



Stigma and Discrimination around HIV and HCV in Healthcare Settings: Research Report

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Supporting the HIV, Viral Hepatitis and Sexual Health Workforce



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1 Executive Summary

Introduction

Stigma and discrimination towards people with HIV or hepatitis C (HCV) has been associated with negative health outcomes for affected populations both within Australia and internationally. Whilst policies, legislation and guidelines have been developed at State and Federal level to protect people living with HIV and HCV, evidence suggests that within health care settings these people continue to report stigma and discrimination. The NSW Ministry of Health funded ASHM and National Centre for HIV Social Research to undertake a study to describe the current experiences of stigma and discrimination within health care settings for people living with HIV and/or hepatitis C. The report also makes three recommendations to address these issues.

Methods

The study consisted of a literature review and stakeholder interviews. An extensive review of the Australian and International peer-reviewed and grey literature on stigma and discrimination towards people living with HIV (PLHIV) and/or people living with HCV (PLHCV) was undertaken. Twenty-four interviews were conducted with key stakeholders including physicians, dentists, pharmacists, nurses, academic researchers, and service providers working in the HIV and/or HCV related health sector in order to develop an understanding of the key issues relevant to HIV or HCV related stigma and discrimination. A steering committee and expert reference group oversaw the development and progression of the study.

Findings

Key themes from the literature review and the stakeholder consultations show that stigma and discrimination can have a negative influence on both mental and physical health. In Australia, the groups most commonly associated with HIV are:

1. Men who have sex with men (MSM);
2. People who inject drugs (PWID);
3. Immigrants and ethnic minority groups; and
4. Sex workers.

In all these cases, PLHIV face some degree of marginalisation from mainstream society, largely stemming from the perception that they engage in

behaviours viewed as deviant or different. Similarly, HCV is an illness that attracts a large amount of stigma and discrimination because of its association with injecting drug use, also perceived as deviant and immoral. Research suggests that health care workers often hold negative views of people with HIV and HCV, mirroring those of the general public. These negative views may then be transformed into discriminatory practices and behaviours ranging from subtle to overt forms of discrimination. The literature suggests that stigma and discrimination within the health care sector may have a major impact on receipt of care and may act as an impediment to disclosure, testing, and treatment.

The literature identified four areas where stigma and discrimination could occur in interactions between health care workers and patients:

1. **Standard precautions:** The literature suggests that in some cases healthcare workers may make decisions about infection control procedures according to their judgement about patients' infectious risk and not the risk inherent in the procedure. Research indicates that correct use of standard precautions could help reduce the real and perceived stigma and discrimination among PLHIV and PLHCV.
2. **Disclosure:** Despite the benefits of disclosure of HIV or HCV status in health care settings, fears of discrimination can result in PLHIV and PLHCV attempting to hide stigmatised behaviours such as drug use, or their HIV or HCV positive status from health care professionals. Non disclosure denies a person the opportunity to find psychological and social support and facilitate appropriate and necessary treatment.
3. **Testing for HIV and HCV:** Research has frequently revealed that people who have experienced, or who worry about experiencing discrimination or stigmatisation will be less likely to be tested for HIV or HCV.
4. **General healthcare and HIV-and HCV-related treatment:** Experiencing stigma and discrimination has been found to lead to a variety of negative health outcomes and has a major impact on the willingness to access general healthcare and can affect the uptake of HIV or HCV treatment and the adherence to treatment regime.

Consultations

All participants felt that healthcare services should be non-judgemental and should not discriminate on any level. Many interviewees had experienced, witnessed or heard of incidents of discrimination in the health care system. Participants considered the impact of perceived stigma as a major barrier to accessing the health system and on the willingness of a person to seek treatment for HCV or HIV. Interviewees identified confidentiality, unclear policies around stigma and discrimination in health care services and non-specialised care as key areas for concern. It was noted that people in rural areas may not disclose their status to their GPs as it is more difficult to remain anonymous in small towns and this often translates into people with HCV or HIV engaging with different healthcare providers depending on their health concerns. This 'shopping around' for different doctors could ultimately undermine the holistic model of care.

While it is widely recognised among the participants that there has been a shift in public opinion and policy around HIV and HCV over time, several participants believed that stigma and discrimination by health professionals

receives little attention in the policies and procedures of health care organisations. Participants felt that by emphasising the legal responsibilities of health workers around issues of discrimination there could be a real impact on management approaches and behavioural changes.

Recommendations

Based on the findings the report makes three key recommendations, these include:

1. The implementation of a three year communication campaign targeting healthcare workers to increase knowledge around HIV and HCV in the hopes of decreasing discriminatory behaviour and stigmatising beliefs. It is envisioned that this campaign will promote the use of standard precautions and inclusive practice.
2. Further research into protective and resilience-building factors for people living with HIV/HCV.
3. Policy support for these recommendations through the development of the NSW HIV and Hepatitis C Strategies.

2 Introduction

Stigma and discrimination towards people with HIV or hepatitis C (HCV) has been associated with negative health problems ranging from increased depressive symptoms to engaging in risky sexual behaviour (Kinsler, Wong, Sayles, Davis & Cunningham, 2007; Sayles et al., 2008; Vanable, Carey, Blair & Littlewood, 2006). Furthermore, experiencing stigma or discrimination in a healthcare setting has been found to adversely affect the health behaviours of people living with HIV (PLHIV) or HCV (PLHCV); such as accessing treatment, seeking testing for HIV or HCV, and adhering to medical regimes (Butt, 2008; Fortenberry et al., 2002; Pascoe & Smart Richman, 2009). Due to the ongoing impact of stigma and discrimination, it is important that our understanding of these issues is current, and develops alongside changes in the provision of healthcare, in order to provide the best quality care to PLHIV and PLHCV. This report will review the existing evidence on HIV- and HCV-related stigma and discrimination in the health care sector, with specific emphasis on analysing the experiences and implications of this for people living with either HIV or HCV.

In this report you will find:

- A review of the Australian and international peer reviewed and grey literature on stigma and discrimination in relation to HCV and HIV, with specific focus on patient experiences in the health care sector.
- Interviews with key stakeholders from various relevant sectors identifying key points in the health care journey where patients may experience stigma and discrimination, and appropriate strategies to address stigma and discrimination in the health care sector.
- Recommendations for intervention to attempt to break the cycle of experiences of HIV/HCV-related stigma and discrimination within the health care sector.

3 Methodology

This report reviews the Australian and international peer-reviewed and grey literature on stigma and discrimination towards PLHIV and/or PLHCV. Specific attention was paid to literature that addressed stigma and discrimination within the health care sector. This included health consequences for PLHIV and PLHCV, and the impact stigma and discrimination has on service delivery and the quality of care provided. Major sociological, psychological and medical databases were utilised to find relevant literature. The databases that were used include: Medline, Pubmed, Psycinfo, Sociological abstracts and Applied Social Science Index and Abstracts. The following keywords were used in multiple combinations to direct the searches: HIV; AIDS; stigma; discrimination;

stereotypes; hepatitis C; HCV; healthcare; gay; injecting drug use; sex work; immigrant; women. The search focused on articles published after the year 2000 and that were framed in an Australian or western context. Through the literature review process, it became apparent that the research conducted on issues surrounding HIV and HCV was quite diverse. For this reason, after the definition of key concepts is presented, the next section of the literature review is separated into two different sections, the first addressing HIV-related stigma and discrimination and the second addressing HCV-related stigma and discrimination. In the final sections, HIV and HCV stigma and discrimination in health care settings are discussed together.

4 Defining relevant concepts

4.1 Stereotypes

A stereotype is a set of beliefs about the characteristics or attributes of a group of people, which can lead to stigma and discrimination. The characteristic or attribute that the stereotype is centred around is considered as either more or less prevalent in one group, relative to other groups, and therefore distinguishes one group from another (Judd & Park, 1993). Stereotypes need not be negative or inaccurate; they simply distinguish a particular group from another (Brigham, 1971; McCauley, Stitt, & Segal, 1980).

Although, as a concept, stereotypes are not innately negative, they can become so because they form the cognitive component of stigmatising attitudes (Harding, Proshansky, Kutner & Chein, 1969; Secord & Backman, 1974). This means that the stereotyping of individuals can often lead to stigmatisation, which in turn leads to discriminatory behaviour. Stereotyping, stigma, and discrimination are three different aspects of the same response (Fiske, 1998; Rüsche, Angermeyer & Corrigan, 2005).

4.2 Stigma

The concept of stigma is the process of perceiving a characteristic of another, as deviant from the social expectations that are held by the majority. Classic social psychological theory provides a useful framework in which to examine the foundation and expression of stigma. Stigma has been defined as a trait that is deeply disreputable to an individual or a group of people (Goffman, 1963). Stigma arises in various spheres of life, including relationships with other people, in feelings we have about ourselves, and throughout various interactions we might have with the broader community, such as in the workplace or health services. Stigmatised people are labelled as different and structures are put in place to protect the majority from whatever negative attribute they are believed to possess

(Gilmore, 1996). Parker and Aggleton (2003) further expanded upon Gilmore's (1996) description of the stigmatised by describing it as a means to reinforce social power. This is accomplished by marking and establishing social inequalities through the use of boundaries or 'norms', such as ethnicity, gender, sexuality, and socio-economic status.

