

**Enhancing Consumer Participation in a  
Medically Supervised Injecting Centre  
through Participatory Action Research**

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# **CERTIFICATE OF ORIGINAL AUTHORSHIP**

I, Mark Goodhew declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise reference or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

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## Style notes

**'Single quotation marks' without italics** indicate colloquial phrases used to illustrate a point.

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**"Double quotation marks" with italics** are verbatim quotes, phrases or words from individual participants (consumers and staff members) taken from the satisfaction surveys, my journal, meeting minutes or transcripts of recorded structured interviews or CAG meetings.

## Glossary of terms

**Consumer** refers to a person that uses a health service.

**Consumer participation** is when a consumer is involved in the planning, delivery or evaluation of health care service delivery.

**Provider/Staff member** is an individual that provides health care delivery.

**Substance dependence** is when an individual is physically or psychologically dependent on a psychoactive drug or substance.

**Supervised Injecting Facilities** are services where people who inject drugs can legally inject under the supervision of professionals to reduce the harms associated with injecting drug use.

**Participatory Action Research** is a methodology that uses action research cycles to empower marginalised people.

**Harm reduction** concentrates on practical methods and ideas that can reduce the harms that are associated with drug use.

## Abbreviations

<b>AA</b>	Alcoholics Anonymous
<b>AIVL</b>	Australian Injecting & Illicit Drug Users League
<b>AIHW</b>	Australian Institute of Health and Welfare
<b>CAG</b>	Consumer Action Group
<b>HEO</b>	health education officer
<b>MSIC</b>	Uniting Sydney Medically Supervised Injecting Centre
<b>NA</b>	Narcotics Anonymous
<b>NHMRC</b>	National Health and Medical Research Council
<b>NSP</b>	Needle and Syringe Program
<b>NSW</b>	New South Wales
<b>NUAA</b>	NSW Users and AIDS Association
<b>NZ</b>	New Zealand
<b>PAR</b>	participatory action research
<b>PWID</b>	People who inject drugs
<b>SIF</b>	supervised injecting facility
<b>UK</b>	United Kingdom
<b>US</b>	United States
<b>WHO</b>	World Health Organization

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## Abstract

Consumer participation in health care refers to consumer involvement in decisions regarding the planning, delivery and evaluation of services. Consumer participation has been occurring in drug treatment services for over a decade, but progress has been slow due to poor organisational commitment, negative attitudes and power imbalances between consumers and providers. There are no reported consumer participation studies in harm reduction settings. This study investigated how the process of forming a consumer action group (CAG) influenced consumer participation at the Uniting Sydney Medically Supervised Injecting Centre (MSIC), a service designed to reduce the negative impacts of injecting drug use.

The aim of this study was to investigate how the process of forming a consumer group influenced consumer participation at MSIC. A participatory action research method was employed. The first stage investigated current levels of consumer participation at MSIC and motivation to form a CAG. Data for this stage included a consumer satisfaction survey (n=100), a staff brainstorming exercise (n=36) and structured interviews with consumers (n=12) and providers (n=7). In the second stage, MSIC consumers (n=11) and staff (n=5) developed a CAG. The third stage involved the implementation of the CAG's goals to enhance consumer participation. The fourth stage comprised an evaluation using a consumer satisfaction survey (n=100) and structured interviews with CAG members (n=13) and MSIC staff (n=10), and the process of the author's withdrawal from the study.

There were considerable challenges in establishing a CAG. These included: consumers' marginalised lifestyles, MSIC's biomedical model and negative attitudes of staff. Despite these constraints, there was active interest in developing the CAG. The group successfully implemented strategies to enhance MSIC's consumer participation. The consumer CAG members reported that the group helped them to improve their relationships with each other and staff, reduce drug use, address health problems and consider employment in the drug treatment services. A key factor that facilitated the group's success was the support the consumer members received from MSIC staff.

In line with previous research findings from drug treatment services, this study revealed that consumers' drug use and lifestyles can constrain consumer participation. However, the results also demonstrated that these factors were mediated by the staff's

efforts to focus on the consumers' strengths. Participation not only empowered consumers, but also increased their social capital and prompted them to make positive lifestyle changes. Overall, this study provides evidence that highly marginalised consumers can successfully contribute to service delivery when a strength-based approach is adopted.

# CHAPTER ONE: INTRODUCTION

Consumer participation refers to consumers being actively involved in decisions regarding their own care and the delivery, planning and evaluation of their health care (ACT Government Health 2011). The aim of this research was to examine consumer input into service delivery and planning through the formation of a Consumer Action Group (CAG) at the Uniting Sydney Medically Supervised Injecting Centre (MSIC) in Sydney, Australia. MSIC is a harm reduction health service that offers a supervised injecting facility where people can legally consume drugs under the supervision of health professionals (Schatz & Nougier 2012).

This chapter outlines the origins of my research, the prevalence and consequences of injecting drug use and health system responses to injecting drug use, the state of drug treatment consumer disempowerment and how their participation in decisions about service can potentially empower them. The chapter concludes with the aims and objectives of the research and summarises the remaining chapters of this thesis.

## The origin of the research

I am a registered nurse who has worked mainly in mental health settings for 30 years. I began working at MSIC in 2012, and until 2016 I was employed full-time as MSIC's mental health coordinator. The main purpose of this role was to improve MSIC consumers' access to mental health care and treatment. I resigned from the mental health coordinator role so I could concentrate on this research, and now work at MSIC part-time as a registered nurse.

The idea for my PhD project emerged from a conversation I had with the previous service manager. The manager wanted to expand consumer participation beyond MSIC's existing mechanisms, which only involved complaints and suggestions from consumers. I offered to lead a project that would help the service to realise this goal by forming a consumer group that would function to incorporate the consumer voice into MSIC's service delivery and planning. I thought I was the right person to lead this initiative, as I have worked in mental health services where consumer participation has been occurring for the past four decades. I also passionately believe that the strengths of MSIC consumers, who are some of society's most stigmatised and marginalised people, can be realised when they are given a voice.

# Injecting drug use

## The global context

A recent multistage systematic review revealed that approximately 15.6 million people aged 15–64 inject drugs worldwide (Degenhardt et al. 2017). An estimated 12.4 million of these people are men and 3.2 million are women. However, gender composition varies hugely by location, as 30% of people who inject drugs (PWID) are female in North America, 31–36% in Australia and 3% in South Asia (Degenhardt et al. 2017). Eighty-three per cent of PWID worldwide mainly use opioids and 33% mainly use stimulants (Degenhardt et al. 2017).

## The Australian context

In 2014, it was revealed that there were approximately 68,000 to 118,000 Australians aged 15–64 years that had injected drugs (Larney et al. 2017). These figures most likely represent a minimum estimate of the number of PWID in Australia.

## The consequences of injecting drug use

People who inject drugs have high rates of debilitating health and social consequences, including premature death, physical and psychological ill-health, poverty and social marginalisation.

### Premature death

People who inject drugs face a much higher risk of premature death than those who have never injected drugs (Copeland et al. 2012; Mathers et al. 2013). Nambiar et al. (2015a) estimated that Scottish PWID were nine times more likely to die prematurely than the general population. Furthermore, the median age of death among 24 injecting drug users in a longitudinal study in Melbourne, Australia, was 28 years (range 19–31) (Nambiar et al. 2015b). Premature death among PWID worldwide is predominately related to drug overdose and HIV-related illness, especially in low-income countries that have high rates of HIV infection among their injecting drug user populations (Mathers et al. 2013).

## **Physical health**

Injecting drug users are at high risk of developing serious physical health problems. For example, it was estimated that worldwide 2.8 million PWID worldwide live with HIV, 8.2 million have the hepatitis C virus and 1.4 million have chronic hepatitis B (Degenhardt et al. 2017). Exposure to these blood borne viruses may lead to serious chronic illness; HIV can develop into AIDS and Hepatitis B and C into cirrhosis of the liver (University of Michigan 2019). PWID are also at risk of developing abscesses and leg ulcers (Coull et al. 2014), endocarditis (Wurcel et al. 2016), and those that inject in the groin are 100 times more likely to develop a deep vein thrombosis than the general population (Cornford, Mason & Inns 2011).

## **Psychological health**

Studies reveal that PWID experience high rates of mental illness and associated conditions, including depression (Mackesy-Amiti, Donenberg & Ouellet 2012; Reddon et al. 2018; Ross et al. 2005), anxiety (Reddon et al. 2018; Ross et al. 2005), personality disorders (Mackesy-Amiti, Donenberg & Ouellet 2012; Ross et al. 2005), suicidality and self-harm (Dore et al. 2012; Ross et al. 2005), and post-traumatic stress disorder (Dore et al. 2012; Mills, Teesson, Ross & Peter 2006; Reddon et al. 2018). Their poor psychological health is often associated with traumatic events such as witnessing serious injury or death, life-threatening accidents, being threatened with a weapon, being held captive or kidnapped, and physical and sexual abuse (Dore et al. 2012; Goodhew et al. 2016; Mills, Teesson, Ross & Peters 2006). This trauma often occurs before the age of 16 (Dore et al. 2012; Goodhew et al. 2016) and precedes the onset of their injecting drug use (Mills, Teesson, Ross & Peters 2006). Despite poor psychological health, PWID often encounter barriers to accessing mental health treatment, because of the stigmatising and discriminating attitudes of some health professionals (Goodhew 2013; Griffin, Campbell & McCaldin 2008; Todd, Sellman & Robertson 2002).

## **Social marginalisation**

PWID are highly socially marginalised, because they are often publicly stigmatised for injecting drugs (Nieweglowski et al. 2017), are unlikely to have completed secondary education (Mills et al. 2005), be unemployed (Mills et al. 2005; Whittaker et al. 2015), have unstable housing or be homeless (Topp et al. 2013; Whittaker et al. 2015), and

have been incarcerated or in trouble with the law (Heard et al. 2018; Whittaker et al. 2015).

Health systems' responses to drug use have failed to improve high rates of social marginalisation in this population. This is because drug treatment policies are influenced by the global war on drugs, which perpetuates the stigmatisation and criminalisation of drug use (Drug Policy Alliance 2018; Moore & Elkavich 2008), and neo-liberal philosophies that hold that individuals are responsible for their own lives (Moore & Fraser 2006).

## **Health systems' responses to drug use**

### **Influence of policy**

Since the early 1970s, governments' policies on drug abuse have been greatly influenced by the worldwide war on drugs. The war on drugs began in June 1971 in the United States (US), when President Richard Nixon declared drug abuse to be 'public enemy number one', and on 28<sup>th</sup> January 1972 signed the war on drugs into law (Vulliamy 2011). Nixon increased federal funding for drug control agencies and drug treatment (Drug Policy Alliance 2018). Stern measures were applied to prevent drug smuggling, and increased penalties were developed for those convicted of drug offences. Later, governments used ineffective education programs, such as Nancy Reagan's 'just say no' campaign and stigmatising ad campaigns, to try to reduce drug abuse, while few efforts were made to improve access to drug treatment (Drug Policy Alliance 2018; Suddath 2009). The poor and people of colour were and remain the main victims of the war on drugs, as they are most likely to be arrested for drug offences (Moore & Elkavich 2008).

Neo-liberal reforms in health care have also influenced drug treatment and harm reduction policies (Moore & Fraser 2006). Neo-liberalism posits that "individuals are required to assume the status of being the subjects of their own lives" (Horton 2007 p. 1), and this includes individuals taking responsibility for their own health (Moore & Fraser 2006). Moore & Fraser (2006) argued that people who use drugs having agency over their health and drug use is empowering in theory, but this can only occur when "the political economic conditions that contribute to the marginalisation of drug users" (Moore & Fraser 2006 p. 3041) are addressed. This is because poor housing, ill-health,

poor education, unemployment, family breakdown and incarceration can intensify an individual's drug use and exclusion from society (Neale, Tompkins & Sheard 2008).

## **Australian drug policy**

There are three pillars to Australia's drug strategy: demand reduction, supply reduction and harm reduction (Department of Health 2017). Demand reduction involves reducing the community's uptake and misuse of alcohol, tobacco and other drugs and supporting individuals to recover from substance dependence through evidence-based treatment. Supply reduction involves preventing, stopping, disrupting and reducing the production of illegal drugs. Harm reduction focuses on reducing the negative health, social and economic consequences of substance use.

Because of the war on drugs, Australia and other western nations such as the US, United Kingdom (UK), Germany and Sweden spend the majority of their drug budget on supply reduction through law enforcement (Ritter 2016). Between 2009 and 2010, Australia spent 66% of its \$1.7 billion drug budget on law enforcement and only 21% on drug treatment (Ritter, McLeod & Shanahan 2013). This allocation of funds means that many Australians are unable to obtain treatment for their drug use. One study estimated that 200,000 Australians use drug treatment in a given year, but 200,000–500,000 more would benefit from it (Ritter et al. 2014). In Australia, drug treatment predominately consists of rehabilitation and detoxification services and harm reduction services (AIHW 2018).

## **Drug treatment in Australia**

Counselling, case management, withdrawal management, rehabilitation and pharmacotherapy are the main therapies used in Australia to treat problematic drug and alcohol use (AIHW 2018). Counselling is the most common treatment for problematic drug and alcohol use, and may involve motivational interviewing, cognitive behavioural therapy or relapse prevention (AIHW 2018). Case management involves structured holistic support and advocacy to help people to control their substance use, and withdrawal management involves medicated or non-medicated detoxification to reduce or cease use (AIHW 2018). Rehabilitation concentrates on helping people to prevent the psychological, financial, legal and social consequences of problematic drug and alcohol use (AIHW 2018). "Pharmacotherapy is the replacement of a person's

choice of drug with a legally prescribed and dispensed substitute” (AIHW 2018 p. 57); replacement therapies for opioid dependence include methadone and buprenorphine.

Many people who use drugs choose not to stop, or find it difficult to adhere to drug treatment (Harm Reduction International 2018), because substance dependence is a chronic relapsing condition (National Institute on Drug Abuse 2017). Therefore, harm reduction policies, practices and programmes are essential, as they have been proven to reduce the risks associated with drug use and keep people alive (Harm Reduction International 2018).

## **Harm reduction**

Harm Reduction International is a global non-government organisation that aims to reduce the negative, health, social and legal outcomes of drug use and drug policy. According to this organisation, harm reduction refers to:

“policies, programmes and practices that aim to reduce the adverse health, social and economic consequences of the use of legal and illegal psychoactive drugs without necessarily reducing drug consumption. Harm reduction benefits people who use drugs, their families and the community”. (Harm Reduction International 2018)

Harm reduction policies, programs and practices became more prevalent when HIV arose as an issue among PWID in the 1980s. At the start of the HIV epidemic the Australian government took quick and decisive action to set up needle and syringe programs (NSP), enabling sterile injecting equipment, lessening sharing of used equipment, and reduced transmission of blood borne viruses. As a result, the fraction of Australian PWID with HIV remained at or around 1%, which is drastically lower rate than countries that were slow to set up NSPs (Madden & Wodak 2014).

