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- | A low cost effective and innovative method for the reduction of Catheter Associated Urinary Tract Infection rates in a tertiary care centre in Kolkata, India
- | On Humanistic Culture: A Brief Introduction of Nanjing Drum Tower Hospital
- | Patient-friendly begins with a smile
- | Towards the Unknown Future: Health Governance and Applications Development Interconnected with Smart Health IoT
- | Addressing stigma and discrimination to increase access to the health system for people at risk of or living with HIV, hepatitis B and hepatitis C
- | Healthcare Reform – What we can learn from Yozan Uesugi –
- | Assessment of Public Hospitals in the Eastern Mediterranean Region, WHO

## Opinion Matters

- | Healthcare technology with a Human touch for a 'Patient Positive' experience

Abstracts: Français, Español, 中文



# Addressing stigma and discrimination to increase access to the health system for people at risk of or living with HIV, hepatitis B and hepatitis C



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**ABSTRACT:** Australia is a leader in its response to HIV, and most recently, hepatitis C –embracing the latest research, building evidence-based responses founded on multisector collaboration, and offering universal access to treatments.

However, stigma and discrimination by the health workforce towards those at risk of or living with HIV, hepatitis B and hepatitis C may hinder patient access to the health system. The impact is considerable, not just for the individual involved, but also on efforts to effectively and efficiently reduce disease prevalence.

This article discusses the comprehensive and collaborative approach being led by the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM), with funding from the Australian Government Department of Health, addressing stigma and discrimination to increase access to the health system by people at risk of or living with HIV, hepatitis B and hepatitis C.

## **B**ackground.

Australia is a leader in its response to HIV, and most recently, hepatitis C –embracing the latest research, building evidence-based responses founded on multisector collaboration, and offering universal access to treatments.

However, stigma and discrimination within the health system towards those at risk of or living with HIV, hepatitis B and hepatitis C may hinder patient access to health care. The impact is considerable, not just for the individual involved, but also on efforts to effectively and efficiently reduce disease prevalence.

*'HIV and viral hepatitis are about sex and drugs. It is all too easy for value judgements to compromise the fundamental Hippocratic principles of quality, compassion and unbiased health care.'*

*The discrimination can take many forms, including denial of care, inferior care, unjust barriers to service provision and lack of respect. It might be as simple as the terminology used on patient documentation, or the language used when communicating with colleagues.'*  
(Crooks)

## Leading a comprehensive and coordinated response

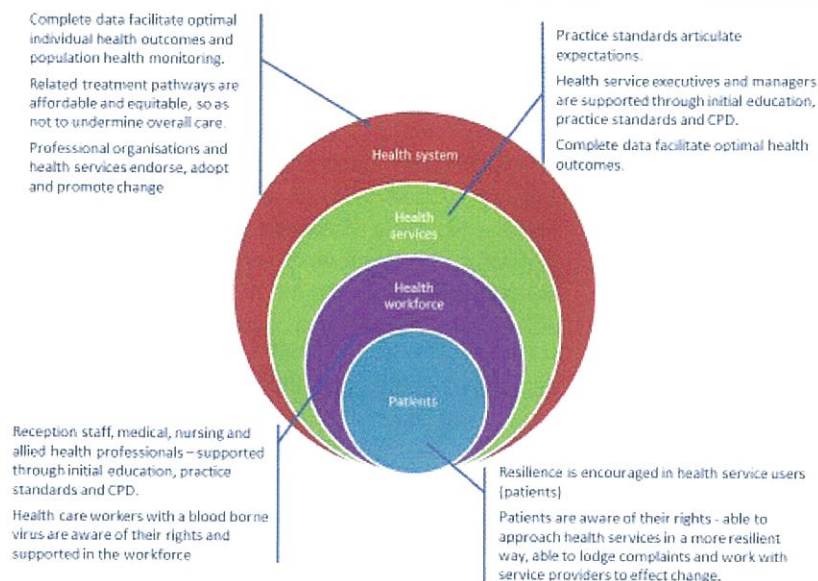
The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM), with funding from the Australian Government Department of Health, is addressing stigma and discrimination to increase access to health care by people at risk of or living with HIV, hepatitis B and hepatitis C.

The two-year project commenced in July 2016 with a literature review, community consultation and a review of existing health services to identify potential health care access barriers to people at risk of or living with HIV, hepatitis B and hepatitis C due to stigma and discrimination.

Through this process, a number of priority areas were identified at patient/consumer, health workforce, health services and more broadly at health system level (Figure 1).

Interventions in these priority areas were designed through working groups consisting of members of collaborating health services, implementation partners (i.e. other peak bodies across the health sector), research and communication partners, community collaborators, peer-led service organisations and additional subject-matter experts. In April 2017, representatives of these collaborators came together to participate in a



**FIGURE 1. PRIORITY AREAS IN ADDRESSING STIGMA AND DISCRIMINATION OF PEOPLE ACCESSING THE HEALTH SYSTEM**

workshop facilitated by the Australian Healthcare and Hospitals Association (AHHA) to:

- Increase awareness of the interventions being pursued within this project
- Workshop how they and their organisation/service could systematically and sustainably integrate them in their own activities, to achieve the greatest impact.

The interventions and resources now being pursued can be embraced by all those working in the health sector to address stigma and discrimination, and consist of:

- Supporting **patient resilience and awareness of rights**, including where patients are health care workers themselves
- Providing education across the **health workforce** (reception and front line staff, medical, nursing and allied health professionals; undergraduate through to continuing professional development)
- Considering broader health system factors such as **data completeness** and the **affordability of related treatment pathways**.