Research on stigma broadly differentiates between enacted and internalised stigma, referring to the source of the stigmatisation. Enacted stigma is stigma one experiences from an external source, such as an individual or organisation. By contrast, internalised or self stigma stems from within and occurs when an individual internalises the dominant cultural norms as part of being a member of a stereotyped minority group (Jacoby, 1994; Sayles et al., 2008; Scrambler, 1998; Simbayi et al., 2007). Stigma is also understood in terms of institutional or structural stigma, which is stigmatisation of a group of people through the implementation of policy and procedures (Corrigan, Markowitz & Watson, 2004).

4.3 Discrimination

Stigma becomes discrimination when thoughts, beliefs or attitudes evolve into direct action. Discrimination is defined as any unfavourable treatment of an individual based solely on their membership of a certain group (Giddens, Duneier, Appelbaum & Carr, 2009). Discrimination involves exhibiting a negative behaviour towards members of a social group, other than one's own, and can result in limiting members of one group from opportunities that are available to others. It is the unfair treatment of someone based on a particular characteristic that defines discrimination. Particular characteristics include; race, sexual orientation, or particular physical attributes, and lead ultimately to some form of rejection or exclusion (Giddens et al., 2009).

5 The stereotyping, stigmatisation, and discrimination of people living with HIV

Research has shown that stigma and discrimination may have a direct negative influence on an individual's mental, psychological and emotional health (Link, Struening, Rahav, Phelan & Nuttbrock, 1997; Logie & Gadalla, 2009; Minior, Galea, Stuber, Ahern & Ompad, 2003; Young, Stuber, Ahern & Galea, 2005). Furthermore, being stigmatised or discriminated against may also impact on an individual's access to health care and on how the health care they require is delivered (Alonzo & Reynolds, 1995; Chesney & Smith, 1999; Fortenberry et al., 2002).

People living with HIV (PLHIV) experience stigma and discrimination for several reasons, which predominantly relate to societal perceptions around how HIV is transmitted. A large body of literature exists on the impact of HIV-related stigma on psychological and physical health of PLHIV. Among the most common of these are increased feelings of despair (Buseh & Stevens, 2006), increased rates of depression (Berger, Ferrans & Lashley, 2001; Vanable et al., 2006; Wright, Naar-King, Lam, Templin & Frey, 2007), decreased self-esteem (Berger et al., 2001; Bunn, Solomon, Miller & Forehand, 2007), and increased mental health issues (Mak, Poon, Pun & Cheung, 2007). The seriousness of these potential effects is highlighted by a review conducted by Logie and Gadalla (2009) that examined the relationships between HIV-related stigma and a range of demographic, social, physical and health characteristics. They found that higher levels of stigma were consistently and significantly associated with low social support, poor physical health and poor mental health, and concluded that the association between HIV-related stigma and physical health has potential implications for treatment, care and support for people at different stages of HIV infection (Logie & Gadalla, 2009). This research accentuates the wide-ranging personal health consequences which may be associated with stigma, as well as the need to address this in order to provide better care to stigmatised groups.

HIV-related stigma arises from the association of HIV with particular transmission routes. In Australia, the groups most commonly associated with HIV are:

- Men who have sex with men (MSM)
- People who inject drugs (PWID)
- Immigrants and ethnic minority groups
- Commercial sex workers

What these four groups have in common is some degree of marginalisation from mainstream society, which relates to the perception that they engage in either a behaviour or culture seen as deviant or different. In Australia and internationally, women also represent a unique group of people living with HIV because of the growing number of new diagnoses and their unique experiences living with the disease.

5.1 Men who have sex with men

In Australia, MSM account for the largest proportion of existing and new HIV diagnoses (NCHECR, 2010). Stigma associated with HIV and same-sex attraction is rooted largely in societal intolerance around homosexuality (Derlega, Winstead & Brockington, 2008; Dodds, 2006; Fay et al., 2010; Greene & Banerjee, 2006; Jones, Rasch, MacMaster, Adams & Cooper, 2009; Pickles, King & Belan, 2009). It has been argued that part of the stigmatisation around HIV and homosexuality comes from the perception that this perceived sexually deviant behaviour constitutes a 'choice' (Deacon, 2005). The notion of choosing to engage in behaviours perceived as 'deviant' or different to the norm evokes particularly negative feelings and MSM are seen as less deserving of health care (Crocker, Major & Steele, 1998; Tindal, Cook & Foster, 2010).

Issues around HIV-related stigma and MSM may be less pronounced than in other populations, due to success of the global movement, sometimes referred to as the 'gay rights movement', around the rights and freedoms of non-heterosexual people. With the advancement of the gay rights movement, there were similar advancements in the ideas and perceptions that surrounded HIV, leading to the establishment of organisations in the early 1990s founded by gay men who worked to combat stigma around HIV in several ways (Whittaker, 1992). According to Whittaker (1992), there was an attempt to rewrite the discourse around HIV and claim ownership over it, while redefining HIV as 'just another virus.' Furthermore, steps were taken to engage the research community to change the ideas around HIV as something other than terminal. These strategies have since been employed in a collective and individual manner to address HIV-related stigma towards MSM (Siegel, Lune & Meyer, 1998).

While same-sex attracted men experience stigma and discrimination as a function of their sexuality, they may also employ HIV-related stigma against other MSM as a “governance mechanism to exclude HIV-positive people from tightly woven networks of support” (Dodds, 2006, p. 472). This is an additional aspect of stigma directed towards MSM with HIV from within the gay community, which is less clearly defined, but can be detrimental to the ostracised individual. Such attitudes have been described as a denial of HIV from the broader gay community that effectively strips away the solidarity that otherwise sustains the relevant political and social issues of the gay community (Ware, Wyatt & Tugenberg, 2006). Within-group stigmatisation, stigma directed towards one’s own cultural group, highlights the multi-dimensional nature of stigma, which can result in a group of people, such as MSM, being stigmatised internally (within group) and externally (other groups).

5.2 People who inject drugs

Past research surrounding injecting drug use and blood borne viruses (BBVs), particularly HIV and HCV, draws on the strong correlation found between the legality of drug use and the stigma and discrimination faced by PWID (Hopwood & Treloar, 2007; Paterson, Backmund, Hirsch & Yim, 2007). This reflects the societal perception that drug use is a risky and personally destructive behaviour (Chan & Reidpath, 2007; Chan, Stoové & Reidpath, 2008; Chan, Yang, Li, Stoové & Reidpath, 2009; Chan, Yang, Zhang & Reidpath, 2007). In Australia, the transmission of HIV through injecting drug use is quite low compared to international studies, while the prevalence of HIV among PWID has remained consistently low (NCHECR, 2010). Overall, Australia has been successful in managing HIV-related risk among PWID. However, a disproportionate rate of HIV infection via injecting drug use exists among Aboriginal Australians (Lelutiu-Weinberger et al., 2009) and other ethnic minority groups, such as the Vietnamese community (Ho & Maher, 2008). Due to Australia’s success in managing HIV among PWID, much of the stigma and discrimination that is associated with HIV is not affiliated with injecting drug use. However, this cannot be said for HCV, which will be discussed in further detail later in the report.

5.3 Immigrants and ethnic minority groups

Immigration to another country is a difficult transition for anyone, particularly if the country is culturally and linguistically different. Immigrants and ethnic minority groups may face a variety of forms of discrimination and stigma. This has been found to be particularly true for immigrants and ethnic minority groups living with

HIV. Xenophobia and racism have been described as being directly related to the discriminatory treatment reported by African immigrants with HIV in the UK (Dodds, 2006).

Like MSM, immigrants living with HIV can face stigma and discrimination, not just from those outside of their cultural group, but from within that group as well. As Körner (2007) described, HIV in many countries is strongly associated with evil and death. These strong negative associations will often foster stigmatising beliefs that isolate immigrants with HIV from their ethnic communities. This type of isolation, coupled with the challenges of forming social connections in culturally and linguistically diverse culture, can create social isolation. Social support is key to mitigating the negative effects of stigma and discrimination (Logie & Gadalla, 2009) and without social support, immigrants living with HIV may experience more stigma and discrimination than other populations. Given that immigrants also experience financial and cultural barriers to accessing healthcare services (Körner, 2007); the barriers to managing various aspects of HIV are especially difficult for this population. For example, in Australia, being unable to speak or understand English can be a barrier in managing one’s HIV status (Boyd et al., 2005; Kelaher, Williams & Manderson, 1999).

Within-group stigmatisation has also been found in ethnic minority groups. Gay men from ethnic minority groups have reported experiencing stigma from their cultural groups as a function of being gay, and also from the gay community as a function of not being white (Jones et al., 2009). In Australia, Chinese men (Ayres, 1999), Southeast Asian men (Ridge, Hee & Minichiello, 1999), and Asian Pacific Islander men (Wilson & Yoshikawa, 2004) face similar experiences of marginalization. Not only does within-group stigma deprive members of the social support that is required to combat stigma, but it has been demonstrated to foster unsafe sexual practices (Han, 2008; Henry, 2007).

5.4 Sex workers

Sex work is a highly stigmatised activity. Sex workers have reported stigma and discrimination from the general community, related to their line of work as a major concern. Sex workers, whether male or female, experience stigma and discrimination regardless of HIV status, both in Australia (Jeffreys, Matthews, & Thomas, 2010) and internationally (Infante, Sosa-Rubi, & Cuadra, 2009; Ngo et al., 2007). However, research suggests that sex workers are judged particularly harshly when it comes to perceptions of HIV risk. For example, a study found that people who

had contracted HIV through drug use or sex work, when compared to those who had contracted it through blood transfusion, faced far more negative stigma and disapproval (Chan, Rungpuend & Reidpath, 2009). Route of transmission is frequently drawn upon as a source of discrimination, with research suggesting that those who contracted HIV via blood transfusion are viewed more positively than those who were infected via unsafe sex or drug use (McBride, 1998).

