Responding to a national policy need: development of a stigma indicator for bloodborne viruses and sexually transmissible infections

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In Australia, there are five strategies that set out a national response to HIV, viral hepatitis and sexually transmissible infections.[1-5] Each strategy contains a set of objectives that work towards reducing the transmission, morbidity and mortality associated with these infections, with progress monitored via a set of related indicators. A clear objective exists within each of the five strategies to "eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health".[1-5] However, until recently, there has been no indicator to measure stigma and monitor progress against these objectives. This commentary outlines an approach taken to develop a stigma indicator and lessons learned from its implementation in surveys of priority population groups.

Stigma

Stigma is a complex construct, referring to a social process of exclusion, whereby an individual or social group possesses a "deeply discrediting" attribute that contradicts what a broader social group deems to be "normal".[6] The individual is therefore reduced from "a whole and usual person to a tainted, discounted one".[6] When people perceive themselves as being stigmatised, they may also come to hold the same negative perceptions about themselves, leading to an internalisation of stigma and acceptance of a "spoiled identity".[6,7] Parker and Aggleton[8] argue that stigma must be understood as reflecting relationships of power and control, enabling dominant social groups to justify their positions of power within contexts of inequality. Enacted stigma (i.e. discrimination) takes many different forms (e.g. avoidance, excessive pity, blame, shame, abuse, exclusion) and occurs in a range of different contexts and settings. Structural stigma can also serve to legitimise the exclusion of stigmatised groups through coercive public policies, criminalisation and negative media portrayal.[8,9]

Stigma can be directed towards many different attributes (e.g. physical characteristics, lifestyle choices, religious affiliation, socioeconomic status, gender, sexual orientation) with the enactment of stigma and related health outcomes varying greatly between different stigmatised groups.[10] Communicable infections may attract stigma due to a fear of contagion,[11] which is often exacerbated by negative attitudes towards behaviours that increase risk of infection, e.g. unprotected sex, shared use of equipment for injecting drugs.[12-14] The combination of co-occurring stigmatised attributes (infectiousness and perceived mode of transmission) may result in a layering of stigma,[15] with the individual being viewed as irresponsible for both acquiring an infection and for potentially placing others at risk.[13,16,17] This multi-layered stigma has significant implications for healthcare, treatment delivery and health outcomes.[15,18,19]

Research has widely demonstrated the negative impacts of stigma. Whether a person anticipates, perceives or experiences stigma and discrimination, this can result in harmful effects on their quality of life, relationships and healthcare utilisation.[20,21] Common adverse outcomes include stress, shame, depression, isolation, maladaptive coping, poor emotional regulation and increased risk taking.[22-26] Stigmatised individuals are also less likely to disclose health conditions (in both healthcare and interpersonal contexts), more likely to avoid healthcare consultations, and less likely to adhere to treatment, thereby reducing treatment effectiveness.[26-29] In addition, some healthcare workers may hold negative attitudes towards stigmatised client groups, resulting in discriminatory practices, e.g. unwillingness to administer treatment, reluctance to perform medical procedures, use of excessive infection control.[30,31]

Stigma indicators monitoring project for bloodborne viruses and sexually transmissible infections

> Stigma remains the single most important barrier to public action. United Nations General Secretary, 17th International AIDS Conference in Mexico City (August 2008)

In 2015, the Australian Government Department of Health provided funding to the Centre for Social Research in Health (UNSW Sydney) to develop an indicator of stigma among priority groups identified by the national strategies:

- Gay and other men who have sex with men
- People who inject drugs
- People living with HIV
- People living with viral hepatitis (B and C)
- People who engage in sex work.

Development of this indicator required careful thought regarding the complexity of stigma, the range of contexts and relationships in which discrimination can occur, and the different priority groups for whom the indicator was being developed. The strengths and limitations of an indicator were considered alongside the need for a broad measure that would encompass the spectrum of potential stigmatising experiences. While an indicator cannot capture the complex nature of stigma, differentiate between types of stigma (e.g. internalised, structural) or measure its impact, indicator measures are useful for monitoring prevalence over time. Additional detailed measures must be administered alongside the indicator to more comprehensively investigate stigma and associated outcomes. A single question was selected to be applicable across all priority groups, shown in Figure 1.