## **Supervised injecting facilities**

Around the same time as needle and syringe programs were introduced into Australia, supervised injecting facilities (SIFs –also known as health rooms, supervised injecting rooms, drug consumption rooms and safer injecting rooms) were being developed in Western Europe in response to the escalating HIV epidemic and opioid-related deaths (Wright & Tompkins 2004). Some clinicians and policymakers began to question the effectiveness of abstinence-based treatment programs and law enforcement responses

and initiated plans to introduce SIFs in Switzerland, Germany and the Netherlands (Schatz & Nougier 2012). SIFs target the most vulnerable PWID, including those who use heavily, consume opioids, and/or inject drugs (Belackova et al. 2017). In 2016 there were 92 SIF in 11 countries (Belackova et al. 2019) and over 50 are located in Canada (Government of Canada 2019). Recently, one SIF each has opened in Melbourne, Australia, Canada and Luxemburg and there are discussions about opening SIFs in Ireland and the US (Belackova et al. 2019). Systematic literature reviews have reported that SIFs are cost effective services that are associated with positive public health outcomes that include reduced rates of overdose, less risky injecting practices, improved access to drug treatment, health and welfare services, decreased injecting and disposal of used syringes in public places, and reduced crime (de Vel-Palumbo et al. 2013; Kennedy, Karamouzian & Kerr 2017; Potier et al. 2014)

### **The Uniting Medically Supervised Injecting Centre in Sydney**

The MSIC, until mid-2018 Australia's only SIF, is located in Kings Cross, an inner-city suburb of Sydney. This area had the highest frequency of overdoses in Australia in the 1990s, which led to the selection of this suburb as the site for the establishment of MSIC (Uniting 2016). MSIC opened in May 2001 on a trial basis; the New South Wales (NSW) parliament decreed it a permanent service in October 2010 (Uniting 2016). MSIC is operated by the Uniting Church and supported by the NSW Police, NSW Health Department and the local community (Uniting 2016b). Independent reports reveal that MSIC is a cost-effective service (KPMG 2011; National Centre in HIV Epidemiology and Clinical Research 2007). MSIC has been shown to reduce drug overdose deaths, provide a gateway to drug treatment for its consumers, reduce public injecting and discarding of syringes, reduce the spread of HIV and hepatitis C, and decrease ambulance call outs (KPMG 2011; National Centre in HIV Epidemiology and Clinical Research 2007).

MSIC employs a medical director, registered nurses and health education officers, but, unlike some other SIFs, it does not have paid or volunteer peer workers. There is evidence that a substantial number of people with a lived experience of drug use contribute to SIF service delivery; in one study, 24% of 49 SIFs reported that they employed paid peer workers and 7% had peer volunteers (Belackova et al. 2017). The fact that peer workers are involved in service delivery at SIFs in countries other than Australia was one of the reasons why my project aimed to increase consumer

involvement at MSIC, with the aim being to ameliorate the conditions that disempower consumers in drug treatment and harm reduction services.

## **Consumer disempowerment**

The war on drugs and its punitive response to illegal drug use has encouraged the public to characterise consumers of drug treatment and harm reduction services as untrustworthy and deviant people. Therefore, social control is used to monitor consumers' behaviour, leading to significant power imbalances between consumers and providers (Cohen 1985). Moreover, consumers are defamed via institutional, stigmatisation, which is when institutions have negative attitudes about PWID in their culture and policies (Harris & McElrath 2012).

### **Social control**

“Social control is the organised response to deviance” (Cohen 1985 p. 3) that is thought essential to bring about order, demarcate moral boundaries and monitor deviants. A critical feature of social control is a power imbalance: individuals in positions of power can track, control and punish behaviour. Crawford's (2013) description of receiving care at a pharmacotherapy clinic from a consumers' perspective demonstrates that social control and power imbalance are present at such services. According to Crawford (2013), therapeutic relationships are made difficult between clinic staff and consumers because of the prison-like atmosphere, with buzzing doors and bulletproof glass. This makes communication between staff and consumers arduous, because individuals have to shout to be heard yet often are reprimanded for doing so. In addition, Crawford (2013) stated that consumers are “generally treated like naughty patients” (p. 15), due to long queues and waiting times, random urinalysis and restrictive takeaway doses.

Harris & McElrath (2012) investigated Irish clients' experiences of receiving methadone maintenance and found that they experienced methods of social control similar to those described by Crawford. Another study reported that restrictive dosing times infringed on consumers' confidentiality (Anstice, Strike & Brands 2009). This is because consumers were forced to disclose that they were being prescribed methadone to employers, colleagues or teachers, so they were able to dose.

## **Institutional stigma**

There is reliable evidence that stigma in health care facilities dampens successful treatment, diagnosis and health outcomes (Nyblade et al. 2019). The social controls in Harris & McElrath (2012) study were also found to be closely aligned with institutional stigma, as service providers often imposed the label of the 'addict' as they interpreted them "to be untrustworthy and part of a dangerous class" (p. 819). McMurphy et al. (2006) examined barriers and facilitators to treatment in medical clinics in New York State and found similar results: 90% of medical directors characterised opioid-dependent people as manipulative, demanding and disruptive.

Radcliffe & Stevens (2008) explored how English drug treatment consumers characterised themselves and the clinics they attend. Their study revealed that the consumers used the stigmatising term 'junkie', "which is often used to illustrate the close association between drug use and crime in popular discourse" (Radcliffe & Stevens 2008 p. 1065). This study also reported that concentrating prolific offenders in drug treatment might exclude those who do not associate with the junkie identity. A study conducted in the US reported that people prescribed methadone often experience multiple forms of stigma that extend beyond drug use. Conner & Rosen (2008) conducted interviews to explore multiple stigmas, including those based on drug addiction, old age, psychotropic medications, depression, methadone maintenance, poverty, race and medical conditions. The more forms of stigma that the participants experienced, the lower their likelihood of engagement in treatment.

Overall, consumers of drug treatment services find it difficult to engage fully with treatment because of social control and institutional stigma that influence the way services are delivered. However, there is a growing consensus that treating drug treatment consumers like criminals is counterproductive and it would be more beneficial to work in partnership with PWID to provide more humanistic treatment and care.

## **Engaging consumers**

Worldwide, there is increasing awareness that solving problematic drug use with prohibition is ineffective, as it only intensifies the problem and violates human rights (Gotsis, Angus & Roth 2016; New Zealand Drug Foundation 2017; Werb 2018). According to Werb (2018), "the only way to meaningfully tailor drug prevention

interventions is to engage directly with populations of people who use or are at risk of using drugs” (p. 162). PWID are rarely consulted about drug policy, but a recent study revealed that their lived experience of drug use and marginalisation provides a unique perspective that could help reform drug laws (Greer & Ritter 2018). The participants in the study reported that they wanted to be consulted, have their voices heard and for those in power to learn from them (Greer & Ritter 2018).

A possible way of creating more engaging and effective drug treatment and harm reduction organisations is to create services that operate via the principles of humanism. Humanism involves respecting individuals’ concerns, values and dignity (Law 2013); these principles could be enacted by involving consumers in decisions about service planning, delivery and evaluation. This has the potential to create services where consumers are more empowered, less stigmatised and where power is more equally distributed amongst service providers and consumers.

## **Research aim and questions**

The aim of this study was to investigate how the process of forming a consumer group influenced active consumer participation in service planning and delivery at the Sydney MSIC. Research questions developed to meet this aim were as follows.

1. At what level of consumer participation were MSIC service providers and consumers engaged, before, during and at the end of the project, and what was their understanding of consumer participation over this time?
2. What are the processes involved in the development of objectives and action plans to implement consumer participation at MSIC?
3. How does consumer participation affect consumer staff - relationships?
4. What are the factors that facilitate and constrain consumer participation?

## Outline of thesis

Chapter two addresses consumer participation in health care and its philosophical basis, historical backdrop, policies and advantages. Mental health services are highlighted as the sector that has made the most advances in involving consumers in service delivery. The chapter concludes with the policies and a typology that inform consumers' involvement and activities in service delivery in drug treatment and harm reduction services.

Chapter three is a systematic review of literature that examines the benefits, constraints and facilitators of consumer participation in drug treatment services. It includes the manuscript of a published journal article (Goodhew, Stein-Parbury & Dawson 2019).

Chapter four provides a description of the theoretical framework, methodology and procedures that were employed to conduct this study. Details of the study aims, design and setting, study population, recruitment and consent procedures, data collection, management and analysis procedures, and ethical considerations are provided.

Chapter five presents the results from the 'assessment' stage of this study. This stage consisted of a consumer satisfaction survey, brainstorming exercise and structured interviews to help determine participants' attitudes and ideas about forming a consumer group.

Chapter six presents the results of forming a MSIC consumer action group (CAG). This stage involved a group of MSIC consumers and staff who attended 20 meetings over 18 months to develop the CAG's terms of reference, norms and goals to help the group function and be sustained into the future.

Chapter seven presents the results of the 'action' stage of this study. This stage involved the putting the CAG's goals into action to enhance consumer involvement in MSIC service delivery and planning.

Chapter eight presents the results of the 'evaluation' stage of this study. This stage consisted of a consumer satisfaction survey and structured interviews to evaluate the formation of the CAG.

Chapter nine discusses the findings of the study and examines how they relate to the study's aims and research questions and the literature covered in the systematic review. This chapter also addresses the limitations of the study and concludes with consideration of the implications of the study for research and practice.

## **CHAPTER TWO: BACKGROUND**

### **Consumer participation in health care**

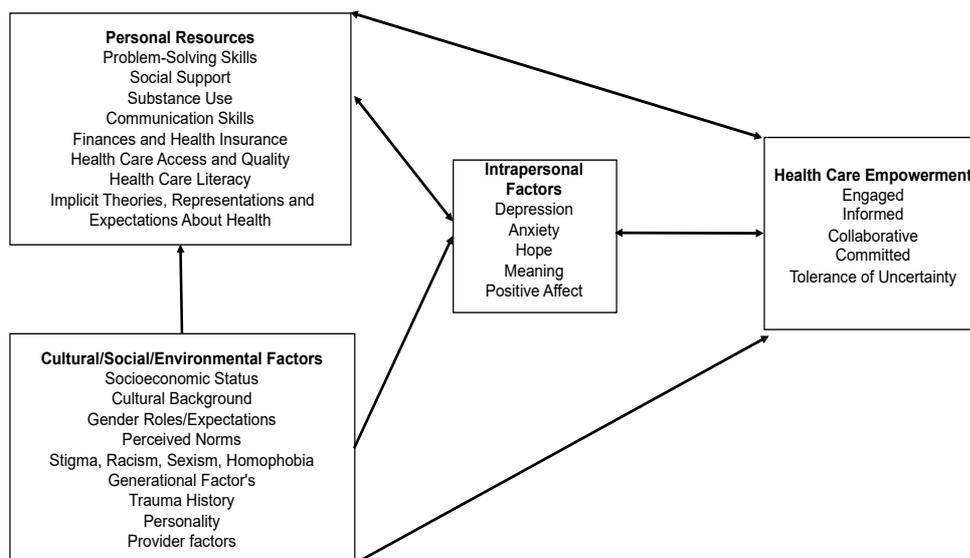
#### **Historical backdrop**

The consumer movement in health care was prompted by social change movements in the 1960s and 1970s that included black power in the US, feminism and gay liberation (Tomes 2006). The World Health Organization (WHO) introduced the concept of consumer participation in health care in 1978 (Shea et al. 2005) via the Declaration of Alma Ata. This declaration endorsed equality and social justice in health care through ensuring people have “the right and duty to participate individually and collectively in the planning and implementation of their health care to enhance individual and group consumer participation in the planning and delivery of health care” (WHO 1978 p. 7). Because consumer participation is closely related to the emancipation of marginalised people, its theoretical basis is closely aligned with various empowerment philosophies and models.

#### **Philosophical basis: empowerment**

According to Feste and Anderson (1995), “the empowerment philosophy is based on the premise that human beings have the capacity to make choices and are responsible for the consequences of their choices” (Feste & Anderson 1995 p. 139). In health care, the notion of empowerment is increasingly being employed to challenge unequal provider/patient relationships and provide patients with an alternative to blindly complying with medical decisions and prescriptions (Aujoulat, d'Hoore & Deccache 2007).

Consumer empowerment in health care is defined as “the process and state of being engaged, informed, collaborative, committed, and tolerant of uncertainty regarding health care” (Johnson 2011, p. 265). Johnson developed a health care empowerment model (see Figure 1) that provides insight into interrelated cultural, social, and environmental factors, personal resources and intrapersonal factors that may affect an individual’s empowerment in health care settings (Johnson 2011).



**Figure 1. A model of health care empowerment (adapted from Johnson 2011)**

In addition, external societal forces such as stigma, racism or homophobia, and internal factors such as personality and negative life experience (e.g. trauma) can reduce an individual's empowerment. A health care provider's early experiences with health care, training, health knowledge and views of shared decision-making with consumers are also factors that affect consumer empowerment.

Personal resources that influence health care empowerment include an individual's personal support, assertiveness, communication skills, access to quality health care, financial stability, health insurance, substance use and personal implicit theories, representations and expectations about health, illness and treatment (Johnson 2011). As Johnson (2011) noted, "these personal resources or deficits influence health care empowerment both directly and indirectly through their mediating effects on intrapersonal factors" (Johnson 2011, p. 268). Negative intrapersonal factors include depression and anxiety and positive factors include hope, meaning and positive effect. It is assumed that these factors occur through directly through psycho-neuro-physiological pathways or indirectly through their effect on treatment-seeking and health-promoting behaviours (Johnson 2011).

Health care consumers who have adequate personal resources and an enabling cultural and social environment may be able to attain critical consciousness (a concept described by Freire (1993) and thereby attain empowerment. Critical consciousness involves the oppressed (health care consumer) engaging in reflective and critical

dialogue with their oppressors (health care providers) to expose and provide an in-depth understanding of social and political contradictions (Freire 1993). Hage & Lorensen (2005) discussed how nurses and frail elderly patients can partake in reflective dialogue to become critically aware of the patients' health needs. Reflective dialogue occurs when nurses do not solely rely on their professional knowledge but work collaboratively with patients, so patients can decide on care and treatment that suits their own circumstances and life priorities (Aujoulat, d'Hoore & Deccache 2007; Hage & Lorensen 2005).