HIV rates among sex workers in Australia are low. This is likely to be the result of a decriminalised industry, which provides health guidelines for sex venues to follow. In Sydney, it has been reported that the prevalence of HIV among female sex workers is extremely low at 0.4% (Estcourt et al., 2000). While rates are not as low for male sex workers; they were still significantly lower than the general population of homosexual men (Estcourt et al., 2000). However research from Prestage et al. (2007) found an increased risk of HIV infection among gay male sex workers but this increase does not appear to be directly related to the context of their sex work.

Unfortunately, sex-workers are a population with traditionally poor access to healthcare (Estcourt et al., 2000; Jones et al., 2009). As a population whose work life puts them in direct contact with risk of HIV transmission, attention must be paid to their unique and complex health needs. More so, some groups of sex workers are more vulnerable than others, such as those who work on the streets, suggesting particular attention should be paid to these at-risk groups.

5.5 Women

Women living with HIV experience stigma and discrimination that is often unique to this group. This could stem from the fact that in western countries like Australia, HIV is constructed as a 'male disease' (Bennett, 2007). Stigma experienced by women living with HIV appears to be significantly higher than among men (Colbert, Kim, Sereika, & Erlen, 2010). Women have been found to be judged more severely based on the way it is perceived that they contracted HIV (Lawless, Kippax & Crawford, 1996). Past research also found that women with HIV (including those who had contracted it via blood transfusion) were frequently labelled as drug users or sex workers and assumptions were made about their lives and the choices they had made (Lawless et al., 1996). HIV-related stigma towards women has been found to play out in particular in relation to pregnancy (Turan, Miller, Bukusi, Sande, & Cohen, 2008). In a recent Canadian study, it was found that women living with HIV who were trying to become pregnant were judged more harshly and experienced more HIV-related stigma and discrimination than women not trying to have a child. Research has shown that, for women with HIV, the fear of stigmatisation and judgement, both of themselves and of their children, fosters uncertainty and concern during pregnancy (Kisakye, Akena, & Kaye, 2010; Lekas, Siegal & Schrimshaw, 2006; Rahangdale et al., 2010; Turan et al., 2008; Wagner et al., 2010).

6 The stereotyping, stigmatisation, and discrimination of people living with HCV

Hepatitis C is an illness that attracts a large amount of stigma and discrimination because of its association with injecting drug use (Anti-Discrimination Board, 2001; Butt, 2008; Day, Ross & Dolan, 2003; Fontana & Kronfol, 2004; Treloar & Hopwood, 2004). In Australia, injecting drug use is the main route of transmission of HCV with 90% of new infections and 80% of existing infections being attributable to injecting drug use (Robotin et al., 2004; NCHECR, 2010). As a result, it is frequently assumed that anyone with HCV has a history of injecting illicit drugs, even when infection was acquired via another route such as tattooing, the use of inadequately sterilised medical equipment or cosmetic and cultural practices (Link et al., 1997; Paterson et al., 2007).

The stigma associated with PLHCV has developed out of legal and moral trepidation associated with injected drug use. That drug use is illegal is important in understanding why both injecting drug use and HCV is so highly stigmatised (Hopwood and Treloar, 2007). As a result of the criminal status of injecting drug use, PWID are viewed as engaging in deviant behaviour, which is considered socially reprehensible (Paterson et al., 2007; Fife & Wright, 2000). The stereotyped image of PWID as deviant, non-productive and irresponsible members of society is further enhanced by the media's presentation of the drug users as immoral and deserving of punishment

(Crocker et al., 1998; Elliott & Chapman, 2000). Hence, along with the assumption that PLHCV have a history of injecting drug use, PLHCV are also affiliated with the stereotypical notions association with injecting drug use.

Stigma and discrimination surrounding PLHCV can also stem from the assumption that HCV is an infection that can be reduced by individual control. When a disability or illness is believed to be caused by the person, outcomes are less favourable compared to when the person is seen as having no control over what has happened to them (Bordieri & Drehmer, 1986; Hebl & Kleck, 2002). The way in which a disease is acquired, and/or whether the disease is controllable, affects the ways in which people are viewed. For example, PLHCV are seen as making a personal choice to engage in a behaviour (injecting drug use) causing illness (HCV) and are therefore held responsible for their actions (Dolan, MacDonald, Silins & Topp 2005). For this reason, many PLHCV are perceived to have brought the illness upon themselves because of their injecting behaviour. Therefore PLHCV are often blamed for their illness and seen as less deserving of treatment (Crocker et al., 1998; Tindal et al., 2010). Hence, research suggests that the suffering experienced by PLHCV may elicit less pity, less empathy and less willingness to assist (Menec & Perry, 1998; Weiner, Perry & Magnusson, 1998).

7 Stigma and discrimination around HIV and HCV in healthcare: Manifestations and impact

7.1 Attitudes and discriminatory practices of healthcare workers

7.1.1 Towards HIV

Research suggests that health care workers often hold negative views of people with HIV and that their views tend to mirror those of the general public (Ahsan Ullah, 2011). Furthermore, when compared to other illnesses, biases towards HIV are far more negative (Li et al., 2007). Prejudicial attitudes of health care workers towards other stigmatised groups, such as PWID, have been shown to have a negative impact on treatment adherence (Brenner, Von Hippel, Von Hippel, Resnick, & Treloar, 2010), while satisfaction with a healthcare provider has been shown to increase medication and appointment adherence in adults with HIV (Bodenlos et al., 2007).

In a study that examined the attitudes of nurses towards HIV positive patients, Pickles et al. (2009) found that issues surrounding homophobia, injecting drug use, fears of transmission and knowledge of HIV/AIDS all contributed to stigma and discrimination among nurses. Even though research has shown that the majority of healthcare workers understand how HIV is transmitted, they still revealed fears of the disease and those who were more fearful were more likely to hold stigmatising views (Chan et al., 2009; Hossain & Kippax, 2011; Pisal et al., 2007; Vance & Denham, 2008).

Previous research has also found that negative attitudes towards people with HIV among healthcare workers was associated with age, whether they ranked religion as important in their lives, and if they were not doctors (Hossain & Kippax, 2011). Furthermore, it has been shown that doctors, when compared to other staff members, are less likely to discriminate based on HIV status (Mahendra, et al., 2007). Another study found that nurses tended to provide differential care based on HIV status, while doctors were more likely to violate privacy by disclosing status and testing without consent (Andrewin & Chien, 2008). The differences between the level of stigma and discrimination displayed by doctors and nurses or other staff members could be explained by research suggesting that people with higher levels of education demonstrate lower levels of stigma (Amuri, Mitchell, Cockcroft & Andersson, 2011; Messer et al., 2010). However, stigma and discrimination should not be solely affiliated with level of education.

Aside from attitudes, research has reported on specific stigmatising or discriminatory behaviours among healthcare workers. Research illustrates some of the ways in which stigmatising attitudes of healthcare workers are transformed into discriminatory practices and behaviours. Rintamaki, Scott, Kosenko and Jensen (2007) found that lack of eye contact; clipped or brusque speech and differential precautions were all attributed to HIV-related stigma, when describing the experiences of HIV-positive patients in the US. They also found more overt forms of discrimination, such as blaming patients for their status, physical abuse and the denial of care, and that many of the patients reported being very upset and even emotionally scarred (Rintamaki et al., 2007). Patients also reported experiencing substandard care, ranging from an inadequate time spent on their needs, to being left in extreme pain for an extended period of time.

In a study from the UK, African immigrants living with HIV discussed their experiences in healthcare settings (Dodds, 2006). These experiences included dentists dressed in full sheets of plastic during procedures and an overarching inference from healthcare workers that, as immigrants from a less-wealthy country, they should be appreciative of any treatment they received for their HIV. In a study conducted in Thailand, Chan (2009) found that healthcare workers do not always recognize their behaviour as discriminatory. Chan (2009) showed that nurses would modify their duties (e.g. avoiding taking blood or touching patients with HIV) or make assumptions based on the patient's HIV status around risk behaviours associated with HIV (e.g. injecting drugs, unsafe sex practices) without realising that they were being discriminatory. Several studies have discussed the need for healthcare workers to confront their own ideas around HIV and stigma in order to provide the best possible care for patients with HIV (Blake, Jones Taylor, Reid & Kosowski, 2008; Chan, 2009; Turan et al., 2008). The use of educationally-based interventions has been suggested as a way for healthcare workers to confront their ideas on HIV and reduce stigma associated with the disease in healthcare settings. Many studies have reported the effectiveness of educationally-based interventions in addressing health workers' fears around HIV and the effects of stigma (Gupta et al., 2010; Li, Cao, Wu, Wu, & Xiao, 2007; Odindo & Mwanthi, 2008; Pisal et al., 2007; Pulerwitz, Michaelis, Weiss, Brown & Mahendra, 2010; Wu et al., 2008). Such

findings are a positive step in increasing knowledge and awareness of the disease, while also combating the HIV-related stigma and discrimination found in healthcare settings.

