strategy to reach the different members of the health workforce

Action: ASHM to work with CDNA on language throughout the revised guidelines, noting that there are some specific terms that relate to the actual testing of an individual and language may need to be specific to reflect this

2. Communication with health care workers with a blood borne virus

It was discussed that support would be needed for health care workers with blood borne viruses, as the release of new guidelines may activate/reactivate ongoing trauma associated with disclosure. These health care workers will need to re-consider whether they disclose their health status, and may need support in this process. It was noted that there was a national support program for nurses and midwives in Victoria that case manages those with blood borne viruses. A similar one exists for medical practitioners as well.

Action: To consider support required for health care workers with a blood borne virus with the release of the revised guidelines.

3. Support for managers when health care workers choose to disclose infection status

It was discussed that health care workers who disclose that they have HIV, hepatitis B and hepatitis C puts them in a vulnerable state. As such it would be valuable for managers to have a framework for responding to those who disclose, to help guide a compassionate response. This would include an example response that thanks them for trusting them in disclosing this information, and reassuring them it will be kept confidential.

Action: Develop a framework and supporting resources to support Managers when responding to a health care worker who discloses that they have HIV, hepatitis B and hepatitis C.

4. Interventions to address the systemic barrier of data completeness

Background to interventions

Incomplete data can make it more difficult for people with or at risk of HIV or viral hepatitis to access the health system. Incompleteness can be related to the way software captures data in electronic health records (e.g. how gender is recorded; providing options of Indigenous vs Australian), or how data is communicated between providers (e.g. a former positive Hepatitis C result being included in a referral note when the patient is no longer positive or the result irrelevant to the current condition being managed). This may be a result of or contribute to stigmatising and stereotyping behaviour, potentially compromising health outcomes.

Overview of interventions

Interventions identified as being most influential in addressing this priority area require broad system reform, e.g. national primary care datasets, standards and accreditation of software systems in general practice. Considerable work is progressing in this area and a summary document was included in the workshop papers (see Attachment 3). Other opportunities for interventions included incorporating data completeness as an element in accreditation process audits and exploring how feedback/reports on data can be fed back to those who provide the data as a stimulus for improvement.

Recommendations

1. Participate in reform opportunities, rather than drive reform

Workshop participants discussed that standardised data collection and monitoring was the focus of a number of organisations and programs, e.g. Australian Digital Health Agency, the Australian Commission for Safety and Quality in Healthcare, Australian Immunisation Register, National Notifiable Diseases Surveillance System, Primary Health Networks, RACGP eHealth committee. It was discussed that it would be a more effective and efficient use of resources to look at how ASHM and collaborating groups could participate in and contribute to this work.

Action: To identify the patient outcomes that are compromised as a result of poor data, and prioritise data required to address those patient outcomes.

Action: To identify current activity occurring in the area of data collection, monitoring and reform; map the identified data requirements against these activities; and participate in influencing these activities to achieve improved data.

Action: Work with AHHA and the Deeble Institute on their health data initiatives, including contributing evidence to the AHHA Data Collaboration Network.

2. (Within the scope of this project) Promote data quality, improved data collection and use of data.

Benefits from changes to data collection will be reliant on good existing data. Workshop participants discussed the value of promoting best data quality and the health workforce having an understanding of the importance of data quality and the use of data.

Action: Include a module on data quality in the training for frontline and reception staff.

Action: Explore the possibility of a Data Quality Audit with the Primary Health Networks.

5. Interventions to address the cost of opioid substitution therapy as a systemic barrier to treatment for hepatitis C infection

Background to interventions

The recent introduction of highly effective hepatitis C treatment has the potential of eliminating hepatitis C in Australia. These new treatments, which are available to everyone with chronic hepatitis C, irrespective of the stage of their illness, have begun to change the hepatitis C landscape. However, this significant investment in universal treatment by the Australian Government, has come with challenges; most notably, finding effective ways to engage with one of the largest hepatitis C cohorts – people who inject drugs, while also strengthening existing and creating new pathways to treatment within a range of community based settings.

A draft paper (see Attachment 4), titled 'Poor access to pharmacotherapy will jeopardise HCV eradication' was circulated to workshop participants on the current arrangements for opioid substitution therapy in Australia and the implications for hepatitis C treatment, asking; what are the real or additional costs of making pharmacotherapy unaffordable and inaccessible for people who undertake hepatitis C treatments.