Landmark research conducted by the Institute of Medicine (2001) in the US revealed that collaborative and patient-centred care can enhance the quality and safety of health service delivery. The study recommended that clinical care should be respectful of patient's needs and values and they should have input into decisions regarding their treatment regime. Consequently, health care professionals are beginning to develop collaborative relationships with patients to help them become more empowered and enabled to self-manage chronic conditions such as diabetes (Anderson & Funnell 2005). However, health care providers are often socialised and taught to solve their patient's problems and, as a result, some perceive patient empowerment as an assault on their "deeply imbedded professional roles and responsibilities" (Anderson & Funnell 2005 p. 155). In addition, providers are concerned that collaborative relationships take more time, whereas they are increasingly expected to be more efficient by seeing more patients in less time.

Consumer participation not only involves an individual's participation in decisions about their own care and treatment but includes them as partners in the development of health service delivery, design, improvement and policy. The philosophical basis of consumers' involvement in service delivery and planning is psychological empowerment. Psychological empowerment is different from an individual's sense of confidence, because it relates to active engagement in an individual's community and an understanding of its sociopolitical environment (Zimmerman 1995). Therefore, psychological empowerment occurs when a person actively participates in their community and organisational activities (Zimmerman & Rappaport 1988). Furthermore, psychological empowerment is:

"an intentional, ongoing process centred in the local community, involving mutual respect, critical reflection, caring and group participation, through which

people lacking an equal share of valued resources gain greater access to and control over those resources.” (Cornell Empowerment Group 1989 p. 427)

## **Policy frameworks**

In many countries there are compelling social and political grounds for governments’ and health providers’ action on consumers’ requests to be more involved in their care and treatment and decisions about health care planning and service delivery (Consumer Focus Collaboration 2001). Therefore, consumer participation in health care is a priority for many governments and policymakers (Tambuyzer, Pieters & Van Audenhove 2014) and considered to be an essential element of the co-production of health care (Batalden et al. 2016).

In Australia, consumer participation in health care is guided by policies, guidelines and projects at national, state and territory and local levels. At a national level, the Australian Charter of Health Care Rights declares that all consumers have a right to be involved in decisions and choices about their care (Australian Commission on Safety and Quality in Health Care 2008). Furthermore, standard two of the National Safety and Quality Health Service Standards requires that consumers participate in organisational and strategic procedures that drive the planning and design of health services (ACSQHC 2017). The National Health and Medical Research Council (NHMRC) also states that consumers, community members, researchers and research organisations need to work in partnership in health and medical research projects to improve Australians’ health and well-being (NHMRC 2016).

Examples of state and territory consumer participation documents and endeavours include Victoria’s ‘Doing it with us not for us’ policy (State Government Victoria Department of Health 2011); the NSW Department of Health’s Consumer and Community Representative Guidelines (NSW Department of Health 2005); the NSW clinical excellence commission’s consumer engagement program, which uses consumers’ voices and expertise to transform health care (NSW Health Clinical Excellence Commission 2016); and the ‘Strong Voices’ guidelines that outline consumer health service representation in the Northern Territory (Northern Territory Government 2015). Some local health districts in NSW have consumer participation guidelines and frameworks to assist consumers and the communities to participate in their care and service delivery (Sydney Local Health District 2016).

## **Advantages of consumer participation**

There is reliable evidence that consumers' involvement in the delivery of health care contributes to increased satisfaction, safer and higher quality care and improved health outcomes (Institute of Medicine 2001). Similarly, active consumer participation can lead to improvements in health outcomes and consumers effectively self-managing their health conditions (Consumer Focus Collaboration 2001), increased consumer satisfaction (Goodhew, Stein-Parbury & Dawson 2019), more accessible and effective health services (Consumer Focus Collaboration 2001; Doggett 2015; Goodhew, Stein-Parbury & Dawson 2019) and increased community support for health services (Doggett 2015). Doggett (2015) also found that consumer input can improve existing services and create new ones, enhance organisational culture by enriching professionals' attitudes and communication with consumers, and improve the provision of information about chronic illnesses.

In Australia, consumer participation has predominantly been occurring in cancer care (Victorian Government Department of Human Services 2007), diabetes management (Department of Health 2015), and disability services (Ottmann, Laragy & Damonze 2008). However, the most substantial advances in consumer participation have been achieved in mental health services (AIVL 2008).

### **Consumer participation in mental health services**

In Western countries consumer participation in mental health services has been occurring for over 40 years, strengthened by the recovery movement that campaigned for mental health consumers to have control over their treatment and care and the right to live full and independent lives (Tomes 2006). This movement led to the creation of autonomous consumer-run enterprises, user-led or self-help services by people with a lived experience of mental illness, oversight of service delivery in partnership with mental health services, and employment of consumers in mental health services (Doughty & Tse 2011).

Salzer (1997) developed a conceptual hierarchy to illustrate levels of consumer empowerment in mental health organisations. The first level of power – 'power to consumers' – is positioned at the bottom of the ladder and refers to consumers working with service providers to gain access to resources and power-based activities such as

decision-making, leadership, and responsibility. The second level of power – ‘consumer power over’ – is positioned in the middle of the ladder, and involves consumers having access to resources and opportunities to enable them to develop and run their own services. The third aspect of power – ‘consumer power from’ – is at the top rung of the ladder and is concerned with the ability of consumers to oppose being labelled and stigmatised and fight against poor-quality services that infringe on their dignity and integrity. This aspect of empowerment occurs when organisations are responsive to consumers’ demands for improvements in service delivery.

Consumers in mental health services are mostly employed as peer support workers. A peer support worker is defined as someone with a lived experience of mental illness and recovery (Kilpatrick, Keeney & McCauley 2017). Typical duties include working with and advocating for peers, facilitating groups, care coordination, education and research (Cleary et al. 2011). Recent research has indicated that peer support worker roles are often tokenistic and poorly supported, and inadequately defined roles, power imbalances and that a lack of resources prevent the role from being fully realised (Cleary et al. 2018; Kilpatrick, Keeney & McCauley 2017). Doughty & Tse (2011) conducted an integrated review of research that compared consumer-led and traditional mental health services in high-income countries. They reported that consumer-led services had similar outcomes to traditional mental health services, especially with respect to employment and accommodation, and resulted in fewer hospital admissions and lower service costs. It is envisaged that similar benefits can be attained in drug treatment services, now that consumer participation is gaining impetus within drug treatment policies (AIVL 2008).

## **Consumer participation in drug treatment and harm reduction services**

The ladder of consumer participation (Table 1) by Bryant et al. (2008a) outlines the various levels of consumer activity and was developed to determine the degree of consumer participation occurring in Australian drug treatment settings. Bryant’s ladder is based on Arnstein’s (1969) ladder of citizen participation, which shows who has power when important decisions are being made. At the bottom rung of the consumer participation ladder are activities that are concerned with consumers receiving or providing information, in the middle rung of the ladder activities are concerned with

consumers running their own groups or educating staff and at the top rung of the ladder consumers are involved in activities that involve decision making.

Bryant's typology differs from Salzer's hierarchy as involvement in decision making is on the top rung of the ladder, while consumers gaining access to decision making this is on the bottom rung of Salzer's schema.

**Table 1. Ladder of consumer participation (Bryant et al. 2008a, 2008b)**

<b>Level</b>	<b>Type of Participation</b>	<b>Example of activity</b>
HIGH	Consumers share in decision-making activities.  Consumer participation is built into service's values and policies.	<ul style="list-style-type: none"> <li><input type="checkbox"/> Consumers are involved in service planning.</li> <li><input type="checkbox"/> Consumers attend staff meetings.</li> <li><input type="checkbox"/> Consumers participate in staff selection and performance appraisal.</li> <li><input type="checkbox"/> Consumer participation is incorporated into vision or mission statement.</li> </ul>
MID	Activities that promote and support consumer involvement but ones in which consumers have non-decision-making roles.	<ul style="list-style-type: none"> <li><input type="checkbox"/> Consumers are supported to conduct their own group activities.</li> <li><input type="checkbox"/> Consumers are involved in staff training.</li> </ul>
LOW	Activities concerned with providing information to or receiving information from consumers.	<ul style="list-style-type: none"> <li><input type="checkbox"/> Service displays user group publications.</li> <li><input type="checkbox"/> Consumer councils provide advice as to how services and programs should run.</li> <li><input type="checkbox"/> Forums are held so that consumers can express their views on service delivery.</li> <li><input type="checkbox"/> Surveys are conducted that ask consumers for their opinions about how services can improve.</li> <li><input type="checkbox"/> Complaints process is in place where consumers can register their complaints about service delivery</li> </ul>

Prior to the contemporary consumer participation movement, people with alcohol and drug problems had been actively involved in their recovery through the abstinence-based self-help organisations Alcoholics Anonymous (AA) and Narcotics Anonymous (NA). These organisations operate through a 12-step program which consists of teachings that assist individuals to 'live right' through taking a personal inventory of their strengths and shortcomings, making restitution for past wrongs, and helping others discover sobriety (Liotta 2013).

## **Peer education**

Another form of consumer participation is peer education, defined as:

“...a process controlled, devised and implemented specifically by members of a peer group to address the education needs of other members of that peer group. An example is people who inject drugs developing and delivering messages about safe injecting practices to other people who inject drugs.”  
(Department of Health and Ageing 2005 p. 37)

Many believe that the involvement of PWID in peer education emerged during the HIV/AIDS epidemic in the 1980s, but it had its roots in through community drug outreach in the late 1960s, when heroin addiction was a major problem in the US and Western Europe (WHO 2004). Former heroin users encouraged PWID to be prescribed methadone and community-based peer outreach groups educated drug users about avoiding hepatitis B and other injecting-related problems. Today, peer-based drug user groups such as the Australian Injecting and Illicit Drug Users League (AIVL)<sup>1</sup> and peer educators are still actively involved in teaching methods to reduce blood-borne virus transmission and other injecting-related harms.

## **Policy frameworks**

In AIVL's (2008) policy audit of consumer participation within drug treatment services, it was reported that momentum for consumer participation in drug treatment was gaining internationally, with countries such as the UK, New Zealand (NZ), Canada, the US and some European countries embedding consumer participation within drug treatment policies (AIVL 2008). The UK and NZ have the most comprehensive government policy

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<sup>1</sup> AIVL's website: <http://aivl.org.au/>

frameworks to support the implementation of consumer participation in drug treatment services.

The UK parliament passed the *Health and Social Care Act 2001*, which “made it a legal duty for every National Health Service organization to consult and involve patients and the public in its activities” (Fischer et al. 2007 p. 1). As a result, several case studies of successful consumer participation are highlighted in the national user service involvement guidelines for drug and alcohol services (Public Health England 2015). The UK government also collects mutual aid engagement<sup>2</sup> activity data, on activities such as peer-run 12-step recovery groups and smart recovery groups that are centred on the principles of cognitive behavioural therapy (NDTMS 2016).

In NZ, drug and alcohol treatments are funded by Mental Health Directorate section of the NZ Ministry of Health (AIVL 2008). In 1995 the NZ Ministry of Health published ‘A Guide to Effective Consumer Participation in Mental Health Services’ which included consumer participation in drug and alcohol treatments (NZ Ministry of Health 1995). These guidelines point to three levels of consumer participation: the individual level, which involves input into a service or one’s treatment as an individual; the organisational level, which involves input into service provision; and the policy level, which involves contributing to the development of policy (NZ Ministry of Health 1995).

Compared to other countries, Australia is lacking in drug treatment policies related to consumer participation, with few examples of policies at the national level (AIVL 2008). In the National Drug strategy 2017–2026 there is mention of consumer involvement, but no framework to guide its implementation. Mention of consumer participation is included in drug and alcohol service accreditation policies, but there is little uniformity regarding the definition of consumer participation in these documents (AIVL 2008).

In 2005, NSW developed the ‘Consumer Participation in NSW Drug and Alcohol Services’ document, which outlines a set of principles to guide health staff to instigate appropriate consumer participation programs in services (Mental Health and Drug and Alcohol Office 2005). The document was developed because there was scant

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<sup>2</sup> Mutual aid engagement is when social, emotional and informational support is provided by, and to, members of a 12 steps recovery or smart recovery groups (NDTMS 2016)

information available about consumer participation in drug and alcohol services in NSW, and is now in its second edition (NSW Health 2015). Consumer participation is also a feature in two other Australian states. The Association of Participating Services Users in Victoria developed 'Straight from the Source', a set of guidelines for the Victorian Drug and Alcohol Sector to aid development and implementation of sustainable consumer participation (Clarke & Brindle 2010). Western Australia developed a set of principles and best practice strategies to guide consumer engagement in drug and alcohol services (Health Consumers' Council Western Australia 2016).

## Summary

In this chapter I reviewed empowerment philosophies that underpin consumer participation in health care and how reflective and collaborative dialogue between consumers and providers has the potential to liberate health service users. Consumer participation was triggered by social movements that aimed for self-determination in the 60s and 70s, and this led the WHO and governments to introduce policies to involve consumers in health care delivery.

Evidence indicates that consumer participation enhances health and service delivery outcomes. Mental health services have made the most substantial advances in consumer involvement in service delivery. However, the notion of including consumers in mental care and peer worker roles can be tokenistic and poorly supported, because of lack of resources, power imbalances, and provider's negative attitudes.

Before present-day consumer participation, drug treatment and harm reduction service consumers were involved in their treatment and service delivery via self-help organisations such as AA and NA and safer injecting peer education. At an international level, UK and NZ have the most comprehensive drug and alcohol service consumer participation policies. Australia is lacking in national policies, and only three states (NSW, Victoria and Western Australia) have drug and alcohol consumer participation guidelines. However, the ladder of consumer participation is used as a way to assess the extent of participatory activities in drug and alcohol services in Australia.

The next chapter presents a systematic review of literature that examines the benefits, constraints and facilitators of consumer participation in drug treatment services.

# CHAPTER THREE: CONSUMER PARTICIPATION IN DRUG TREATMENT: A SYSTEMATIC REVIEW

This chapter is the accepted version of the following published manuscript:

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## Keywords

Consumer participation, drug treatment service delivery, professional attitudes

## Abstract

### Purpose

It is unclear how consumer participation (CP) can be optimised to transform drug and alcohol treatment services and improve health outcomes. This paper presents the findings of a systematic review examining the types and benefits of activities, and the factors that facilitate CP in drug treatment services.