It is worth noting that some research demonstrates that people with HIV sometimes report positive experiences in healthcare settings. For example, gay men in the UK described a high level of competent and sensitive treatment of issues related to HIV (Dodds, 2006). However, that same study highlighted the marked difference in treatment between gay men and immigrants with HIV with immigrants reporting less positive treatment experiences. This suggests that health care experiences of people with HIV will differ depending on a range of personal and situational variables, but the encounters will not always be negative.

7.1.2 Towards HCV

Much of the reported stigma and discrimination in relation to HCV appears to occur within the healthcare sector (Anti-Discrimination Board, 2001; Crofts, Louie & Loff, 1997; Hopwood & Southgate, 2003; Hopwood, Treloar & Bryant, 2006). In Australia, it seems that many of the experiences of discrimination towards people with HCV go unreported. Hence it may even be the case that there are more undocumented cases of discrimination than what is reported in the literature (Crofts et al., 1997).

Research suggests that staff attitudes are an important factor in the quality of care that is provided to PLHCV (Humphreys, Noke & Moos, 1996; Reid, Crofts & Hocking, 2000). Prejudicial attitudes of health care workers are likely to influence their treatment and relationship with these clients as well as the willingness of clients to seek treatment (Capplehorn, Lumley & Irwig, 1998; Gifford, O'Brien, Bammer, Banwell & Stooze, 2003). Clients with a positive HCV status are often assumed by health care practitioners to inject drugs and are commonly described as the most unpopular of patients (Fontana & Kronfol, 2004; McLaughlin, McKenna & Leslie, 2000). Furthermore, research has documented that health care workers may view injecting drug users as less co-operative, more dangerous, less truthful, and more demanding, and they expect patients to be more dangerous (Brenner et al., 2010; Link & Phelan, 2006). Patients with HCV who have never injected drugs frequently report that they have received inadequate healthcare because they were assumed to inject drugs (Dunne, 2001; Gifford et al., 2005).

These negative attitudes of health care workers towards PWID can manifest into discriminatory behaviour towards people with HCV. Discriminatory practices towards PLHCV

in the healthcare setting have included the unwillingness by staff to perform surgical or dental procedures, hasty discharge from hospitals, unwillingness to provide pain relief medicine, breach of confidentiality, and refusal to administer medical treatment (Brenner, von Hippel & Kippax, 2007; Crofts et al., 1997; Day et al., 2003; Hopwood & Treloar, 2003). There is also evidence to suggest that the quality of care received by patients diminishes when hepatitis C status becomes known (Anti-discrimination Board, 2001). Refusal of pain relief, or inadequate pain management, in healthcare settings has been reported. In addition, evidence to the Anti-Discrimination Board enquiry indicated that PLHCV are often placed at the end of a surgery list (Anti-discrimination Board NSW, 2001).

Another common form of discriminatory practice found in the healthcare setting is the breach of confidentiality. A number of reports on the breach of confidentiality were presented to the Anti-Discrimination Board enquiry including confidential medical records being erroneously completed and mishandled (Anti-discrimination Board of NSW, 2001). Further examples of breaches of confidentiality include clients being made to wear coloured wrist bands signifying positive HCV status, staff speaking loudly in public wards and unwarranted disclosure of status in front of family and friends (Hopwood & Treloar, 2003). Fear of disclosure and breach of confidentiality can be even stronger in rural areas. People living with HCV in rural areas are afraid to disclose their status to local GPs for fear of being isolated in the community (Anti-discrimination Board of NSW, 2001).

Stigma and discriminatory practices within the health care sector can have a major impact on receipt of care and may act as an impediment to disclosure, testing, and treatment (Cunningham, Sobell & Chow, 1993; Day et al., 2003; Hajela, 1998; Kurtz, Surratt, Kiley, & Inciardi, 2005; Wilson et al., 2010). Discriminatory behaviour by health care workers can lead to less frequent healthcare visits, negative relationships between doctors and patients, and lower levels of adherence to medical regimes (Brenner et al., 2010; Lawless et al., 1996; Miller, Sheppard, Colenda & Magen, 2001).

Limited knowledge about hepatitis C amongst health care workers may be a factor contributing to negative attitudes and ultimately even discriminatory behaviour towards PLHCV. There is a large body of evidence indicating that health care workers lack knowledge about hepatitis C (Crofts et al., 2007; Day et al., 2004; Frazer, Glacken, Coughlan, Staines & Daly, 2011; Paterson et al., 2007; Richmond, Dunning & Desmond, 2007; van de Mortel, 2002). For example Richmond et al. (2007) revealed

significant associations among health professionals' HCV knowledge, attitudes and behaviour toward PLHCV. They found a reduced willingness to care for people with HCV based on health care workers' fear of acquiring the virus themselves or intolerance towards PWID. This suggests that ongoing education strategies within the health care sector aimed at improving knowledge on HCV, changing attitudes toward PLHCV and ensuring adherence to infection control may aid in reducing discriminatory practices and behaviour (Anti-Discrimination Board of NSW, 2011; Frazer et al., 2011; Richmond et al., 2007, Treloar & Hopwood, 2004).

7.2 Perceived discrimination

It is often difficult to ascertain what is actual discrimination and what is perceived discrimination, but the impact of both types of discrimination on PLHCV and PLHIV is powerful, and can lead to negative effects on personal health and reduced effectiveness of public health programs (Jaramillo 1998, Herek, Capitano & Widaman, 2003). Being part of a stigmatised group may influence PLHCV and PLHIV perceptions of healthcare workers (Crocker et al., 2000). Studies on perceived stigma have found that expectations can alter what is focused on in a social situation and the conclusions drawn from the interaction by the stigmatised individual (Strenta & Kleck, 1984). People living with HCV or HIV may interact with others in a particular way because of anticipated discrimination or stigma. For example, PLHIV and PLHCV may expect to be stigmatised by healthcare workers because of previous unpleasant experiences and therefore change their behaviour towards the healthcare worker. This change in behaviour in turn modifies the behaviour of the healthcare worker, which may be perceived by the patient as related to the stigmatised condition, rather than the result of the patient's own change in behaviour (Edlin, Kresina, Raymond, Carden & Gourevitch et al., 2005). People living with HIV and HCV may possess a set of expectations of healthcare workers predicting discrimination practices, which can result in their fears being actualised. The literature describes a complex relationship between perceived and actual stigma and discrimination. Underpinning many of the interactions between people living with HIV and HCV and health care workers is a cycle of mistrust, anger and lack of cooperation which in turn contributes to strained and uncomfortable interactions (Paterson et al., 2007; Link, Streuning, Neese-Todd, Asmussen & Phelan, 2001). Perceived discrimination has been associated with a range of negative health behaviours including missing doctors' appointments, failing to disclose health conditions, failing to adhere to

health regimes and failure to complete treatment (Brenner et al., 2010; Clarke, Anderson, Clark & Williams, 1999; Miller & Kaiser, 2001; Pascoe & Smart Richman, 2009). The impact of perceived discrimination is a serious impediment to testing, treatment and disclosure and acts as a significant barrier to accessing HCV and HIV information and support.

7.3 Standard precautions

The use and implementation of standard precautions continues to need attention. The National Health and Medical Research Council and the Australian National Council on AIDS (NHMRC & ANCA, 1996) recommend that all health care workers follow 'standard precautions' to protect against the transmission of all blood-borne viruses. These precautions include safe handling and disposal of sharps into sharps containers, the use of personal protective equipment to prevent exposure to blood or body fluids, and hand washing following all patient contact, whether or not the patient is known to have a blood borne virus (van de Mortel, 2002). Many studies have documented a lack of compliance with these infection control guidelines (Henderson, 2001, Anti-discrimination board, 2001). According to Treloar & Hopwood (2004) some healthcare workers make decisions about infection control procedures according to their judgement about patients' infectious risk and not the risk inherent in the procedure. Furthermore, studies into the practice of standard precautions suggest that the decision to employ these precautions can be based on the HIV status of patients (Rintamaki et al., 2007; Welch & Bunin, 2010). For example, in a study examining the experiences of 50 male American military veterans living with HIV and their perceptions of HIV stigma within health care contexts, Rintamaki et al. (2007) described an incident where a nurse used gloves to draw blood only for the patients known to have with HIV. Another study found that treatment satisfaction actually decreased when patients perceived differential treatment regarding the use of gloves (Welch & Bunin, 2010).

Similar to research on HIV, inconsistencies around the employment of standard precautions has been found among nurses (Frazer, et al., 2011) and dentists (Temple-Smith, Jenkinson, Lavery, Gifford, & Morgan, 2006) working with patients who disclosed their HCV status. For example, many dentists reported wearing two pairs of gloves during procedures with people who disclosed their HCV status (Temple-Smith, et al., 2006). However, that same study reported that most dentists did not realise the discriminatory nature of their actions or consider how a patient might perceive such choices.

According to Treloar & Hopwood (2004) standard precautions was perceived by HCV-positive patients as a tool to express disapproval about their lifestyles and choices. Research into standard precautions has revealed inadequate knowledge of the correct procedures among healthcare workers (Bennet & Mansell, 2004; Stein, Makarawo, & Ahmad, 2003). Such findings suggest that the use of standard precautions by healthcare workers at a universal level, as well as increasing healthcare workers' knowledge of the correct standard procedures, could help reduce the real and perceived stigma and discrimination among PLHIV and PLHCV.