This approach allows investigation of stigma in relation to individual attributes, as well as layered stigma due to the presence of

multiple stigmatised characteristics. While an individual can report the frequency of stigma in relation to one or more attributes, the indicator is limited in that it does not enable attributes to be ranked in terms of the personal impact of stigma, nor the contexts in which it is most salient. The question's broad phrasing allows individuals to respond based on their personal understanding and experience of stigma. A time period of 12 months was included to allow periodic measurements and analyses of change over time. The 'not applicable' option was included to enable respondents to indicate that they did not possess the attribute in question.

A related indicator was also developed, which can be adapted for use among populations such as health workers or the general population. This mirrored indicator is designed to measure the expression of stigma towards the priority groups, such as discriminatory treatment of patients by healthcare professionals. More detail on the mirrored indicator is available in the project summary report.[32]

In 2016, the stigma indicator was first used in a series of surveys of the priority groups. These surveys also contained validated measures of stigma (e.g. internalised stigma, discrimination) as well as other measures known to be associated with stigma (e.g. psychological distress, wellbeing). Findings provided some support for the validity of the indicator as a single item measure. For example, the HIV indicator was correlated with experiences of discrimination (r_s=0.35, $p<0.001$), internalised stigma (r_s=0.39, $p<0.001$), psychological distress (r_s=0.45, $p<0.001$) and personal wellbeing (r_s=-0.43, $p<0.001$). Similar results were found regarding injecting drug use and experiences of discrimination (r_s=0.28, $p<0.01$), psychological distress (r_s=0.26, $p<0.01$) and personal wellbeing (r_s=-0.21, $p<0.05$), although the correlation with internalised stigma was not statistically significant. The hepatitis C

indicator was correlated with experiences of discrimination (r_s=0.26, $p<0.01$), although correlations with internalised stigma, psychological distress and personal wellbeing were not statistically significant. Data also suggested some degree of conflation between 'not applicable' and 'never' responses. Future data collection will remove the 'not applicable' option and participants will only be asked about their experiences of stigma and discrimination in relation to those attributes they identify as having.

Reflections on developing a stigma indicator

Developing an indicator of stigma poses substantial challenges, particularly related to reducing the complexity of stigma and its vast range of manifestations into a single measure. The indicator is therefore necessarily broad in its wording and scope, in order that the full breadth of stigmatising experience can be captured. However, consultation with community groups and advocates throughout this project has emphasised their desire to understand stigmatising experiences in greater detail – the contexts in which stigma occurs (where, by whom) and the types of stigma that are experienced (internalised, structural, anticipated) – all of which cannot be adequately addressed by an indicator alone.

There is clear benefit to establishing an indicator of stigma across the priority population groups, particularly in monitoring progress against the national strategies' objectives to eliminate stigma's negative impacts. Compared to longer measures, using a single item simplifies comparisons over time; however, there is an inherent tension in reducing such a complex social experience to a single measurement. A single measure indicator is able to identify the prevalence of stigma among surveyed groups, but on its own is unable to provide the nuanced data that are necessary to inform stigma reduction

strategies.[33] It is therefore important to use the indicator alongside more detailed measures of stigma and associated outcomes in order to provide a comprehensive understanding of the extent and impact of stigma. Efforts to develop and implement a measure of stigma against current policy objectives are also likely to raise expectations from affected community groups that interventions will be put in place to achieve the targeted reduction in reported stigma; however, this is currently not yet occurring on a scale required to achieve population level change. The stigma indicator is a starting point to this end, although ongoing research, consultation and collaboration is required for its implementation and appropriate interpretation, as is more in-depth research to inform interventions to reduce stigma and its negative effects.

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Figure 1: Stigma indicator for use with priority population groups.

In the last 12 months, to what extent have you experienced any stigma or discrimination (e.g. avoidance, pity, blame, shame, rejection, verbal abuse, bullying) in relation to your:

	Never	Rarely	Sometimes	Often	Always	Not applicable
Sexual orientation	☐	☐	☐	☐	☐	☐
Use of drugs for injecting	☐	☐	☐	☐	☐	☐
HIV status	☐	☐	☐	☐	☐	☐
Hepatitis B status	☐	☐	☐	☐	☐	☐
Hepatitis C status	☐	☐	☐	☐	☐	☐
Sex work	☐	☐	☐	☐	☐	☐
Other (please specify):	☐	☐	☐	☐	☐	☐

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