### Design

A structured search of four databases was undertaken to identify peer reviewed primary research literature in English. Screened articles were appraised. A content analysis was applied to examine the types and outcomes of CP and the associated factors affecting the process. Sixteen articles were included for review.

### Findings

A range of CP activities were identified, and benefits included increased consumer satisfaction, and improved health service delivery. Factors that facilitated the process of CP included positive attitudes of both consumers and providers and employment of people with a lived experience of drug use. However, the lack of consumer and organisational capacity, negative attitudes of providers and power imbalances between consumers and providers constrained CP efforts.

## **Practical implications**

To maximise the benefits of CP in drug and alcohol treatment services, negative attitudes about CP and power dynamics between consumers and health providers need to be addressed. This can be achieved - through the strategic use of strengths-based interventions and consumer led education to enhance social capital.

## **Originality/Value**

This is the first known review to examine the benefits and facilitators of consumer participation in drug treatment services.

## **Background**

Consumer participation (CP) in health care transpires when consumers are “meaningfully involved in decision-making about health policy and planning, care and treatment, and the wellbeing of themselves and their community” (ACT Government Health 2011, p. 7). CP arose from social change movements in the 1960’s and 1970’s that included Black Power in the US and women’s and gay liberation (Tomes 2006). In 1978 the WHO initiated CP in health care (Shea et al. 2005). This action is supported by the Declaration of Alma Ata that promotes equity and social justice in health care by ensuring people have “the right and duty to participate individually and collectively in the planning and implementation of their health care” (WHO 1978, p. 1). There is reliable evidence that involving consumers in the delivery of health care leads to more satisfactory, safer, higher quality care and improved health outcomes (Institute of Medicine 2001). As a result, CP has become a high priority for many governments and policy makers (Tambuyzer, Pieters & Van Audenhove 2014) and is necessary to achieve the co-production of health care services (Batalden et al. 2016).

Several governments around the world have introduced policies and guidelines to guide consumer involvement in drug treatment services. The government of the United Kingdom (UK) was the first to legislate CP in drug treatment services and, as a result, is considered a world leader (Hinton 2010). The UK collects data about CP in mutual aid engagement activities, such as peer run groups and smart recovery, that are based on the principles of cognitive behavioural therapy (NDTMS 2016). Examples of successful drug treatment involving CP are provided in the national guidelines (Public Health England 2015). Despite these efforts, CP in drug treatment services in the UK

are “patchy and sometimes tokenistic” (Hinton 2010, p. 25). This is because CP is often poorly resourced and not embedded into strategic objectives of the service (Hinton 2010). As a result, services are streamlined and cannot be tailored to meet individual’s needs. Furthermore, some consumers are excluded from contributing to service delivery because they are incarcerated or live in rural areas with poor transport and services that are geographically dispersed (Hinton 2010).

CP has been implemented for several decades in mental health services. One review in this care context demonstrated that employing consumers within these services leads to greater consumer satisfaction and reduced hospital admissions (Simpson & House 2002). Consumer-led services have also resulted in positive employment and accommodation outcomes for mental health consumers (Doughty & Tse 2011).

Four reviews have explored CP in drug treatment services. The first focused on consumers’ perspectives regarding provider training to determine if it is responsive to consumers’ needs (Wylie 2010). The second reviewed studies that focused on the involvement of people who use drugs in policy and program development noting the scarcity of evidence regarding their participation on policy committees (Ti, Tzemis & Buxton 2012). The third critically reviewed studies that reported results of consumer satisfaction surveys in drug treatment services (Trujols et al. 2014). The fourth investigated how consumers’ perspectives are incorporated into surveys designed to inform service development (Hyshka et al. 2017).

While these reviews are informative, gaps remain in fully understanding the factors that enable or inhibit consumers’ involvement in drug treatment services. Awareness of these factors is critical to realising the benefits of consumer involvement in these services.

## **Levels of CP**

Bryant et al. (Bryant et al. 2008a, 2008b) have conceptualised the participation of consumers in drug treatment services in a hierarchical manner, illustrated as a ladder that depicts various levels of involvement (Table 2). At the lower rungs of the ladder consumer participation is classified as activities such as surveys to gain insight into consumer satisfaction with services (Bryant et al. 2008b; King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Roussy et al. 2015; Schulte et al. 2007). At the upper end of the ladder are more

complex activities, for example, the involvement of consumers in decisions about service planning and delivery and the selection of new employees.

**Table 2. Ladder of Consumer Participation**

Level	Type of Participation	Example of activity
<b>HIGH</b>	<p>Consumers share in decision-making activities.</p> <p>Consumer participation is built into service's values and policies.</p>	<ul style="list-style-type: none"> <li>• Consumers are involved in service planning.</li> <li>• Consumers attend staff meetings.</li> <li>• Consumers participate in staff selection and performance appraisal.</li> <li>• Consumer participation is incorporated into vision or mission statement.</li> </ul>
<b>MID</b>	<p>Activities that promote and support consumer involvement but ones in which consumers have non-decision-making roles.</p>	<ul style="list-style-type: none"> <li>• Consumers are supported to conduct their own group activities.</li> <li>• Consumers are involved in staff training.</li> </ul>
<b>LOW</b>	<p>Activities concerned with providing information to or receiving information from consumers.</p>	<ul style="list-style-type: none"> <li>• Service displays user group publications.</li> <li>• Consumer councils provide advice as to how services and programs should run.</li> <li>• Forums are held so that consumers can express their views on service delivery.</li> <li>• Surveys are conducted that ask consumers for their opinions about how services can improve.</li> <li>• Complaints process is in place where consumers can register their complaints about service delivery</li> </ul>

There is a need to understand the factors that impact on CP policy, the ability of organizations and individuals to successfully engage consumers in all aspects of service delivery and the socio-economic outcomes that arise as a result. The aim of this systematic review therefore is to identify the types of activities that are associated with CP, their associated outcomes and the factors that facilitate or constrain consumer participation in drug and alcohol treatment services.

## Methods

### Search strategy

A search of the electronic databases Medline Ovid, Embase Ovid, and Scopus and Drug Database was performed in January 2018 to retrieve peer reviewed research publications in English. One additional article was sourced from a reference list. While no date limit was applied, no literature regarding CP and drug treatment was retrieved prior to 2007. The search was conducted using the following key terms: ‘consumer participation’, or ‘patient participation’ or ‘client participation’ or ‘user involvement’ or ‘peer’ or ‘empowerment’ and ‘drug treatment’ or ‘drug treatment services’ or ‘harm reduction services’ or ‘drug and alcohol services’ or ‘substance abuse treatment centers/centres’. Table 3 outlines the inclusion and exclusion criteria that were applied.

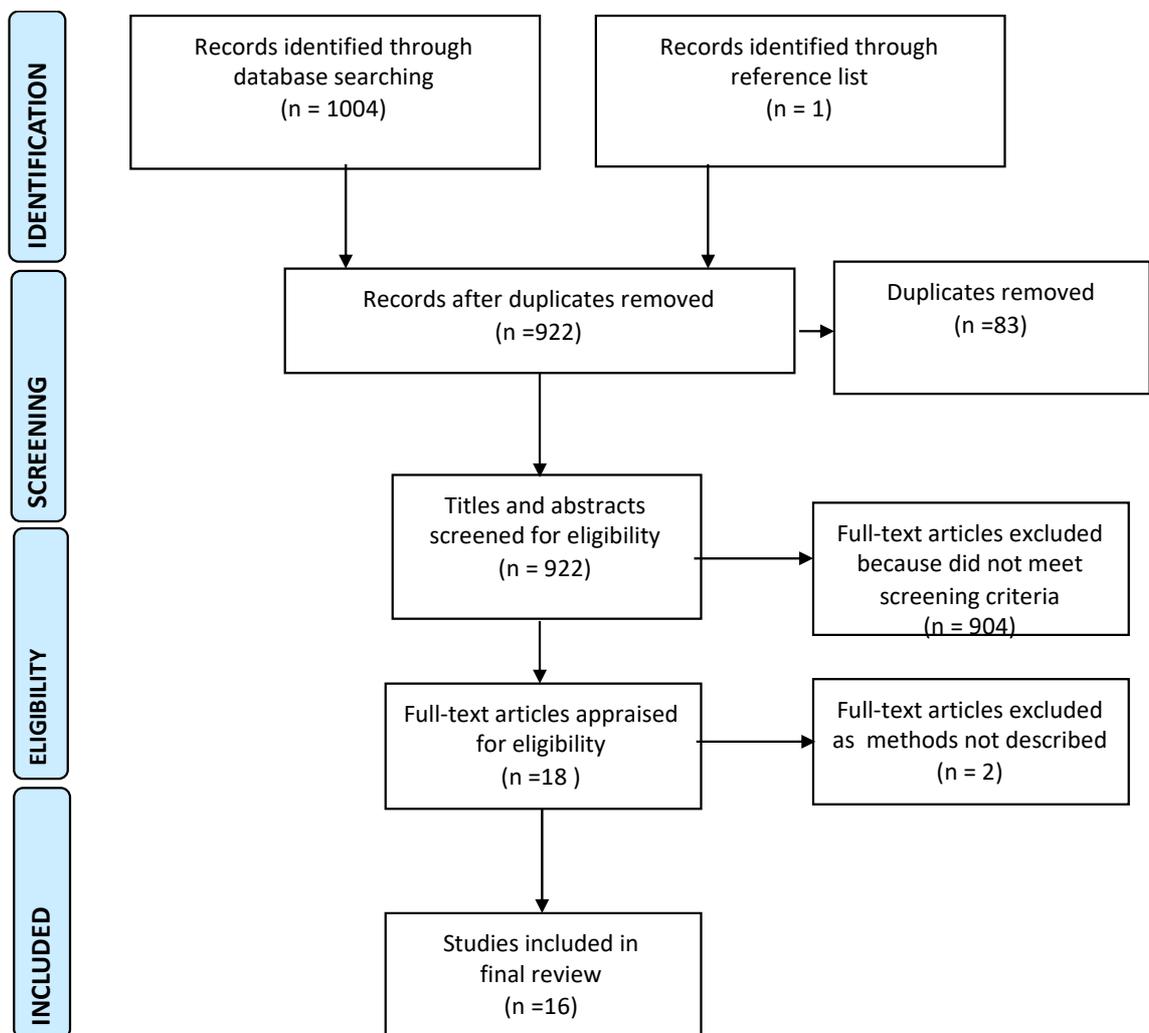
**Table 3. Inclusion and exclusion criteria**

Criteria	Inclusion	Exclusion
Language	English language	Non- English language
Type of studies	Peer reviewed qualitative, mixed method or quantitative studies	Grey literature or discursive papers
Focus	Studies examining how consumers have influenced the design, implementation and evaluation of drug treatment service (e.g. detoxification, rehabilitation, opioid replacement therapy clinics and harm reduction services) and drug treatment policy through being involved in participatory activities.	Studies that primarily focus on consumers delivering services to each other (e.g. peer run services), consumers providing support to each other, delivering peer education or commodities such as clean needle kits
Participants	Consumers and staff of drug treatment services.	Consumers and staff of services that primarily focus on treatment for alcohol addiction or problems

The initial search located 1004 items that was reduced to 18 after removing duplicates and those that did not meet the inclusion criteria (see Figure 2).

## Appraisal of studies

The criteria outlined in Critical Appraisal Skills Programme (CASP 2014). were used to appraise the quality of the nine qualitative studies; two were excluded as they did not fully outline the methodology. The CASP Case Control Study Checklist, CASP Cohort Study Checklist and the Joanna Briggs Checklist for Analytical Cross-Sectional Studies (Joanna Briggs Institute 2017) were applied to the seven quantitative studies; none were excluded.



**Figure 2. Consumer participation in drug treatment (PRISMA) showing selection of publications for review**

## **Data extraction and synthesis**

Full text data were extracted from the 16 papers and first described according to general study characteristics. A directed content analysis was then employed, as outlined by (Dawson, Nkowane & Whelan 2015), to organise the data on a table based on the CP ladder, thus enabling comparison of the findings across key areas. Activities were identified as lower, mid and higher on the ladder alongside the reported associated benefits and the factors that facilitated or constrained them. Table 4 outlines the characteristics and findings of the 16 studies.

**Table 4. Characteristics and findings of studies**

Author	Participants	Aims	Method			Findings							
			Quant	Qual	Mixed	Improved service delivery	Increased Satisfaction & goal achievement	Empowerment	Supportive attitudes	Employment of consumers	Perceptions of consumer capacity	Power imbalances	Low organisational Capacity
Brener et al. 2009	492 consumers from 5 sites	Explore CP related satisfaction & goal achievement	✓				✓				✓		
Bryant et al. 2008a	179 consumers at 64 drug services	Determine consumer knowledge of CP	✓								✓		
Bryant et al. 2008b	As above	Determine service provider & consumers' perceptions of CP.	✓			✓					✓		
Greer et al. 2016	Staff & 2 consumers	Assess consumers' engagement service decision-making		✓		✓		✓	✓			✓	✓
King 2011	8 consumers from 12 methadone programs	Investigate consumer & staff perceptions of CP		✓		✓		✓	✓	✓	✓	✓	✓
Lancaster et al. 2017	41 members (7 consumers) of drug policy committees	Analyse CP discourses in drug policies.		✓								✓	
Leppo and Perällä 2009	Consumers of a needle exchange service & drug treatment service	Explore the effects of CP		✓				✓				✓	

Patterson et al. 2009	139 Staff & consumers	Explore the process & purpose of CP		✓				✓	✓		✓	✓	✓
Patterson et al. 2009b	50 service commissioners, providers & consumers	Examine CP benefits & barriers.	✓			✓	✓		✓	✓	✓	✓	✓
Patterson et al. 2010	139 staff & consumers.	Describe process & outcomes of consumer groups.			✓	✓		✓	✓		✓	✓	✓
Rance & Treloar 2015	57 consumers & staff from 3 Services	Investigate CP initiatives & the therapeutic alliance		✓				✓	✓			✓	
Roussy et al. 2015	125 staff at the intervention site & 115 at the control site.	Evaluate the effectiveness consumer-led training			✓			✓					
Schulte et al. 2007	46 consumers & 51 service provider	Determine consumer & provider views on the type and extent of CP		✓						✓	✓		✓
Treloar et al. 2011	108 consumers & staff of 5 services	Determine level of CP		✓						✓	✓	✓	✓
Tober et al. 2013	20 Mentors, 8 consumers, 6 staff, 3 academics	Describe the process of co-producing an aftercare addiction service		✓		✓		✓	✓	✓	✓		
Van Hout & McElrath 2012	30 service providers, 12 consumers	Investigate user & provider views of CP		✓		✓			✓		✓	✓	✓

## Results

Of the sixteen studies included in the review, four employed quantitative research methodologies, ten used qualitative approaches and two applied mix methods methodologies. Seven of the studies originated in Australia, seven in the United Kingdom, one in Finland and one in Canada. The study sites included government and non-government detoxification services, residential rehabilitation units, opioid substitution clinics, drug and alcohol policy committees, harm reduction service and drug and alcohol counselling services.