7.4 Disclosure

Some people choose to avoid disclosing their positive HIV or HCV status to prevent discrimination from healthcare workers, family and friends (Hopwood & Southgate, 2003). In particular, injecting drug use can be considered a 'concealable stigma', but when a person is diagnosed with HCV it may be difficult to keep the source of stigma hidden (Goffman, 1963). The transition from being able to conceal the stigma to making it visible may prevent people from disclosing their HCV status. Submissions to the Anti-Discrimination Board of New South Wales (2001) revealed that disclosure usually precipitated discriminatory behaviour. Incidents of breaches of confidentiality, discrimination in the work place and social ostracism have all been reported following disclosure of a positive status (Crofts et al., 1997; Hopwood & Treloar, 2003).

Non-disclosure of positive HIV or HCV status allows for the short-term protection of an individual identity, but continuing to hide illnesses such as these may be stressful and mentally taxing (Smart & Wegner, 1999; Frable, Blackstone & Scherbaum, 1990). Not only does this reticence to disclose limit opportunities available for support and treatment, but the energy required to keep a stigma hidden places a further burden on the physical and mental wellbeing of the individual (Frable, Platt & Hoey, 1998; Hepworth & Krug, 1999). Hiding a stigma may also come at tremendous personal cost of not being able to discuss issues related to the illness with others (Glacken, Kernohan & Coates, 2001). Despite the benefits of disclosure, fears of discrimination can result in PLHCV attempting to hide both their drug use and their HCV positive status from health care professionals (Hepworth & Krug, 1999; Link et al., 1997; Kurtz et al, 2005).

The disclosure of one's HIV status in health settings remains central to many PLHIV fears around HIV. Most of these fears include how information about their status will be used and shared (Greeff, Phetihu, Makoae, Diamini

& Holzemer et al., 2008). Greeff et al. (2008) held focus groups for women with HIV during which a deep mistrust of health professionals emerged as a central theme related to the ways in which women disclosed in health settings. Other research has demonstrated that most people are willing to disclose their HIV status to health professionals, even in the face of concerns about stigmatisation or discrimination (Agne, Thompson & Cusella, 2000).

Disclosing one's HIV or HCV status has been examined closely, particularly looking at the positive and negative aspects of disclosure. On one hand, disclosing one's status can, in some settings, negatively affect access to housing, education, and employment (Hadjipateras, 2004). However, disclosing one's status can also offer an opportunity to find psychological and social support through those in similar situations, decrease stress, and facilitate appropriate and necessary treatment (Edwards, 2006; Link & Phelan, 2006; Paterson et al., 2007).

7.5 Testing for HIV and HCV

Research has frequently revealed that people who have experienced, or who worry about experiencing discrimination or stigmatisation will be less likely to be tested for HIV or HCV (Flowers, Knussen, & Church, 2003; Nanin et al., 2009; Parisaei, Hemelaar, & Govind, 2010; Sambisa, Curtis, & Mishra, 2010).

The stigma and shame associated with requesting an HIV test has led to some people using 'psychological covers', by coupling a request for an HIV test with various other innocuous tests (Young & Bendavid, 2010). Such findings suggest that people attempt to mitigate stigma around HIV testing by presenting it as an afterthought to other standard tests. This presents an obvious health concern for unidentified positive individuals and suggests that stigma is a central issue in preventing people from being tested (Blake et al., 2008).

There are several personal and institutional barriers that could explain the poor uptake of testing for HCV including lack of knowledge about HCV, lack of awareness about the test procedure, and concerns about confidentiality and stigma (Khaw, Stobbart, & Murtagh, 2007). Given that approximately 80% of PLHCV have a history of drug use and approximately half of those who are attending needle and syringe programmes (NSP) have an HCV positive status (NCHECR, 2001), testing among this population should be high. Yet 35% of IDUs who participated in the 1998 NSP survey reported that they had not been tested for hepatitis C in the previous 12 months, and 16% had never been previously tested (MacDonald & the Collaboration of Australian NSPs, 2000).

7.6 General healthcare and HIV- and HCV-related treatment

Experiencing stigma and discrimination has been found to lead to a variety of negative health outcomes, given the strong relationship between stress and poor health (Rosmond, 2005; Segerstrom & Miller, 2004). Stigma has also been shown to increase negative health behaviours such as smoking (Guthrie, Young, Williams, Boyd, & Kintner, 2002). Furthermore, stigma and discrimination can have a major impact on people's willingness to access general healthcare (Sayles, Wong, Kinsler, Martins & Cunningham, 2009). In a study that evaluated the relationship between perceived stigma from a healthcare provider and access to general care among low income, HIV-infected individuals in the U.S., stigma was found to be significantly associated with low access to general health care, even after adjusting for a host of socio-demographic and clinical characteristics (Kinsler et al., 2007). Such findings suggest that patients' perceptions that their healthcare providers are treating them in a stigmatised or discriminatory manner could greatly affect their use of necessary medical services.

In addition to general care, fears around stigma and discrimination can affect the uptake of HIV treatment and the adherence to HIV treatment. Internationally, stigma has been described as a major barrier to accessing HIV treatment (Duff, Kipp, Wild, Rubaale, & Okech-Ojony, 2010; Sabin, et al., 2008). A recent study examining PLHIV in the U.S. showed that higher levels of stigma were associated with not taking up HIV treatment, as well as lower HIV treatment adherence (Sayles et al., 2009). Similarly, research from South Africa found that the main barrier to treatment adherence was HIV-related stigma (Coetzee, Kagee, & Vermeulen, 2011).

The reluctance to engage in treatment seems to stem from fears around the unwanted disclosure of one's HIV status and subsequent stigma and discrimination (Konkle-Parker, Erlen, & Dubbert, 2010). Specifically, PLHIV felt that if others saw them taking or collecting their medication, their HIV status could become disclosed (Rao, Kekwaletswe, Hosek, Martinez & Rodriguez, 2007; Ware et al., 2006). In situations where an individual's status was known, it was reported that the shame of taking medication in a social setting contributed to

poor medication adherence (Rao et al., 2007; Ware et al., 2006). In a study by Ware et al. (2006), participants also discussed disguising the nature of their medication and medical appointments to circumvent unwanted disclosure or shame.

People living with HCV have high rates of psychological symptoms and reduced quality of life compared with the general population (Cordoba, Reyes, Esteban, & Hernandez, 2003; Coughlan, Sheehan, Hickey, & Crowe, 2002; Dieperink, Ho, Thuras, & Willenbring, 2003). The considerable burden of stigma on PLHCV has been linked to decreased psychological health, reduced treatment seeking, reduced access to treatment access, poor treatment compliance, and even with reduced treatment success (Jamison, 2006). Commencing treatment for HCV is a difficult decision affected by many factors and is closely related to issues around disclosure (Doab, Treloar & Dore, 2005). High levels of social support are an important consideration in the decision to accept treatment, because of the mentally and physically draining nature of the treatment (McNally, Temple-Smith & Pitts, 2004). However as noted earlier, fearing discrimination from health workers, family and friends, PLHCV may choose not to disclose their status and thus isolate themselves from much-needed social support and care.

Crockett & Gifford (2004) found that inadequate care from health professionals at the time of diagnosis of HCV had a negative impact on the ability of women to seek out treatment and support. At the time when clear information regarding treatment, transmission and support is needed, participants frequently reported problematic interactions with limited and unclear information from healthcare workers. In a study by Faye & Irurita (2003) participants experienced stigma from healthcare workers at the time of their diagnosis and felt condemned by their diagnosis of HCV-positive. Similarly Zickmund, Ho, Masuda, Ippolito, & LaBrecque (2004) found poor communication skills and incompetence by physicians, together with feelings of abandonment and stigmatisation at the time of diagnosis. Clear, concise information regarding transmission and treatment, together with counselling at the time of diagnosis could positively affect the uptake of both general medical treatment and treatment specific to HCV.

8 Consultations

The next section of the report outlines the finding of consultations undertaken with key stakeholders and service providers working in the HIV/HCV health sector. The aim of this part of the study is to develop an understanding of the key issues relevant to stigma and discrimination with regard to PLHIV and PLHCV in the Australian healthcare context.

8.1 Methodology

Consultations were undertaken with 24 key informants. At the outset of the project a steering committee and an expert reference group were formed. Key stakeholders to interview were identified by both committees. The people identified to be interviewed were individuals from organisations that had particular expertise in either HIV or HCV, as well as individuals that worked in relevant health-related professions outside the sector. Interviews were conducted with the aim of identifying key points in the healthcare journey where patients may experience stigma and discrimination and appropriate strategies to address stigma and discrimination in the healthcare sector. Service types represented included consumer organisations, non-profit organisations, hospitals, treatment facilities and educational and research institutions. Some participants, while interviewed as stakeholders, also spoke from a personal perspective of having HCV or HIV. Participants included physicians, dentists, pharmacists, nurses, academic researchers, and service providers (e.g. needle and syringe programme workers). There were also several participants who worked for community or advocacy groups as senior administrators, programme facilitators, or service directors.