Recommendations

1. Agreement that cost of opioid substitution therapy is a systemic barrier to those with or at risk of hepatitis C from accessing healthcare

It was discussed that there needed to be increased awareness of the link between opioid substitution therapy and the prevention/treatment of hepatitis C, in particular in terms of the Government's investment in hepatitis C treatment (reinfection is expensive).

It was discussed that while opioid substitution therapy itself is PBS-funded, dispensing fees for those receiving care in community pharmacies are met by the patient/client and vary significantly between States/Territories (estimated between \$30 and \$85 per week). This can constitute a significant proportion of a patient/client's income, and thereby compromise patient outcomes, including in relation to hepatitis C treatment.

Action: With agreement that the cost of opioid substitution therapy through community pharmacy is a systemic barrier to those with or at risk of hepatitis C from accessing healthcare, interventions that address this should continue to be considered within the scope of the ASHM project.

2. Pursue broader stakeholder engagement and consultation around this issue

It was discussed that community pharmacies have a central role in the provision of opioid substitution therapy. Approval of and processes for the provision of opioid substitution therapy through community pharmacy are regulated by State/Territory governments, as such funding and support varies between States/Territories. Access may be impacted by both cost to patients/clients and number/location of participating pharmacies

Discussion included:

That provision of opioid substitution therapy needed to be considered a public health issue
 mainstream and normalised

Shared planning towards common goals

- The dispensing of opioid substitution therapy should not be provided in isolation;
 dispensing should be provided within holistic models of care
- Consideration of whether any funding/incentives to community pharmacies from government could be linked to stigma/discrimination training

While cost was the primary issue, it was also discussed that clarity was needed about whether there were a sufficient number of pharmacies providing services (with adequate opening hours), and if not, whether barriers to recruiting pharmacies relating to stigma and discrimination could be addressed.

The potential for innovative models for providing opioid substitution therapy were discussed. One example raised was the service provided through CoHealth (Melbourne), with patients/clients paying an annual fee and then being entitled to free dispensing.

Action: Engage with community pharmacy organisations and State/Territory Governments (Drugs and Poisons) to address cost of opioid substitution therapy as a barrier to those with or at risk of hepatitis C accessing healthcare; both from a public health perspective and for cost-effectiveness. Facilitate a round-table to discuss options for pursuing work in this area.

Action: Engage with community pharmacy organisations to promote the benefits of opioid substitution therapy and educate on addressing stigma and discrimination in the provision of opioid substitution therapy services. Build on the current work done with community pharmacies on dispensing of HIV medicines.

Action: Review innovative models for providing opioid substitution therapy; pursue piloting alternative models of care that provide more holistic and integrated care.

Action: Identify a model that brings together a multidisciplinary team consisting of primary health, primary mental health and pharmacotherapy programs for persons being released from prison are implemented. These services need to be integrated with existing alcohol and drug treatment, housing and employment services to ensure greater impact on a client's overall wellbeing.

6. Interventions to support patient resilience

Background to interventions

Across all interventions, it is important to ensure patients (or would be patients) are:

- Aware of their rights
- Able to approach health services in a more resilient way
- Able to lodge complaints and work with service providers to achieve change.

Capacity must be built for both patients and services in this respect.

Recommendations

1. Peer advocates and navigators

It was discussed that patient advocates and/or navigators, people with lived experience who were available to attend healthcare services with someone at risk of or with HIV, hepatitis B and hepatitis C, would be beneficial. It was discussed that complaints need to be made by the patient/client with support of a peer advocate. It was debated whether advocates/navigators should be brought by the patient/client themselves, or provided by the service. The cost-effectiveness of high caseload services providing this support was considered valid, while exploration of different models or referred pathways for lower caseload services was recommended.

Action: Explore models for patient advocates and navigators

2. Feedback and complaints

It was discussed that various avenues for providing feedback and complaints were needed. Services should not restrict mechanisms to 'in writing' only; there needs to be quick and verbal mechanism supported.

It was discussed that processes to consider feedback and complaints should be transparent, e.g. with them being considered by patient advisory groups so patients/clients can be assured their feedback will be treated with integrity.

Action: See Recommendations under 2.1 Front-line and reception staff and 2.4 Health service managers and executives.

7. Next steps

It is intended that:

- ASHM will consider the recommended actions from this workshop and use them in building a work
 plan to utilise funding provided under this project in the most effective and efficient manner in
 order to address systemic barriers and stigma and discrimination to increase access to the health
 system by people at risk of or with hepatitis B, hepatitis C or HIV.
- Collaborating health services, health service implementation partners, research and communication partners, and community collaborators will continue to consider how the activities being pursued by ASHM and recommendations from workshop participants can be embedded in their ongoing activities.