Consumers were involved in a variety of lower to mid activities that included completing satisfaction surveys, facilitating groups, operating a café and a drop-in centre and educating providers. A range of higher-level activities were also described, including: involvement in the development of a consumer charter of rights, consumers serving as members of committees, attending staff meetings, and participating in staff recruitment, quality assurance activities, research commissioning and coproducing services.

### **Benefits of CP:**

#### **Improved service delivery**

In five studies (Bryant et al. 2008b; Greer et al. 2016; Patterson, Weaver, Agath, Rutter, et al. 2009; Tober et al. 2013) service quality was enhanced when the views of service users were incorporated through consumer representation on decision making committees, open councils or forums and service expansion projects. These improvements included: enhanced consumer-centred care (King 2011), decreased waiting times and revised operating hours (Bryant et al. 2008b; Patterson, Weaver, Agath, Rutter, et al. 2009), increased consumer survey response rate about service reconfiguration (Patterson, Weaver, Agath, Rutter, et al. 2009) and better opportunities for social support, self-help, and networking (Patterson, Weaver & Crawford 2010). Consumer groups were found to support consumers through the stages of addiction and recovery by assisting them to better access treatment services, providing additional information about services, offering advocacy in the case of problems with a provider, and providing alternative forms of support for consumers who did not wish to engage in prescriptive programmes such as Narcotics/ Alcoholics Anonymous (Van Hout & McElrath 2012).

Consumer input was found to expand the current range of available services such as the development of an aftercare service (Tober et al. 2013), an inpatient unit, a day program, and mobile treatment service and the introduction of buprenorphine to increase treatment options (Patterson, Weaver, Agath, Rutter, et al. 2009). Consumer input also led to the development of improved harm reduction interventions, such as a take home naloxone program and the provision of a wider range of safer inhalation supplies (Brener et al. 2009; Greer et al. 2016) and injecting equipment (Patterson, Weaver, Agath, Rutter, et al. 2009).

### **Increased satisfaction and goal achievement**

Studies revealed that consumers who participated in planning and delivering services including the type of drug treatment they wished to undertake, enjoyed high levels of satisfaction (Brener et al. 2009; Patterson, Weaver, Agath, Rutter, et al. 2009) and goal achievement (Brener et al. 2009). A survey of 492 consumers found that consumer satisfaction increased when consumers participated in planning their treatment and that this participation increased awareness of their rights (Brener et al. 2009). Brener et al. (2009) also reported that the achievement of treatment goals was associated with being involved in a review of the service and having knowledge of grievance procedures.

### **Empowerment**

Involving consumers in CP activities was found to foster consumer empowerment as their participation altered the power dynamics of the consumer-provider relationship (King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Rance & Treloar 2015) and reduced the stigmatisation of service users (Patterson, Weaver, Agath, Albert, et al. 2009). CP decreased the interpersonal distance between consumers and providers (Patterson, Weaver, Agath, Albert, et al. 2009), allowing them to see each other's human qualities (Rance & Treloar 2015) and finding common ground (Tober et al. 2013). As a result, consumers were able to gain confidence and a sense of ownership over aspects of the service (Patterson, Weaver & Crawford 2010; Tober et al. 2013).

Consumer empowerment was affected by the ethos underpinning the health service itself. Providers who worked in harm reduction services were found to be less paternalistic than those who worked in more traditional setting such as a drug treatment service for pregnant woman (Leppo & Perala 2009).

Health care organizations that facilitated consumer led training were found to have empowered consumers, improved relations between consumers and providers and decreased stigma and staff discrimination towards consumers (Roussy et al. 2015). As a result, providers stated that they gained a greater understanding of needs of people with both substance use and mental health disorders and felt more competent in their caring role. Consumers also became empowered as members of harm reduction committees, as their membership helped them to become involved in their community, develop confidence and skills, and become inspired by peer leaders (Greer et al. 2016).

Consumers reported that they became more confident to express their needs through their involvement in participatory activities. One consumer expressed this by stating that “I think it is important that users have a voice ‘cause we are people too” (Rance & Treloar 2015, p. 33). Consumers also reported this ‘voice’ could be political in nature (Rance & Treloar 2015), thus invigorating their desire for social justice (Patterson, Weaver, Agath, Albert, et al. 2009). Therefore, a voice helped consumers educate the public and raise awareness about issues that impact them (Patterson, Weaver & Crawford 2010; Rance & Treloar 2015), such as the need for the decriminalisation of drug use, reforms in prescribing policies, and making drug treatment more accessible and respectful (Patterson, Weaver, Agath, Albert, et al. 2009). The consumers’ voice also informed the development of participatory activities that helped to create solidarity among consumers and enabled collective feedback to be presented to service providers (Patterson, Weaver & Crawford 2010).

## **Facilitators of CP:**

### **Supportive attitudes of consumers and providers**

Eight studies revealed that the supportive attitudes of consumers and professionals encouraged consumers to be more involved in drug treatment service delivery and planning (Greer et al. 2016; King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Patterson, Weaver & Crawford 2010; Rance & Treloar 2015; Tober et al. 2013; Van Hout & McElrath 2012). Attitudes reflecting values that CP was fundamental to effective service delivery facilitated consumer-centred care through developing an understanding of service users’ individual and collective needs (King 2011; Patterson, Weaver, Agath, Albert, et al. 2009). Therefore, CP was facilitated by an organisational culture that embodied

optimistic views and an appreciation of consumer contributions (Van Hout & McElrath 2012), and mutual respect (Patterson, Weaver, Agath, Rutter, et al. 2009) that allowed consumers and staff to work towards a collaborative ethos (Patterson, Weaver, Agath, Rutter, et al. 2009).

Such organisations demonstrated these values through adequate funding and dedicated time to participatory initiatives (Greer et al. 2016; Patterson, Weaver, Agath, Rutter, et al. 2009). Other aspects of these organisations included well-defined internal and external communication pathways (Patterson, Weaver & Crawford 2010), clearly articulated expectations (Greer et al. 2016), and the provision of feedback on the progress and outcome of consumer requests and suggestions (Patterson, Weaver, Agath, Rutter, et al. 2009).

### **Employment of consumers with lived experience**

Three quarters of consumers in the Schulte et al. (2007) study were supportive of people with a lived experience of drug use being employed on a voluntary or paid basis. Consumer employment was underpinned by the understanding that they are well-informed, have the knowledge, understanding and credibility to be effective (Treloar et al. 2011) and are more empathic, as they have similar life experiences as consumers (King 2011). The mentors who helped produce an aftercare service reported that their lived experience of recovery helped other consumers to see that it is “possible to move on [and] to learn to live again” (Tober et al. 2013, p. 231).

Patterson, Weaver, Agath, Rutter, et al. (2009) reported that people with a lived experience working in drug treatment facilities required specific training that included information about the service structure and processes and formal meeting procedures such as agendas, chairing meetings and minute taking. It was also recommended that this training should be self-reflective, so consumers can review their learning and performance. Training ultimately helped consumer representatives progress to paid positions within drug services (Patterson, Weaver, Agath, Rutter, et al. 2009).

## **Constraints of CP**

### **Perceptions of consumers’ capacity**

Service providers were reluctant to involve consumers, especially in higher level activities such as staff training, recruitment and performance appraisal, because they thought that consumers did not possess the skills or interest to successfully undertake

such activities (Bryant et al. 2008b; Patterson, Weaver, Agath, Rutter, et al. 2009; Schulte et al. 2007; Van Hout & McElrath 2012). Providers in Patterson, Weaver, Agath, Albert, et al. (2009) study questioned the legitimacy of involving people who “choose” to use illicit substances and therefore have “self-inflicted problems” [p.57]. Even when active CP was embedded into services, providers expressed doubt about the sustainability of these activities as consumers were viewed as unstable, manipulative, untrustworthy, powerless, vulnerable and lacking in capacity to participate because of their chaotic lifestyles and social problems (Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver & Crawford 2010; Treloar et al. 2011; Van Hout & McElrath 2012). Fears that consumers may relapse or would endanger the recovery of those who were abstinent were also expressed (Tober et al. 2013; Van Hout & McElrath 2012). Providers were also reluctant to involve consumers in service delivery because they lacked trust in them, were concerned about their strong opinions (Patterson, Weaver, Agath, Rutter, et al. 2009) and disparate and unrealistic expectations about service delivery (King 2011; Patterson, Weaver & Crawford 2010).

Consumers also expressed the view that it was not their place to be involved in staff matters because they perceived that they did not have: the necessary skills (Bryant et al. 2008b; Patterson, Weaver, Agath, Albert, et al. 2009), stability (King 2011; Treloar et al. 2011), interest, confidence or entitlement to participate (King 2011). Peer mentors who co-produced an aftercare service reported they felt uncomfortable and confused about their boundaries when consumers disclosed information that they usually relayed to a therapist because they lacked counselling skills (Tober et al. 2013). In another study providers were worried that peer workers would disregard guidelines, interpersonal boundaries and confidentiality issues, because they lacked formal training (King 2011).

It was also revealed consumers were unaware of opportunities to participate due to a lack of knowledge about CP in principle or in practice (Patterson, Weaver, Agath, Albert, et al. 2009). Several studies reported that consumers did not know how to make a service complaint (Brener et al. 2009; Bryant et al. 2008a), nor did they know the location of the suggestion box (Bryant et al. 2008a). In another study consumers and providers were unaware of the service user support team whose role was to advocate on behalf of consumers (Van Hout & McElrath 2012).

Studies have also questioned consumer groups' capacity to represent the diverse range of people that engage with drug treatment services (Patterson, Weaver, Agath, Rutter, et al. 2009; Patterson, Weaver & Crawford 2010; Van Hout & McElrath 2012). It was reported that cliques often occur in drug user groups (Patterson, Weaver, Agath, Albert, et al. 2009), and they are perceived as 'exclusive' (Patterson, Weaver & Crawford 2010). Consequently, this limits group membership, as selection of members is frequently based on therapeutic orientation, drug user status or relationship with the group convenor (Patterson, Weaver & Crawford 2010). It was proposed that service user forums need to increase their visibility to broaden their membership and include prisoners, gay, lesbian and transgender people, and migrants to ensure a more accurate representation of drug treatment consumers (Van Hout & McElrath 2012).

### **Power imbalances between consumers and providers**

Providers reported that they were reluctant to involve consumers in service planning and delivery because of the hierarchical professional-client relationship, described as the 'them and us' divide that emphasized beliefs that health care providers know best (Leppo & Perala 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Rance & Treloar 2015). Providers were found to be resistant and concerned about moves towards establishing more equal power relationships (Rance & Treloar 2015; Treloar et al. 2011), as they feared that professional authority might be undermined. Such views were said to perpetuate negative and judgemental views towards consumers (King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Patterson, Weaver & Crawford 2010; Van Hout & McElrath 2012).

Consumer representation on committees (Greer et al. 2016; Lancaster et al. 2017) was found to be "weighted towards scientific voices" (Lancaster et al. 2017, p. 64) that maintained professional dominance in decision making. In addition, consumer knowledge was often seen as illegitimate, as it represented "the antithesis of clear and systematic reasoning" (Lancaster et al. 2017, p. 65).

Power divides and conflicts between consumers and staff were reported to be intensified by abstinence-related punitive rules set by residential treatment services (King 2011). Consumers were reluctant to make complaints against staff because they worried that staff would assert their power by restricting medication or excluding them from services (Patterson, Weaver, Agath, Albert, et al. 2009).

## **Low organisational capacity**

A lack of organisational direction from government and support for consumer positions that enable consumer advocacy was found to negatively affect the ability of managers to bring about change (Van Hout & McElrath 2012). The low value of consumer support positions was also explained by inadequate terms of reference (Van Hout & McElrath 2012), poor organisational drive and obstruction to programs (King 2011), and insufficient commitment from government (King 2011; Patterson, Weaver, Agath, Albert, et al. 2009). Other studies reported that poor allocation of financial and human resources constrained CP projects (King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Patterson, Weaver & Crawford 2010; Schulte et al. 2007; Treloar et al. 2011; Van Hout & McElrath 2012). These studies found that CP was not considered 'core business' and that projects were often disrupted because of staff resignations, poor staff hand over (Greer et al. 2016; Treloar et al. 2011) and organisational time constraints (Patterson, Weaver, Agath, Rutter, et al. 2009).

Patterson, Weaver, Agath, Rutter, et al. (2009) reported that the focus on attaining performance targets, undermined the resources, energy, and commitment required for CP. Staff also often underestimated the amount of work required to undertake a CP project and did not value training in this area (Treloar et al. 2011).

## **Discussion**

This review has revealed that CP has the potential to enhance drug treatment services and health outcomes. CP can increase consumer access to improved and expanded services, improve consumer satisfaction, relationships between staff, and consumers, reduce individual providers' negative attitudes and help consumers achieve their treatment goals. CP activities ultimately empower consumers by giving them a voice and the skills knowledge and confidence they require to actively and meaningfully contribute. However, CP is predicated upon a service delivery context that values consumer contributions through clear commitment that is articulated in policy and resourcing.

Even though CP policy has been enshrined into policy, attitudinal change at an organisational level which facilitates the translation of policy into practice at service level remains a challenge. Despite the existence of CP policies at the macro level,

consumer involvement in drug treatment services is constrained by organisational cultures at the micro level. Consequently, CP initiatives are often poorly conceived and inadequately resourced, especially higher-level activities. Often, attempts to incorporate higher levels activities into drug treatment service delivery are not sustained due to organisational instability, including frequent staff changes, insufficient handover of CP projects and low valuing of CP as core business (Treloar et al. 2011).

The notion that consumers are incapable of contributing also needs to be challenged if CP is to succeed in drug treatment services. Some providers will be reluctant to meet these challenges, as drug and alcohol services “are framed by an environment that is strongly risk averse” (The Royal Australian and New Zealand College of Psychiatrists 2012, p. 18). This is reflected in a physical environment of treatment services that are often fitted out with bullet-proof glass and buzzing doors, which reinforces the notion that consumers are associated with danger and illegal activity (Crawford 2013). As a result, providers are often reluctant to involve consumers in service delivery because they are perceived as ‘criminals’, ‘addicts’ and ‘junkies’ (Crawford 2013; Harris & McElrath 2012; Radcliffe & Stevens 2008). Such conceptions of substance dependence necessitate change to improve attitudes concerning consumer involvement in service delivery.