Stakeholders from the following organisations and health services were interviewed:

- Sexual Workers Outreach Project (SWOP)
- ACON
- Community Pharmacy
- Pharmacy Guild
- National Centre in HIV Social Research (NCHSR)
- Royal Women's Hospital
- Australian Injecting and Illicit Drug Users League (AIVL)
- NSW User and AIDS Association (NUAA)
- Hepatitis NSW
- Albion Street Centre
- Clinic 96 Orange

- The Kirby Institute (formerly the NCHECR)
- Positive Life NSW
- National Association of People with HIV/AIDS (NAPWA)
- Royal Prince Alfred Hospital
- St Vincent's Hospital
- University of Sydney, School of Public Health
- Westmead Hospital
- Sydney Adventist Hospital
- Community Restorative Centre
- A private dentistry practice

Potential participants were contacted via telephone or email, informed of the research and their participation in an interview requested. The interviews were conducted between December 2010 and May 2011, either face-to-face or over the phone. The interviews focussed on the following areas: understandings of stigma and discrimination, views about what constituted a quality health service, incidents or experience of stigma and discrimination in healthcare settings, issues around confidentiality, the influence of perceived stigma on the willingness of patients and clients with HIV and HCV to seek treatment, and attitudes of healthcare workers towards people living with HIV and HCV. In addition, participants were also asked their opinions about ways in which the care and treatment of HIV and HCV could be improved. Interviews were recorded to assist with note taking, but the recordings were not transcribed and were deleted once the interview notes had been finalised. Interview notes were closely read to identify key themes and issues. The study had ethics approval from the University of New South Wales Human Research Ethics Advisory Panel.

The main themes and issues emerging from the consultation interviews are outlined and discussed below. It should be noted that the views of participants do not necessarily reflect the views of the organisations with which they are affiliated.

8.2 Understanding stigma and discrimination

Participants were asked about their understandings of stigma and discrimination. Their responses reflected views that are in line with traditional theoretical definitions reflecting notions, in particular of Goffman's (1963, p.3) seminal definition of stigma as an "attribute that is deeply discrediting."

The most common ways participants talked about stigma were as a form of labelling people, making assumptions, and applying prejudices. Definitions of stigma included:

- a mark of something, a difference, usually associated with deviance or things that are not liked by the general community
- being classed as someone outside the normal group
- social disapproval
- the unwarranted labelling of a group based on preconceptions
- negative and/or unfounded connotations
- misconceptions, preconceived attitudes or ideas by a person or organisation

One participant felt that structural stigma, which has been described as policies of private and governmental institutions that restrict the opportunities of stigmatised groups (see Corrigan et al., 2005), was so ingrained in the community that people do not even know it is there.

Participant definitions of discrimination varied slightly, but they all in some way conveyed the message of negative attitudes that result in sub-optimal care or other prejudiced behaviour. Definitions of discrimination included:

- the actions that result in people receiving poor services because of things about them
- the unequal treatment of people because of a particular attribute that they are known or perceived to have
- the tangible manifestation of stigmatising beliefs through actions
- the acting out of the stigma that leads to deliberate physical or social exclusion.

One participant felt that people were not always aware that they are behaving in discriminatory ways. He went on to speculate that discriminatory behaviour may sometimes be a manifestation of subconscious attitudes and at other times may be intentional, with the aim of assisting the client or patient to see that their lifestyle is socially unacceptable and something they should change. While not endorsing discrimination, he felt that in these cases the healthcare worker may genuinely think that discriminatory behaviour is helping people who are stigmatised. The example he provided was that some people feel that by behaving in a discriminatory way towards people who inject drugs, it may help them to stop using drugs. Another participant discussed how people can disguise stigmatising attitudes. This participant, who

had worked at an urban needle-syringe programme (NSP), noted that most people who work in the health sector in areas related to HCV or HIV are careful about what language they use or behaviours they exhibit, but this may not be about sensitivity but instead is an effort to mask stigmatising beliefs.

8.3 Quality health services

There was a general consensus among the participants that a quality healthcare service is one that is accessible and affordable. All the participants said that healthcare services should be patient-centred, non-judgemental and should not discriminate on any level. A quality health service was seen as one that provides a welcoming environment, a nurturing atmosphere and a standard of care that meets the healthcare needs of a range of different people. Many participants stressed that a quality health service needs to be able to recognize and be prepared for diversity. The majority of participants, believed that, in order to provide a quality health service, healthcare providers, including general clinic staff, needed to provide their service without making judgments based on factors such as ethnicity, sexuality and/or profession.

One participant said that a quality health service should ideally be sustainably planned in consultation with the population it serves. For example, in order to ensure a quality health service for people who inject drugs, it is important to have consumer participation and involvement in the planning and delivery of services. However, as a past employee of a NSP commented, consumer involvement requires funding and resources, and can be difficult to implement. Another participant spoke about working on the ETHOS project (The Enhancing Treatment for Hepatitis C in Opiate Substitution Settings), aimed at increasing uptake of treatment in patients receiving pharmacotherapy. He reported that in one particular clinic, where the ETHOS project was taking place, current pharmacotherapy clients were employed to become HCV peer educators and treatment peer support workers. In his opinion, peer workers improved the environment at the clinic, with staff showing more patience and understanding towards clients. He therefore felt that consumer participation, if well implemented, can assist in changing attitudes of healthcare workers and those who access services.

Another participant spoke about “models of care”, referring to the ways in which health services are delivered. She commented on the challenge of implementing changes in service delivery at an individual level (i.e. staff members) and at structural levels (i.e. policies and procedures). In

her opinion, changes at an individual level need to be accompanied by changes at the policy level for non-judgemental, patient-centred care to be effectively implemented across the healthcare setting. Another stakeholder reflected that in responding to the diversity of patients and clients, services and individual staff needed to be flexible and adaptable in the way they do their work. She went on to say that a quality health service is one that responds in a different way for each patient, depending on circumstance or background. She remarked that it is not expected for healthcare workers to understand every culture, but to recognise that people do things differently.

While all the participants felt it was important to provide a quality health service for all members of the community, most felt that the health care sector failed to provide quality healthcare that was affordable, accessible and delivered service without judgement. This suggests that marginalised populations, such as PWID and PLHIV, are likely to experience stigma and discrimination in relation to access, treatment and care in some healthcare settings.

8.4 Negative experiences in healthcare settings

Almost all the participants reported being aware of, experiencing, or witnessing incidents of stigma or discrimination in a health-related setting. The examples in the following sections demonstrate the wide variety of experiences and settings in which stigma or discrimination was reported by participants to occur in the health services. These negative incidents that are reported here should not overshadow the fact that many people with HCV and HIV do have positive experiences in healthcare environments.

8.4.1 HIV

Some participants felt that being gay was linked to HIV in much the same way that HCV is associated with injecting drug users, and participants were able to provide examples of discriminatory behaviour towards people living with HIV in healthcare settings. For example, one participant described an incident experienced by one of his HIV-positive clients. The client, when hospitalised, noticed that the woman who straightened his bed each day, started wearing plastic gloves when she discovered his HIV status. According to the participant, the client was highly traumatised, both by the incident itself and by the failure of the hospital to address the complaint made regarding the incident. This highlights that discriminatory practices can be carried out by an individual, but then left unaddressed at an administrative or structural level. The failure of the hospital to respond to the incident was as distressing for the patient as the incident itself.

A number of the participants felt that discrimination and stigma were more likely to occur in non-HIV-focused healthcare settings. The most common example was when people living with HIV attended the dentist. Multiple participants spoke of this as an area of particular concern and noted incidents, such as a dentist wearing two pairs of gloves when working on a person with HIV. Several participants felt that non-disclosure is often the easier path to choose than disclosure. They discussed the anxiety created when an individual wrestles with the idea of disclosure to those in the healthcare sector. The fear of stigmatisation seems to stand in the way of disclosure, especially when seeing a healthcare worker who generally has little familiarity with HIV, such as dentists.

Another interviewee noted that, without any legal basis, it is common for dentists to ask on their standard intake form whether a person is HIV or HCV positive. The participant felt this was an unnecessary disclosure and advised HIV-positive people to avoid disclosing to their dentist. In contrast, another participant who is a dentist, was of the view that being aware of a patient's HCV and HIV status assisted in serving the needs of the patient. The dentist recalled an example where being aware that a client had HIV made him more vigilant in looking for soft tissue changes in the mouth and led to him diagnosing a very early case of carcinoma.

Another interviewee, whose organisation serves sex workers, described the stigmatising attitudes of doctors and nurses who sometimes make hurtful or discriminatory comments, such as "why do you have to do sex work, you are so pretty?" Sex workers, like drug users, are more broadly discriminated against and, while this example is not specifically HIV-related, it highlights that discriminatory behaviour can impact on the willingness of sex workers to seek health care and treatment.

The above examples show the complex nature of disclosure and the need for people living with HIV to go to services familiar with blood borne viruses in order to have their healthcare needs met.

8.4.2 HCV

The majority of participants noted that people living with HCV are stigmatised because of the association of HCV with injecting drug use. Participants felt that many healthcare workers still hold negative views about drug users, seeing them as 'junkies' who are unproductive and harmful members of society. Several of the participants felt that healthcare workers were hesitant about working with someone once their HCV status was known, based

on stereotypical assumptions that people with HCV are or have been “chaotic drug users”. Several participants commented that people who use illicit pills or alcohol heavily are not subjected to the same discriminatory behaviour as injecting drug users.

Disclosure of HCV status was seen by many of the interviewees to result in the patient or client being judged or condemned. For example, one participant commented on the instantaneous shift in verbal and non-verbal behaviour of healthcare workers that often accompanies learning of a client’s positive HCV status. A reported change in demeanour of healthcare staff was a common experience recounted by participants, one they felt heavily impacted on patients’ willingness to disclose their positive status in the future.