### Supporting patient resilience and awareness of rights

To effectively access health care, it was identified as important that patients with or at risk of HIV, hepatitis B and hepatitis C be:

- 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.

The value of patients being supported by peer advocates and/or navigators when accessing health care was identified during the workshop. These would be people with lived experience who were available to attend healthcare services with someone at risk of or living with HIV, hepatitis B and hepatitis C. Different models for patient advocates and navigators need to be explored to account for different types and caseloads of different services.

It was also identified that health services needed to provide various mechanisms by which feedback and complaints could be received and acted upon. The processes by which such feedback was considered and actioned by health services would need to be transparent so that patients could be assured it was treated appropriately and with integrity.

Where people with a BBV are health care workers themselves, information needs to be promulgated about upcoming changes to Australian guidelines<sup>2</sup> that relate to them being able to return to performing exposure prone procedures, where this can be done safely. While a welcomed

change, ongoing trauma associated with disclosure of their health status may be activated/reactivated and so they will need to be supported in this process. Furthermore, managers within health services require guidance on responding compassionately when a health care worker discloses this information.

### Education for 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 in-home care and support services'.<sup>3</sup> As such, a range of interventions has been identified to address stigma and discrimination affecting different groups within the health workforce, while also examining opportunities to strengthen requirements for addressing stigma and discrimination, through undergraduate education, registration and re-registration requirements, and continuing professional development (CPD), where applicable.

Front-line and reception staff across all health services, including general practices, sexual health services, tertiary hospitals, community clinics, and pathology collection centres will be provided access to an interactive, online training program. Said training will not only support staff in understanding lived experience, transmission and management of HIV, hepatitis B and hepatitis C, but also in exploring how personal attitudes and preconceptions can influence how we interact with others (including patients), with the introduction of the principles of confidentiality and respect in the health care setting, and providing insights into how these potentially discriminatory behaviours can be managed in the workplace. While there are no mandatory qualifications or training requirements for such staff, embedding competencies that address stigma and discrimination in relevant vocational qualifications will also be pursued.

Primary health care and hospital-based nurses will be provided access to an interactive, online training program that is relevant



to their role in limiting the impact of stigma and discrimination, informing them on how they can address systems-level issues to improve access to care. Such training is also likely to be relevant to nurses in other health care settings caring for people with BBV.

Undergraduate medical and other health professional education is another area of focus. Standards and curricula of the many education programs need to incorporate expectations around stigma and discrimination. A package (including training and tools/resources/checklists) that can be implemented across disciplines, but also with options for tailoring to specific settings, is being developed.

Across all audiences, online training is being developed in the form of a responsive web application which can be used on desktop, mobile and tablet devices. Gamification is being utilised to encourage users to take on the identity of a character and simulate a set of situations where users are expected to make decisions in different circumstances. Users are also encouraged to try out alternative courses of action and experience a range of different outcomes for the characters involved.

### Setting the culture of health services

Health service managers and executives are expected to set the culture of the service/organisation and embed stigma and discrimination in all policies and procedures, as well as model appropriate behaviour and language. In the workshop it was identified that induction and orientation processes should support employees with varied backgrounds and experience in working with different patient/client groups, raise the individual's consciousness of their own stigma, and set an expectation of zero tolerance for stigma and discrimination. Consumers should be engaged in the design, implementation and evaluation of services intended for them. Formal and informal feedback mechanisms should be available, with transparency about how feedback received contributes to the service/organisation's quality improvement processes.

To progress change in this area, ASHM are partnering with the Australasian College of Health Service Management (ACHSM) to incorporate expectations around stigma and discrimination into their CPD offering, internship program, Fellowship program, mentoring and University accreditation requirements for health service managers.

### Quality data collection and use across the health system

It was identified that 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 health service software captures data in electronic health records (e.g. how gender is recorded; providing alternative options of Indigenous versus Australian, when Indigenous people would select both), 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). It was discussed that this may be a result of or contribute to stigmatising and stereotyping behaviour, potentially compromising health outcomes.

The importance of data quality, improved data collection and improved use of data will be incorporated into education for the health workforce, as discussed earlier. The potential for

conducting data quality audits in this area will also be explored.

However, 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; and access to data analytics. Standardised data collection and monitoring is the focus of a number of organisations and programs in Australia, 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, the Royal Australian College of General Practitioners eHealth committee, and the AHHA Data Collaboration Network. ASHM will participate and contribute to this reform process.

### Funding models in related treatment pathways

Recently, there has been a significant investment by the Australian Government in universal access to treatment for hepatitis C. However, with one of the largest patient cohorts with hepatitis C being people who inject drugs, the funding model for opioid substitution therapy (OST) in Australia has the potential to jeopardise this investment.

While the OST itself (typically methadone or buprenorphine) is subsidised by Australia's universal insurance scheme, the Pharmaceutical Benefits Scheme, patients using OST are required to pay a daily fee to the community pharmacy to cover dispensing and compliance costs in some jurisdictions. The amount of this fee varies between States and Territories across Australia. If patients are unable to pay this daily fee, they may leave the OST program and be at risk of getting infected or reinfected with hepatitis C.

ASHM will pursue broad stakeholder engagement and consultation around this issue to ensure the provision of OST is recognised as a public health issue, to achieve dispensing of OST within more holistic models of care, and to explore innovative models of care and alternative funding models.

### Conclusion

Continued collaboration to comprehensively address stigma and discrimination of those at risk of or living with HIV, hepatitis B and hepatitis C, across all levels of the health system, will increase access to the health system, improve patient care and realise the value of Australia's investment in therapies for these diseases.

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