Since the 1970’s substance dependence has been viewed through a pathological lens (Siegal et al., 1995) and over the past twenty years in the American Diagnostic and Statistical Manual of Mental Disorders substance dependence has been increasingly conceptualised as biological in nature (Nathan, Conrad & Skinstad 2016). Furthermore, drug treatment is dominated by programs that claim that individuals with substance dependence are ‘diseased’ and ‘powerless’ (Verde Valley ArizoNA 2014). Describing individuals with substance dependence in this manner reinforces criminal stereotypes such as the ‘junkie’ (Crawford 2013). In addition, stigma and discrimination restrict involvement of consumers in policy and program development (Ti, Tzemis & Buxton 2012). Overall, a purely biological/diseased and stigmatised view of substance dependence reinforces the belief that drug treatment consumers lack capacity not only to contribute to their own care but also service delivery and planning.

A strengths-based model would move beyond a focus on an individual’s pathology or deficits (Rapp & Goscha 2011) in order to overcome the perception that drug treatment consumers lack capacity to participate. This model includes a systematic assessment

of a consumers' skills, attributes and assets (National Registry of Evidence-Based Programs and Practices 2009), this is based on the creation of egalitarian consumer-professional relationships with consumers' directing the helping process (Rapp & Goscha 2011). These strategies flatten the hierarchical expert-patient relationship that dominates drug treatment services and constrains consumer participation (Putnam 1993). More harmonious and equal relationships help to foster an environment where the consumers' input is more likely to be considered. One way to promote such relationships is for services to invest in social capital.

Social capital, as conceptualised by Putnam (1993, p. 35), includes the "features of social organizations, such as networks, norms, and trust that facilitate action and co-operation for mutual benefit". Shared connections between consumers are developed through activities such as the service user support teams (Van Hout & McElrath 2012). Here social capital is built through the bonding of consumers. Bridging social capital or enhancing the connections between different consumers and staff in treatment services can be achieved by consumer training of staff that promotes an understanding of consumer needs and awareness of the importance of mutual respect (Roussy et al. 2015), and well-defined communication channels (Patterson, Weaver & Crawford 2010). Engaging diverse groups of consumers in decision making committees within treatment services is key to linking social capital by increasing the degree to which people create relationships with institutions and individuals who have considerable amount of power over them (Woolcock 2001). Building social capital will therefore help to reduce the power differentials that constrain CP.

Harnessing the opportunities for social capital can help drug treatment organisations improve performance as teamwork is an essential element of quality health care (Norrish et al. 2013). High levels of social capital are associated with improved drug treatment and harm reduction outcomes such as reduced risk of relapse (Panebianco et al. 2016) and overdose (Zoorob & Salemi 2017), recovery from substance and alcohol dependence (Granfield & Cloud 2001; Weston, Honor & Best 2018), and a decreased risk of sharing syringes (Kumar, McNeely & Latkin 2016).

In mental health care, the recovery movement has been particularly successful in supporting people who experience mental illness to gain increased levels of social capital. This has been achieved because the consumer driven nature of the recovery movement focuses on self-determination through the provision of opportunities for

people with mental illness to contribute to mainstream society through work and education (Davidson 2016). This has enabled mental health consumers to gain a voice and a renewed sense of hope (Meehan et al. 2008). In the UK, drug treatment services are starting to follow by providing opportunities such as sustained employment as part of treatment (Black 2016).

While activities to build social capital that addresses the treatment needs of consumers and better engages consumers in their own care are required, these will need to be tailored to fit individual contexts. The ladder of consumer participation depicts a range of activities that can be implemented to change power dynamics and empower consumers. However, the different types of knowledge and expertise that are central to the process of citizen participation requires a comprehensive approach to capacity building. In addition, not all people will desire power or want to be involved in decision-making activities (Tritter and McCallum, 2006).

Even though it is useful to depict the power dynamics at the various levels of the ladder the activities and processes in drug treatment service delivery are not straightforward or linear. This is because the different levels of activity take place simultaneously and there is a variation in the degree to which consumers are willing to participate and the activities in which they are willing to engage. Some consumers will not want to participate, as they may wish to concentrate on their treatment; some will be pleased to contribute by completing a satisfaction survey; while others will be highly motivated to volunteer their time, for example, by being a consumer representative on a committee that informs policy.

A framework for consumer participation would be improved by visualising participatory activities in a more dynamic fashion, with participatory activities displayed in an integrated manner rather than ranked as a hierarchy as implied by the ladder of consumer participation. This will allow reference to 'bundles' of activities from all levels of the ladder to better illustrate the complexity and need for tailoring according to the context. The ladder does not consider the full spectrum of consumer participation. For example, it does not account for consumers who choose not to participate, and consumers who are employed in drug treatment services because of their lived experience of drug use and recovery.

## **Limitations**

A limitation of this review is that literature published only in the English language was included. In addition, there was no literature related to closed settings such as prisons and involuntary treatment, where unequal power dynamics are exacerbated. Therefore, the synthesis may be lacking in detail, particularly in relation to contextual factors that are important to the outcomes of the various CP interventions.

## **Implication for research**

Future research needs to focus on how current policy decisions impact upon providers attitudes towards CP and on the commissioning and monitoring of services. Therefore, it would be useful to investigate staff experience, professional development and communication skills in relation to how these factors impact on their attitudes and the implementation of CP projects. In addition, the barriers to CP for prisoners, migrants, gay, lesbian and transgender people need to be investigated.

## **Conclusion**

Positive attitudes towards CP in drug treatment services may not evolve to successfully address consumer needs if drug treatment services do not invest in social capital. Consumers' capacity to contribute requires a supportive organizational environment that challenges notions of 'staff know best', therefore addressing embedded attitudes and power imbalances. In addition, the current ladder of CP in drug treatment needs to be transformed so all forms of participation are equally valued and increased 'buy in' from strategic bodies and commissioning teams is required.

## **Funding**

This research was unfunded

## **Conflict of interest**

No conflicts of interest declared.

## **Originality of the research**

The consumer participation studies in this review predominately used interview and survey methods to meet their aims and objectives and the participants in these studies played a passive role in the study's design. This research is unique because of its Participatory Action Research (PAR) method where participants are considered to be co-researchers in the study. In addition, consumer participation studies in drug treatment setting have mainly been conducted in drug and alcohol clinics, detoxification and residential facilities. To my knowledge no previous studies have taken place in a harm reduction facility, such as Sydney MSIC. This setting will provide a different perspective regarding consumer participation and drug treatment, because of its unique setting. The next chapter will outline this study's methods.

## **CHAPTER FOUR: METHODS**

The theoretical framework, methodology and procedures employed in the conduct of this study are presented in this chapter. A discussion of participatory action research provides the rationale for the choice of this method in relation to the study aims. The chapter outlines the study's aims, design and setting, study population, recruitment and consent procedures, management and analysis procedures, and ethical considerations.

Data were collected through the use of consumer satisfaction surveys, structured interviews with consumers and providers, a brainstorming exercise and minutes of meetings, audio recordings of the consumer group meetings and reflections on those meetings and the study were recorded in a reflective journal.

### **Research aims and questions**

As noted in chapter one, the aim of this study was to investigate how the process of forming a consumer group influenced active consumer participation in service planning and delivery at the Uniting Sydney MSIC. The questions that had to be answered to meet this aim were:

1. At what level of consumer participation were MSIC service providers and consumers engaged, before, during and at the end of the project and what was their understanding of consumer participation over this time?
2. What are the processes involved in the development of objectives and action plans to implement consumer participation at MSIC?
3. How does consumer participation affect consumer- staff relationships?
4. What are the factors that facilitate and constrain consumer participation?

### **Theoretical framework: social capital**

I employed social capital as an underpinning theoretical concept to understand the relationships between consumers, staff and health improvement. Over the past 40 years, the concept of social capital has become popular amongst policymakers and

academics. Perrier Bourdieu, Alejandro Portes, James Coleman, Robert Putnam and Francis Fukuyama are the principal theorists in the field of social capital (Kreuter & Lezin 2002).

## **Definitions**

Bourdieu (1986) defined social capital as the combination of actual and potential resources that are associated with stable institutionalised networks that comprise shared acquaintances or recognition among individuals. Unlike other theorists, Bourdieu's concept of social capital relates to the individual instead of the collective (Claridge 2015). This is because Bourdieu (1986) argued that social capital is not uniformly available to all people and can only be accessed by people who are able to exert power over individuals or groups that mobilise resources. Therefore, Bourdieu's concept of social capital is related to his ideas of social class and power that accentuate how social connections can increase an individual's ability to advance their status in society (Claridge 2015; Siisi inen 2000).

Portes (1995) definition of social capital is also related to social class; it is an individual's ability to access limited resources through beneficial memberships in society. However, Portes (1995) stressed that the ability to access social capital does not reside within individuals themselves but is embedded in the relationships they have with others.

Coleman (1990) also posited that social capital is not possessed by the individual or produced by the physical tools of production but is created by relationships among people. According to Coleman (1990), social capital has two common characteristics. The first characteristic is the facets of the social structure, and the second is the actions of individuals that belong to that structure. Like other theorists, Coleman (1990) asserted that social capital is productive, as it assists individuals to attain certain resources that would not be possible without social connections. Coleman (1990) also pointed out that the outcomes of social capital are not always positive – they may be useless or harmful to individuals. Examples of harmful social capital include groups that encourage behaviours that degrade economic performance, groups that act as a barrier to social inclusion and social mobility, groups that divide communities, and groups that facilitate crime, educational underachievement, and health damaging behaviours (Aldridge, Halpern & Fitzpatrick 2002)

Putnam (1995) stated that social capital consists of networks, norms, and interpersonal trust, which enable people to function together more efficiently to achieve shared goals. Furthermore, Fukuyama (2000) defined social capital as a collection of informal values or norms that are allocated among members of a group and allow them to cooperate. Both Putman and Fukuyama's define interpersonal trust as a main feature of social capital. Fukuyama stated that "all groups embodying social capital have a certain radius of trust, that is, the circle of people among whom cooperative norms are operative" (p. 3).

Even though the above definitions of social capital differ, they all have features in common. All the definitions other than Bourdieu's highlight that social capital is not individualistic, but a function of collective relationships. Social capital enables people who are within a structure to act and embark on shared objectives, and is articulated by networks, norms and trust that allows members to perform together more effectively (Kreuter & Lezin 2002). Through social capital, scarce resources can be accessed via network membership or wider social structure (Kreuter & Lezin 2002).

## **Levels of social capital**

Social capital consists of three basic components: a network (interconnecting relationships among individuals), "a cluster of norms, values and expectancies that are shared by members; and sanctions – punishments and rewards – that help to maintain the norms and network" (Halpern 2005, p. 10). There is controversy about the range of phenomena that comprises the concept of social capital, because:

"the term has been used to refer not only to community and voluntary associations, but also to large-scale 'cultural' phenomena on the one hand, and to very small-scale, micro-level, intra- family phenomena on the other." (Halpern 2005, p. 13)

Therefore, social capital occurs on macro, meso and micro levels. The macro level refers to a nation; all countries have distinct habits and customs that help people to get along together and attain their goals (Halpern 2005). Examples of macro-level social capital include the formal political, legal and economic institutions of a nation. Meso-level social capital relates to communities, neighbourhoods or workplaces, and the micro level refers to individuals, such as members of families, friends and acquaintances (Halpern 2005) .

## **Types of social capital**

Three types of social capital have been described: bonding, bridging and linking social capital. Bonding social capital is inward-looking and involves shared connections between people within a social group, while bridging social capital is outward-looking and refers to the connections between different groups or networks (Putnam 2000). Linking social capital is similar to bridging social capital, but concentrates on the degree to which people create relationships with institutions and individuals who have considerable amount of power over them (Woolcock 2001).

## **Social capital and health**

Research into the connection between social capital and health has been occurring for 20 years (Moore & Kawachi 2017), and there is evidence that increased levels of social capital are associated with better health (Bolin et al. 2003; Kawachi, Subramanian & Kim 2008; Niemien et al. 2013; Rocco & Suhreke 2012). Furthermore, enhanced social capital is also an important factor in the recovery from drug and alcohol dependence (Granfield & Cloud 2001; Treffers 2016).

Social capital is also increasingly acknowledged as an important factor in health service performance (Norrish et al. 2013). A recent study reported that low levels of social capital amongst mental health care employees led to burnout, whereas high levels of social capital were protective of workplace fatigue (Eliacin et al. 2018). Burnout was also found to reduce the amount of empathy that employees showed to each other and their clients, creating an unfriendly and isolating environment. According to Hofmeyer & Marck (2008), five factors are important for enhancing social capital in health care settings: the creation of relationships that foster bonding, bridging and linking social capital; building solidarity and trust; encouraging collaborative action; enhancing communication and knowledge exchange; and facilitation of social cohesion and inclusion.

Researchers have also investigated the connection between social capital and drug and alcohol dependence and recovery. Studies report that a high level of social support is protective against illicit drug use (Treffers 2016), decreases the risk of relapse (Panebianco et al. 2016) and helps with 'natural recovery', or recovery from drugs and alcohol dependence without medical or 12-step interventions (Granfield & Cloud 2001). Bonding social capital amongst members of an abstinence recovery group helped

members' recovery, but it had the opposite effect for those who found continuous abstinence difficult to sustain (Weston, Honor & Best 2018). A study in the US found that counties with poor levels of social capital (e.g. social isolation) had a significantly increased number of opioid-related overdose deaths (Zoorob & Salemi 2017).

Studies reveal that trust is an important element of effective relationships between PWID and health workers that contributes to increased access to and informed decisions about hepatitis C treatment (Treloar et al. 2016). Trust between consumers and providers also promotes harm reduction interventions. PWID have reported that their access to mainstream health services (including opioid substitution services) is often impeded by professionals who do not trust them. However consumers' experiences of needle and syringe programs were different, because staff in these facilities perceived their primary role to be creating trusting relationship with consumers (Treloar et al. 2016). As a result, consumers reported feeling like legitimate service users who were not stigmatised.

To improve consumers' access to hepatitis C treatment, providers and consumers have recommended that drug treatment service environments needs to be more trusting, supportive and flexible (Harris, Rhodes & Martin 2013). Trusting and supportive relationships between prisoners and nurses has also been reported to empower prisoners to make informed decisions about hepatitis C treatment (Lafferty, Treloar, Guthrie, et al. 2017).