Some of the examples provided focused on differences in treatment or sub-standard care that was a direct result of discrimination around HCV status. One participant who had HCV noted that she had observed and experienced numerous negative experiences within the healthcare setting as a consumer. On one occasion, when she was in the hospital for a hip replacement, the anaesthetist refused to participate in the surgery because she was a drug user, which resulted in a 6-month delay in treatment. A common negative experience reported by participants was the refusal by healthcare workers to provide pain medication. Many of the participants felt that nurses and doctors do not give the same pain relief medication, such as morphine and codeine, to people who use drugs as they would to other patients. One participant recalled that he had seen the staff of a community pharmacy treat drug users differently to the way they would treat other clients. In this particular scenario, the pharmacist behaved abruptly and in an unsympathetic way regarding the filling and obtaining of prescriptions.

One participant spoke in particular of the difficulty prisoners and ex-prisoners face in being prescribed treatment for HCV. She commented that many GPs will simply refuse to refer someone with a prison history for HCV treatment; it is presumed that their lack of social support and poor mental health will leave them unable to cope with the physical and mental demands of HCV treatment. She further explained that a history of incarceration may also act as a barrier to health services. Hence a prisoner or ex-prisoner with HCV may face stigmatisation on more than one front, highlighting the complexity involved in HCV-related stigma and discrimination.

Participants were of the view that most people who work in the HCV sector understand what language to use and how to behave in a non-discriminatory way,

but may still hold negative attitudes or beliefs about the population they serve. One interviewee reflected on his work at an NSP and noted that, while he never encountered negative attitudes towards HCV among the front-line staff, it was apparent that some people higher in the bureaucratic ladder held certain stigmatising beliefs. The man in particular described how some senior-level management or government officials would describe drug-users behaviour as “chaotic” or suggest the notion of an “undeserving drug-user.”

In another example, a participant reported feeling that attitudes towards her changed when she refused a routine HCV test in an antenatal setting. More blatantly, a client of another participant was, post-HCV diagnosis, made to sit separately from other patients and wear a wristband that identified her status. In this incident, the discriminatory behaviour the client received was so traumatic that it left her unable to disclose her HCV status to friends for fear that others would enact similar discrimination. Without support, HCV treatment became very difficult for the client and she eventually withdrew.

A participant who is employed at a public hospital in Sydney commented that he had not observed discriminatory behaviour in the healthcare sector over the last decade and felt that attitudes toward HCV and HIV had changed in a positive way. This participant also noted that there were situations in which it was important for a specialist to know if a person injects drugs. He explained that, as an anaesthetist, it is vital for him to know if a patient has been injecting so that he can modify the anaesthetic to best suit the client. The participant reflected that, while it is possible that the patient might interpret this as discriminatory behaviour, it is necessary to provide the client with the best medical care.

The above examples of HCV-related stigma indicate that discriminatory behaviour occurs in a range of health care settings. In some instances the behaviour is overt while in others it is subtle, but in all cases people living with HCV are being stigmatised because of the association of HCV with injecting drug use.

8.5 Breaches of confidentiality

Half of the participants had personally encountered a situation where a colleague or organisation had breached the confidentiality of a client in relation to HCV. It was significantly less common for participants to have experienced breaches of confidentiality in relation to HIV. Several participants, however, commented that while they had not directly encountered breaches of confidentiality, they had heard anecdotally of such situations occurring,

often in what seemed to be an inadvertent manner. An example given was that, in a hospital setting, a person's family members or friends had been made aware of the person's HIV or HCV status by overhearing conversations between the patient and the doctor, because the doctor had failed to ensure that others were not in earshot.

According to some interviewees, breaches of confidentiality happen even in an environment where this would not be expected. One participant knew a client who had experienced unwanted disclosure from a non-government organisation offering services to people who use drugs. As this should be a safe space, the unwanted disclosure left the client very distressed. Additionally, a complaint was lodged with the agency, but very little was done to address the complaint.

Other examples of confidentiality being breached included a doctor discussing test results related to HIV with a patient in a shared hospital room, or a pharmacist distributing medication and saying: "here is your HIV medication." These events may not even register to the service provider, but expose the patient or client to unwanted disclosure, often to complete strangers. This breach of confidentiality places the patient in a vulnerable position. It also indicates that some health professionals demonstrate a lack of respect and knowledge of guidelines in relation to patient and client confidentiality.

The majority of participants identified hospitals as common sites where breaches of confidentiality occur. One participant speculated that the removal of HIV-specific wards and a decrease in the need for people with HIV to attend hospitals may be contributing factors to an increase in breaches of confidentiality. In his opinion, there is less awareness of and preparedness for treating and managing people living with HIV in hospitals.

In a poignant example of confidentiality being breached, one participant spoke of a woman who attended a hospital to give birth. The woman, who had HCV, was in prison for a time and disclosed this to her attending nurse. Details of her personal life and health situation were shared with staff on the ward and even other patients. In the woman's opinion, her right to privacy was ignored as a direct consequence of her ex-prisoner and HCV status.

Despite a participant commenting that he had not encountered any breaches of confidentiality in the hospital where he worked, he did mention that it was not unusual for doctors and nurses to discuss someone's HIV or HCV status in a professional setting. He commented that there is a need to protect hospital staff and if someone has a transmissible disease, staff do try to inform

healthcare workers who are directly involved in patient care. This particular participant had a view not shared by the majority of participants and that is out of step with the concept of standard precautions. In a related example, a peri-operative nurse discussed how the operating team is always informed if a patient going into surgery has HCV or HIV. She mentioned that this is done to help ensure that the staff practice the utmost caution. However, with standard precautions in place there should be no need to inform assisting doctors/nurses of a patient's health status. It also seems that there are still healthcare workers who are not aware that speaking to another worker about a client's status, regardless of the reason, still may constitute a breach of confidentiality.

While breaches of confidentiality may, in many circumstances, be unintentional, they nonetheless appear to be commonplace within the health care sector. These unintended breaches of confidentiality have potentially devastating implications for the wellbeing of people living with HIV and/or HCV. Unwanted disclosure has the potential to disempower people living with HIV or HCV by removing the possibility to choose whom they share information about their status with.

8.6 Impact on willingness to seek treatment

More than half the participants raised the issue of internalised stigma during the course of the interview and suggested that, in some cases, clients or patients interpreted behaviour in healthcare settings as discriminatory or stigmatising because they expected in advance to be treated badly. One participant commented that internalised stigma is likely to make an individual more sensitive to both actual and anticipated discrimination. Several participants felt that individuals with HIV or HCV may attribute unrelated events to stigma, based on past negative experiences of discrimination. The hypothetical example provided by one participant was that of a nurse who does not look a patient with HIV in the eye while taking a blood sample. The participant observed that this might be due to attitudes the nurse has about HIV, but it may instead be because the healthcare worker is distracted by some extraneous factor such as their ongoing divorce or trouble with their children.

Participants agreed that the impact of perceived stigma on the willingness of a person to seek treatment for HCV or HIV is very large. It was generally felt that having to disclose a positive status to a GP in particular was a major barrier to seeking help and, if the initial disclosure was uncomfortable, it could affect future relationships with healthcare professionals. One participant spoke about

how, after a first disastrous experience of disclosure to a GP, he learnt to shop around for GPs that were more user-friendly.

An area of grave concern is the low rates of HCV treatment uptake. One participant felt that, aside from treatment side effects, the central reason standing in the way of HCV treatment is perceived stigma. He commented that anticipating discriminatory behaviour from healthcare staff involved in HCV treatment was so traumatic that he would rather avoid the treatment. Another stakeholder added to this point of view and noted that going for treatment regularly and being discriminated against on these occasions is too difficult to continually endure. Several participants commented that perceived stigma has a lesser impact on willingness to seek HIV treatment in a context of specialised services providing non-judgmental care.

It was common for participants to express concerns about the ways in which hospital staff made assumptions about injecting drug use. Multiple participants reported that healthcare workers presume that all people with HCV were injecting drug users, refuse to believe that someone who had injected in the past was no longer an injector, and assumed that they were lying about their drug use. Additionally, patients who had contracted HCV via routes other than injecting drug use were automatically assumed to be drug users. These stereotyping assumptions made by health care workers had a negative impact on the willingness of clients to seek treatment in the future.

Many of the participants observed that stigma and discrimination were more likely to occur in primary healthcare contexts compared to tertiary level context. One participant noted that by the time patients have reached tertiary care, they had already seen multiple allied health professionals and dealt with issues of disclosure and stigma. He was of the opinion that any impact on willingness to seek treatment happens in the first stages of treatment seeking. As the hospital where he works is a specialist referral centre for HIV births, this participant felt that clients were treated with respect and by the time they reach tertiary care they are comfortable seeking medical treatment. In contrast, another participant, speaking of the issue in relation to Aboriginal health noted that most of his clients experience stigma and discrimination at a tertiary level. He felt that at a tertiary level there is greater uncertainty about the quality of non-judgmental care. This may suggest that treatment appropriateness or health care worker sensitivity may be different for different groups of people. While treatment for HIV or HCV may be more

specialised or 'sensitive' at the tertiary level, this may not exist for all cultural or community groups.