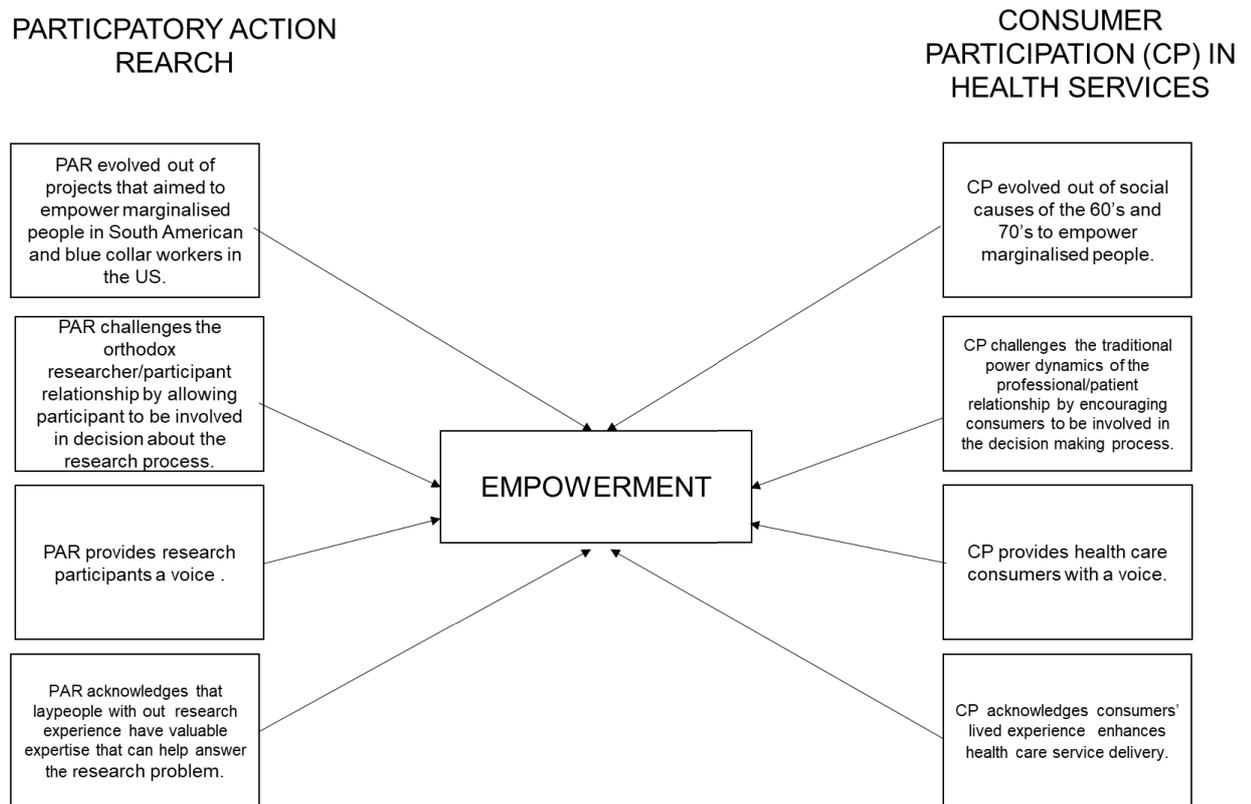
A study reported that increased levels of trust, reciprocity and social support were associated with a statistically significant 35% decreased risk of needle sharing (Kumar, McNeely & Latkin 2016). Similarly, a qualitative study reported that people who used heroin or crack and had trusting, caring and compassionate relationships also had better access to reliable harm reduction information (Kirst 2009).

Social capital is an essential part of effective health care delivery and requires supportive and trusting relationships between consumers and staff members so that they can work collaboratively to ensure consumer participation. Because I wanted my study to be guided by these principles, participatory action research was the obvious choice of methodology. PAR is centred on creating collaborative and equal relationships between researchers and participants and aims to empower marginalised populations such as PWID, thus building their social capital.

# Study design

## Participatory action research

Participatory action research methodology considers participants as equal co-researchers, thus acknowledging their diverse skills and experiences are vital to a study's success. As such, PAR has the potential to empower disenfranchised people (Brydon-Miller et al. (2011)). The active involvement of participants in the research process is congruent with the concept of consumer participation and co-production in health care delivery. In addition, PAR was a fitting methodology for this research study because of its emancipatory qualities, as drug-injecting consumers are some of society's most disempowered, stigmatised and marginalised people. Figure 3 outlines the relationship between PAR and consumer participation. It illustrates that PAR and consumer participation arose out of similar social causes, and how lay people's participation in research and health care disrupts the traditional relationships that usually occur in these fields. In addition, PAR and consumer participation provides the marginalised with a voice that can lead to empowerment and emancipation.



**Figure 3. Relationship between PAR and consumer participation**

According to Lawson (2015), PAR is an investigative methodology that has four interconnecting concerns. First, PAR allows local stakeholders, who are often without any formal research training, to be democratically involved in real-world problem-solving. Second, PAR is a cyclic process that involves stages of planning, action, observation and reflection. Third, PAR produces new knowledge and understandings that are related to local problems and this knowledge can enrich policy and practice at a local level. Fourth, local knowledge safeguards against the “one size fits all” phenomenon that has arisen through the worldwide evidence-based policy and practice movement that has resulted in ‘local voices, choices and knowledge’ being ‘neglected, ignored and discounted’” (Lawson 2015: p.x).

Participatory action research has rules and defining characteristics that govern its practices (Kendon, Pain & Kesby 2009; Lawson 2015). It is unique among research methodologies because of its iterative and recursive process that is directed by clear goals and cycles of inquiry that bring about action, collective learning, and knowledge development (Lawson 2015). This research method also aims to increase self-determination for disenfranchised communities in order “to change practices, social structures, and media which maintain irrationality, injustice, and unsatisfying forms of existence” (Kendon, Pain & Kesby 2009 pg. 91).

Conducted in real-world natural settings such as local community groups, schools and health care settings, PAR involves non-dominant groups and laypeople without research training who have valuable expertise in the research problem; the generation of knowledge therefore depends on their engagement in decisions about the research (Kendon, Pain & Kesby 2009; Lawson 2015; People's Knowledge Editorial Collective 2016). The People's Knowledge Editorial Collective (2016) highlighted significant power differences between formally trained researchers and lay researchers. These differences can be addressed by recognising the equal value of lay and professional contributions. For example, in circumstances such as the publication of research, co-researchers should be acknowledged as co-authors (Lawson 2015).

The PAR process depends on the lead researcher's ability to organise and mobilise the co-researchers to take action (Lawson 2015). It is expected that the lead researcher will be patient, optimistic, practical, sociable, and able to accommodate chaos and uncertainty (Kendon, Pain & Kesby 2009). Therefore, the lead researcher needs to be skilled in managing group dynamics and conflict and able to facilitate group norms that

create a collegial and respectful atmosphere amongst the research team (Lawson 2015).

Participatory action research can be conducted with or without a scientific method; when it is employed as a scientific method, a rigorous literature review is required (Lawson 2015). Active voice is used to document research outcomes, and research solutions are not expected to be generalisable, but when they are, care must be taken to ensure that the research stages are carefully documented (Lawson 2015).

## **Philosophy of participatory action research**

Participatory action research originated in South America in the 1960s and 1970s; the Brazilian philosopher Paulo Freire and the Colombian philosopher Orlando Fals Borda were its principal architects. Freire and Fals Borda's research was grounded in critical social theory and social action that aimed to empower oppressed groups such as workers, peasants, ethnic minorities and the disabled (Breda 2015). Freire (1993) questioned traditional educational relationships in Brazil that were based on power and dominance and developed the theory of conscientização (consciousness-raising). The concept of consciousness-raising allowed the disenfranchised to become aware of the social, political and economic contradictions that oppress them and provided them with tools to take nonviolent action and improve their circumstances (Freire 1993). PAR is also based on the notion that meaningful social and cultural change can only occur if researchers work in partnership with community members (Breda 2015).

Consequently, PAR contrasts with the orthodox philosophy of positivism, where researchers purposefully distance themselves from participants.

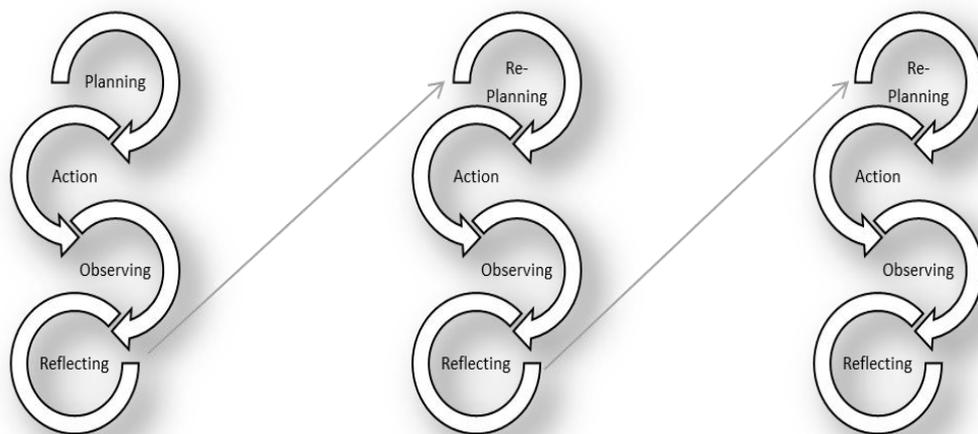
Kurt Lewin, the founder of social and organisational psychology in the 1940s, had a strong influence on the development of PAR (Breda 2015). Lewin argued that social scientists were not well equipped to investigate critical social problems if they did not work in cooperation with the affected individuals and organisations (Lewin 1946). Lewin worked with managers and employees to solve industrial workplace issues, and consequently his work became known as the 'industrial democracy tradition' (Schneider 2012). Lewin also coined the term 'action research' as a practical way of problem-solving and change through cycles of planning, action, and reflection (Schneider 2012).

## Action research cycles

According to Kemmis & McTaggart (2005), PAR consists of iterative reflective cycles, as depicted in Figure 4. These cycles consist of planning, acting, observing, and reflecting stages. Planning involves defining problems and preparing solutions to initiate change; acting entails the execution of change; observing involves an assessment of what occurred during the change; and reflection involves contemplating the cycle in order to enable re-planning for a new cycle. Planning, acting and observing stages are often not sequential because it is common to move between stages as problems and actions are reconsidered (Lawson 2015).

## Stages of the study

This research involved four stages: 'assessment', 'formation of a CAG', 'action', and 'evaluation and withdrawal'. The 'assessment' stage involved collecting data from a consumer satisfaction survey, a brainstorming exercise and structured interviews to establish MSIC consumers' and staff's perceptions about consumer participation and MSIC's level of participatory activities at baseline. The formation of a CAG involved discussions with the members about group norms, terms of reference and the participatory activities they might undertake to enhance consumer participation at MSIC.



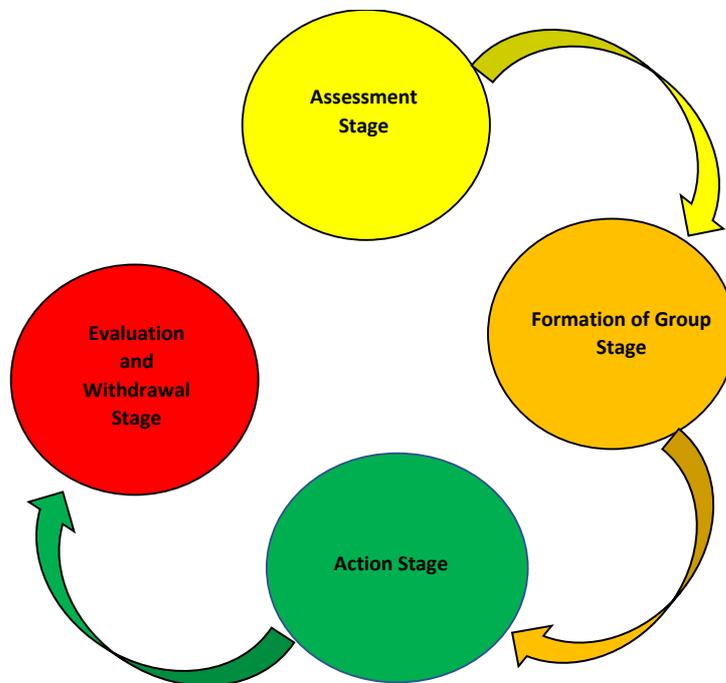
**Figure 4. Action Research Cycle**

The participatory activities were also discussed and negotiated with the MSIC management team. The 'action' stage involved four PAR cycles to enable the

consumers to transform MSIC service delivery and planning. The 'evaluation and withdrawal' stage involved assessing the overall outcomes of the project and planning for the author's withdrawal from the study.

The withdrawal component was borrowed from Meyer's action research stages, and focuses on the researcher's exit from an action research study (Meyer 1995). Withdrawal was necessary because at the end of the study I planned to leave the CAG so I could concentrate on writing this thesis. The process of withdrawal helped me to reflect and plan how the CAG could continue without my input.

Figure 5 illustrates the research process and Table 5 illustrates the study's design, its four stages and activities that occurred in each stage.



**Figure 5. Research process**

**Table 5. Study design**

<b>Stage of study</b>	<b>Activities</b>
<b>Assessment</b>	Analysis of: <ul style="list-style-type: none"> <li>• 2015 consumer satisfaction survey results</li> <li>• Staff brainstorming exercise</li> <li>• Structured interviews</li> </ul>
<b>Formation of Consumer Action Group</b>	Establishment of: <ul style="list-style-type: none"> <li>• Group norms</li> <li>• Terms of reference</li> <li>• Goals to enable the group to function</li> </ul> Negotiation with MSIC management
<b>Action</b>	Four PAR cycles to assist MSIC consumers to influence service delivery
<b>Evaluation and Withdrawal</b>	Analysis of: <ul style="list-style-type: none"> <li>• 2016 consumer satisfaction survey results</li> <li>• Structured interviews</li> <li>• Author's reflections on withdrawal from the study</li> </ul>

## **Setting**

The study took place at the Sydney MSIC in Kings Cross. MSIC is a health service where people who inject drugs can do so legally under the supervision of health professionals, in order to reduce the harms associated with injecting drug use. MSIC is physically divided into three sections: a reception area, injecting room and an aftercare and referrals area, as illustrated in Figure 6.

### **Reception area (stage 1)**

MSIC stage one is a waiting room and assessment area. In this area staff talk to consumers to assess their overdose risk and check their eligibility to use the service.