One participant proposed that one way to reduce stigma around HCV and drug use was to ask all clients and patients for their drug history, in much the same way as clients are asked whether they drink or smoke. She went on to suggest that the information not be recorded on the front page of records for all to see, but included discreetly within the patient record. This, she felt, would take the burden of disclosure away from the client. It may also serve to break down perceived stigma if clients knew that these were standard questions asked of all patients.

8.7 Attitudes of healthcare workers

It was widely recognised among the participants that there has been a shift in public opinion and policy around HIV over time. Societal attitudes towards HIV currently seem to be less discriminatory than in the past. This was reported by participants to be accompanied by greater knowledge amongst healthcare workers about HIV transmission and treatment. Participants saw this shift in attitudes as being related to the development and progression of the gay-rights movement. In contrast, participants did not believe there had been a similar decrease in stigma and increase in more positive attitudes amongst healthcare workers in relation to HCV.

Several participants believed that stigma and discrimination receive little attention in the policies and procedures of most health organisations. For example, when asked about what policies they thought were in place at various healthcare organisations, some participants were sceptical that any such policies existed to directly address these issues. In contrast, other participants indicated that they believed most institutions did have policies around stigma and discrimination, many of them governed by anti-discrimination laws. These conflicting beliefs suggest a lack of clarity around policy and the position of healthcare institutions regarding stigma and discrimination.

Several participants reported that there may have been some improvements in attitudes of health workers towards people living with HCV. For example, one participant noted that the days of signage and bands to indicate positive HCV status seem to be long over. However, multiple participants stressed that there still is a long way to go to change negative attitudes of health care workers towards people who inject drugs and, by association, towards people living with HCV. One participant felt that attitudes had actually worsened over time, as the

number and scope of drug users had increased. In her opinion, attitudes of top management need to change; this change in attitudes would then filter down to all levels of healthcare workers.

One participant reflected that stigmatised views towards people with HCV or HIV are so engrained in our society that they insidiously affect the attitudes of healthcare workers, especially towards those who inject drugs. It was mentioned that even people who are thought to be most supportive may show subtle discrimination, which has an effect on clients. One participant commented that, while there is information about HCV available, there is a need for greater communication about transmission and treatment success in order for stigma and discrimination to be better addressed. Two participants mentioned the success of a pilot study run by the Pharmacy Guild in bringing the human side of people living with HCV to various community pharmacies and services. The pilot study was a public awareness campaign aimed at educating and training pharmacists and pharmacy staff about HCV. Community pharmacists are uniquely positioned to have regular contact with people with or at risk of HCV, through pharmacotherapy dispensing programs and needle and syringe distribution. These interactions provide an opportunity for health education, which the above-mentioned pilot sought to harness and explore.

Several participants stressed the need for improved health and medical training in issues related to HCV. Several participants discussed including additional training in HCV or HIV as part of the mandatory requirements for continuing education of health professionals. Further, a recent medical student discussed the failure to address HIV- or HCV-related concerns during medical training, which would be an ideal time to introduce these topics to future healthcare providers. Several participants commented that compulsory training in how to work with people living with HCV and HIV would likely lead to a shift in attitudes of health care workers that are rooted in misconception.

Several participants mentioned the legality around issues of discrimination. There is a lot of information given to healthcare workers about their legal responsibilities around OHS and child protection but very little, if any, is provided on discrimination. One participant speculated that emphasising the legal responsibilities of health workers could have a real impact on management approaches and effect behavioural changes.

8.8 Difference in rural vs urban healthcare settings

In nearly all of the examples provided of people experiencing stigma and/or discrimination, incidents mostly took place in a healthcare setting that was removed from specialised treatment settings. Several participants specifically noted that the further one moves away from urban areas, the more challenging it is to find competent and appropriate care.

Several interviewees commented on the inadequate and inaccessible health services in rural areas. Participants commented that it can prove particularly challenging to find non-judgemental healthcare in rural or remote areas, where there is typically little anonymity. One participant noted that rural health care often lack the rigors of knowledge, confidentiality and non-judgment that would allow a person to feel safe seeking treatment or advice around HIV or HCV. She commented that it was not uncommon for people living with HCV in rural areas to seek treatment for their HCV far away from where they live and not to inform their local GP or pharmacist.

It was further noted that people in smaller towns may not disclose to their GPs for fear of local people finding out, as it is more difficult to remain anonymous in small towns. One participant mentioned that this often translates into people with HCV or HIV engaging with different healthcare providers depending on their health concerns. This 'shopping around' for different doctors could ultimately undermine the holistic model of care.

8.9 Responses to stigma and discrimination in health care settings

Stakeholder interviews illustrate that experiences of stigma and discrimination related to HIV and/or HCV abound in the healthcare sector. What is of particular interest is how affected individuals, community organisations and health care institutions respond to these experiences.

8.9.1 Affected individuals

According to participants, the ways in which people who experienced stigma or discrimination respond are diverse, but there were a few common themes. It was consistently mentioned that for an individual, experiencing discrimination or stigma in a healthcare setting may be considerably harder than experiencing it in other settings, because the trust required to open oneself up regarding personal health issues leaves one particularly vulnerable. This makes even slight comments or actions by healthcare

workers hard to digest. One participant remarked that doctors and other health professionals are seen to be in positions of power and, when discriminatory experiences are filtered through that power dynamic, they can be far more confronting than in other situations.

For a variety of reasons, including internalised stigma and ineffective health complaints procedure, most people may not follow-up on a negative experience. Although NSW HIV-interest groups encourage reporting of these incidents, it is more common for people to make individual shifts, such as choosing to go to a different hospital or refusing to attend a certain dentist again.

One participant spoke of an incident where a client did follow through with a complaint, but received an unsatisfactory response from the hospital. The client was so traumatised by this experience that he planned on refusing to go to the hospital the next time he got sick. Several participants commented that those clients who do feel confident enough to file complaints or speak up for themselves are likely more resilient to stigma and discrimination. It is often the clients who are most traumatised by the discriminatory behaviour, who do not complain and further internalise the stigmatisation.

8.9.2 Community organisations

Of all the participants who worked in or spoke on behalf of HIV- and HCV-advocacy and interest groups, all stated that part of their organisation's mandate was to advocate on behalf of clients who had experienced stigma or discrimination in a healthcare setting. For some organisations that meant working with clients to file formal complaints and escalate them if necessary; for others it was contacting a clinic or health service directly to discuss the issue and offer training and education. Most commonly though, these organisations were prepared to speak on behalf of their clients and use their organisational structure as a platform for an individual voice. The benefit of such advocacy is that organisations are able to clearly express the views that discrimination based on HIV or HCV is illegal and will not be tolerated.

8.9.3 Healthcare institutions

Participants reported that institutions, and employees within those institutions, tend to respond with surprise when confronted with their discriminatory or stigmatising behaviours and practices. Most were unaware that either these types of incidents were occurring or that certain practices were considered discriminatory. As one participant commented, healthcare institutions generally do not say, "we don't believe that happened," but instead say, "we are sure it wasn't meant like that." However, participants also gave examples of an institution refusing to acknowledge an incident. One participant speculated that this generally happens because large bodies are afraid of being sued or facing legal or government action against them. Another participant mentioned the necessity for health institutions to take responsibility for discriminatory behaviour, acknowledge the violation of trust and outline ways to move forward. There is currently an inconsistency in policies and procedures in the health care sector, as there is no standard anti-discrimination policy across institutions.

8.10 Service recommendations

All participants acknowledged excellent services in New South Wales for people living with HIV. Several participants were warier of services for people living with HCV. Most of the recommendations about quality services for HIV or for Hepatitis C were made with the caveat that even these services were best suited for particular populations. Several participants pointed out that the best service is found in seeking out organisations that serve particular communities (i.e. injecting drug users, CALD communities, and Aboriginal people). It was noted that while one service might provide exceptional care for a particular group of people, it might fail to do so for a different population. Several participants commented that the best service can be found closest to the heart of the sector. A few interviewees went so far as to suggest that it is better in the long run to avoid non-HIV and non-HCV specific GPs, although no particular hospitals were singled-out as offering inadequate service. Some participants stated that they would recommend certain services, but only if they knew which doctors and nurses were on duty in that service. On the negative side, one participant noted that for those who inject drugs, all areas of the health sector could be potentially dangerous.

9 Sector recommendations

In addition to more general discussion and conclusions from the literature review and stakeholder interviews, NSW Ministry of Health have requested strategic recommendations from ASHM, informed by this research and also discussions with stakeholders.

A workshop was held with steering and advisory group members on April 5 2011 where key themes from this research were presented and recommendations were discussed. Draft recommendations have since been circulated, refined and prioritised. The finalised recommendations are as follows:

That NSW Ministry of Health:

1. Fund the scoping and implementation of a multi-pronged three-year social marketing and education campaign targeted at health professionals. Key messages would focus on increasing knowledge about, and decreasing discriminatory behaviour towards, people living with HIV and/or hepatitis C:
 - Promote enhanced understanding of blood-borne viruses
 - Promote standard precautions
 - Promote inclusive practice
 - Includes de-stigmatising people who inject drugs and people involved in the criminal justice system
 - Promote legislative and institutional requirements when providing health services to HIV and Hepatitis C affected communities
 - Discrimination is against the law.
2. Fund research into protective and resilience-building factors for people living with HIV and/or hepatitis C.
3. That these recommendations are built into the 2011 NSW HIV and Hepatitis C Strategies.

Stakeholders further recommend that people with experience of HIV and/or Hepatitis C are engaged in the development of any action plan for reducing discrimination.

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