To be eligible, consumers must:

- Be an injecting drug user
- Be 18 years of age or over
- Not be pregnant or accompanied by a child
- Not be intoxicated (MSIC 2015).

## Injecting area (stage 2)

MSIC stage two is where consumers inject their drugs. This area has eight open booths that can seat two people each. Staff (including registered nurses) supervise activities at all times and intervene when consumers show signs of drug overdose. Staff members also provide injecting equipment and advice on safe injecting practices. The area has secure waste bins for disposal of used equipment (MSIC 2015).

## Aftercare and referrals area (stage 3)

MSIC stage three is the after-care area where consumers remain under the care of staff until they are ready to leave. Tea and coffee facilities are available, and health promotion activities are undertaken in this space. Consumers may be referred to housing, legal, social welfare, mental health and drug treatment and rehabilitation services. Consumers exit the service from stage three (MSIC 2015).

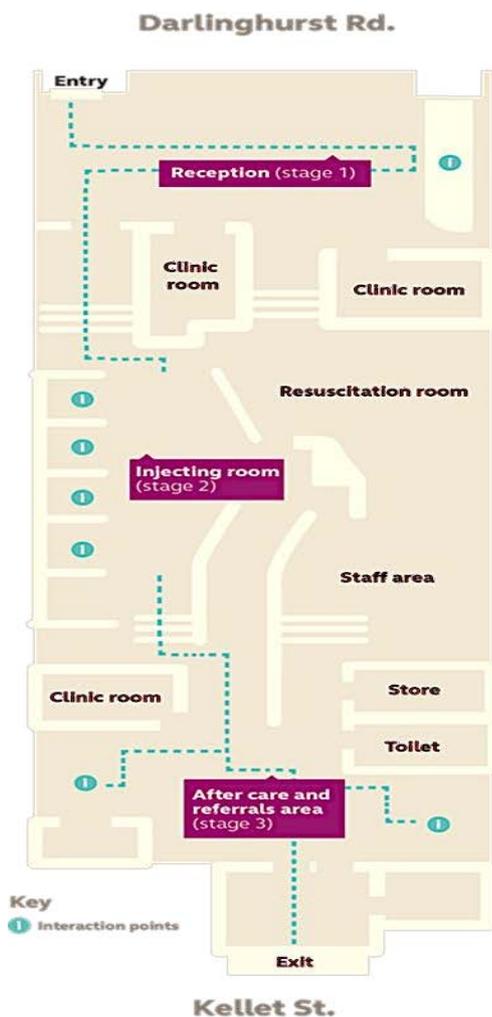


Figure 6. MSIC Layout

# Participants

The study's population was recruited from existing MSIC consumers and staff members. There are over 16,000 registered consumers at MSIC and 70 full-time, part-time and casual staff. MSIC staff work in management, as registered nurses, as health education officers (HEO) or as security guards. HEOs come from a range of professions including drug and alcohol counsellors, welfare workers, psychologists and social workers.

MSIC consumers are some of society's most disadvantaged people. Recent research shows that 75% are male, 23% are homeless, 13% are of Aboriginal or Torres Strait Islander descent<sup>3</sup>, and 43% have been to prison (Roxburgh et al. 2017). Other recent studies conducted with MSIC consumers found that 87–90% were unemployed and 46–66% had not completed secondary school (Lafferty, Treloar, van Breda, et al. 2017; Steele et al. 2018). In addition, a recent study of the mental health of MSIC's 50 most frequently attending clients revealed that the majority suffered poor mental health, had experienced substantial trauma (usually before the age of 16), and were not receiving mental health treatment (Goodhew et al. 2016).

## Selection and exclusion criteria

The study's selection and exclusion criteria were as follows.

- All participants needed to speak English and have the ability and willingness to consent.
- All registered MSIC consumers were eligible to participate in the client satisfaction survey.
- All MSIC employees were eligible to participate in the brainstorming exercise at the MSIC training day.

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<sup>3</sup> Due to the impacts of colonisation, Australian Aboriginal and Torres Strait Islander people have higher rates of mortality, unemployment, domestic violence, imprisonment and lower rates of education compared to the general population. (Australian Human Rights Commission, 2015). <https://www.humanrights.gov.au/our-work/education/face-facts-aboriginal-and-torres-strait-islander-peoples>

- All registered MSIC clients or clinical staff members were eligible to participate in the structured interviews to assess perceptions of consumer participation and MSIC's level of participatory activities. Consumers who were grossly intoxicated (e.g. could not concentrate or answer interview questions) or acutely psychotic were not interviewed.
- MSIC consumers and clinical employees who displayed an interest in participating in MSIC service delivery and planning and who committed to attending three-weekly meetings (without being grossly intoxicated) over 12–18 months were able to join the CAG.
- All CAG members and MSIC staff members were eligible to partake in the structured interviews to evaluate the CAG. Consumers who were grossly intoxicated or psychotic at the scheduled interview time were not interviewed, and another time was arranged.
- Only MSIC consumers who were members of the CAG were eligible for the evaluation interviews.

## **Recruitment of participants**

Convenience sampling was used to recruit the participants. This method involves “a nonprobability sampling strategy where participants are selected based on their accessibility and/or proximity to the research” (Bornstein, Jager & Putnick 2013 p.361). I undertook a variety of recruitment strategies. A consumer participation health promotion poster, listing my contact details, was displayed in MSIC's aftercare area. I also promoted the project at a MSIC staff training day and encouraged staff who were curious about the project to contact me. However, enrolment into the study predominantly occurred through conversations I had with consumers and staff members about the project. If anyone expressed interest in participating and met the study's selection criteria, they were given a study information sheet (Appendix A). In addition, a waiting list for group membership was created. Those on the waiting list were invited to join when members resigned from the group. Members of the group purposefully selected consumers on the waiting list in order to ensure that the group's gender mix was representative of MSIC's population (75% male) and that it included a representative of Aboriginal or Torres Strait Islander peoples, as 13% of consumers identified as such.

## **Ethical considerations**

The study was conducted in accordance with the National Statement on Ethical Conduct in Human Research guidelines (NHMRC 2015). Prior to participant recruitment, research ethical approval was obtained from the University of Technology Sydney Ethics Committee (UTS HREC approval number: 2014000835). Institutional access was granted by the MSIC management team.

Informed consent is crucial for the conduct of ethical human research and entails the disclosure of essential information about the study, as well as the participant's understanding of the process, capacity to make the decision to participate and voluntary participation. These essential principles were upheld by explaining the process of the participants' involvement, the purpose of the study and by allowing MSIC consumers and staff members the freedom to voluntarily choose to participate in the structured interviews or CAG meetings.

### **Voluntary participation and informed consent**

To reduce the risk of coercion, consumers who were interested in the study were referred to a third party, a senior MSIC employee, who provided them with the study information sheet that explained the study's processes, benefits and potential risks. If the person was still interested after reading the information sheet, they were referred to me. I then allowed the person to ask further questions about the study and ascertained willingness to consent (Appendix B). Consenting participants were reminded that they were free to withdraw from the study at any time without explanation or consequences that would jeopardise their future care or employment.

### **Respect**

I respected the participants' privacy and confidentiality by interviewing them in a private room at MSIC. I also took steps to conduct the interview in a caring manner and respected their right to withhold information and/or end the interview if they felt upset, tired or any other reason. At the start of the interview I asked participants if they were comfortable with having the interview audio-recorded before I pressed the record button. I also respected that the consumers were drug dependent and therefore needed to inject before they were interviewed to relieve physical or psychological withdrawal symptoms. In doing so, I also assessed whether they were too intoxicated

to voluntarily participate. Participants who were very drowsy and unable to concentrate on the interview questions were asked to come back at another time when they could focus on the interview properly.

I respected the participants in the CAG meetings by acknowledging that being part of a group and speaking in front of others can be stressful. To reduce possible stress associated with public speaking, I helped the group create group norms that focused on respect amongst group members. I also provided food and beverages to ease socialisation and carefully intervened if conflict occurred.

The consumers' time for participating in the interviews was acknowledged by the receipt of a \$20<sup>4</sup> gift card, and staff members were interviewed within their usual working hours. The CAG consumers received \$40<sup>5</sup> cash for each meeting they attended; staff members were not paid in addition to their usual wage. Some MSIC staff members expressed concerns about giving the consumers cash, because they felt it could be used to buy illicit drugs. However, previous research has noted that the provision of modest cash incentives is an effective and ethical way of attracting PWID to participate in research and that this practice has rarely led to additional drug use (Topp, Islam & Day 2013).

## **Confidentiality**

To protect the participants' privacy, their names (if spoken) were erased from the digital recordings before they were sent for professional transcription. All participants were given a pseudonym that was used in all study reporting. All audio recordings and transcripts were stored on my password-protected computer. Paper copies of the transcripts and consent forms are kept in a locked cabinet.

Data will be archived for seven years after the publication of the report detailing the results and will be destroyed by shredding and/or erasure by the University of Technology Sydney according to university policy. This procedure adheres to NHMRC guidelines (NHMRC 2015).

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<sup>4</sup> From 2015 to 2016 A\$20 equaled an average of US\$14.80 to \$15.00.

<sup>5</sup> From 2015 to 2016 A\$40 equaled an average of US\$29.60 to \$30.00.

## **Potential risks**

It was possible that consumers would recall unpleasant or distressing memories about MSIC during the structured interviews. They were informed that if they became distressed during the interview, they were able to terminate it at any time. A referral pathway with a counselling agency was arranged in case any participants became highly distressed as a result of their involvement in the study.

CAG participants were informed that speaking in a group may be stressful and make them feel embarrassed or anxious. They were also informed that disagreements amongst group members could occur and cause conflict (however, as an experienced mental health nurse skilled in group facilitation and conflict resolution, I felt able to reduce this risk.) The group members developed group norms about respectful communication to reduce the risk of conflict.

I was aware that I had existing relationships with the participants, as a mental health nurse or as a colleague, and my roles could potentially lead to coercion. Participants were reassured that their existing relationship would not be jeopardised if they decided to withdraw from the study. In addition, I realised that there was a risk that my relationships with staff that feel threatened by consumer participation could deteriorate.

## **Potential benefits**

The main potential benefit of the study is that MSIC's services will become more responsive to consumers' needs, as service delivery will be increasingly shaped by consumers' feedback and ideas. There is also the potential for the study to improve consumer–staff relationships at MSIC, as participation in the consumer group creates opportunities for consumers and staff to work in a more collaborative manner.

The study also provided MSIC consumers with a 'voice' that has the potential to empower them and enhance their sense of worth and self-esteem. Participation in the consumer group enabled the consumers to learn new skills, such as learning how meetings are conducted. In addition, there was potential for them to become more conscious of activism and political movements that affect their lives, such as drug law reform.

# Procedure

## Data collection

Table 6 summarises the data collected during the study by stage. The ‘formation of consumer group’ and ‘action’ stages are grouped because they used the same data.

**Table 6. Summary of data collection**

	Assessment Stage			Formation of Consumer Group and Action Stages	Evaluation and Withdrawal Stage		
Data Source	2015 MSIC client satisfaction survey	Brainstorming exercise	Structured interviews	CAG meetings data <ul style="list-style-type: none"> <li>• Meeting minutes</li> <li>• Audio Recordings of meetings</li> <li>• Reflective journal</li> </ul>	2016 MSIC client satisfaction survey	Structured interviews	Reflective journal

## Assessment stage

Data collection methods used in the ‘assessment’ stage were a client satisfaction survey, a brainstorming exercise with service providers and structured interviews with both consumers and providers.

### 2015 MSIC client satisfaction survey

To establish MSIC’s current level of consumer participation and consumers’ perceptions, questions about consumers’ current involvement in service delivery and their interest in being involved in an advisory group were incorporated into the 2015 MSIC client satisfaction survey. Table 7 outlines the survey questions that were related to consumer participation.

Between February and April 2015, MSIC staff members encouraged consumers to complete the satisfaction survey while they were in the aftercare and referrals area. Staff also offered to scribe for those consumers who were highly intoxicated or had limited literacy. To assure anonymity, the consumers’ identifying details were not collected, however the respondent’s MSIC ID was recorded on a spreadsheet to prevent them from participating twice. Consumers who completed the survey received chocolate as a gesture of appreciation for their time.

**Table 7. Consumer participation questions 2015 MSIC client satisfaction survey**

Question Number	Question	Type of question
6	How often are you consulted about your ideas on how things at MSIC can improve?	4-point Likert scale: Never, Rarely, Sometimes, or Often
7	Have you ever completed a client suggestion form?	Yes or No
8	Did you receive a response about your suggestion?	Yes or No and written response
9	Did you feel that your suggestion was taken seriously?	Yes or No and written response
10	Have you ever made a complaint about MSIC's service?	Yes or No
11	Did you receive a response about your complaint?	Yes or No and written response
12	Did you feel that your complaint was taken seriously?	Yes or No and written response
19	If MSIC starts a client advisory group <sup>6</sup> to make MSIC a more client focused service would you be interested in joining?	Yes or No and written response stating why they would or would not like to join

### **Brainstorming exercise at MSIC staff training day**

At an MSIC staff training day on the 14<sup>th</sup> April 2015, I presented my research proposal and then conducted a 10-minute brainstorming exercise (for those who gave consent to participate in this aspect of the study) to determine staff's perceptions about consumer participation. Brainstorming involves a group exploring an issue through allowing all ideas to come to mind and regardless of how inappropriate the ideas might sound (Bhatia 2000). The staff were divided into three groups and provided with butcher's paper and pens to record their ideas about consumer participation. Group one brainstormed the barriers to consumer participation at MSIC, group two brainstormed their vision of how consumer participation might work at MSIC, and group three brainstormed the benefits of implementing enhanced consumer participation at MSIC.

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<sup>6</sup> The term client advisory group is equivalent to consumer action group (CAG).

## **Structured interviews**

To gain a more detailed picture of consumers' and staff's perceptions of consumer participation, I conducted structured interviews between May and November 2015. The interview schedule was as follows:

- How are you currently involved in participatory activities?
- How could consumer participation be improved at MSIC?
- What are the issues that prevent consumer involvement at MSIC?
- Why are you motivated to take part in a consumer action group and other participatory activities at MSIC?

I aimed to interview 20 consumers and 10 staff members prior to the commencement of the consumer action group. Because I was unable to conduct all interviews before the CAG meetings began, participants who were interviewed after 30<sup>th</sup> June 2015 were asked to answer the final question retrospectively. To assist the participants in answering the questions, they were given an information sheet to read about consumer participation (Appendix C), because the term 'consumer participation' was not familiar to all MSIC consumers and staff. All participants provided written consent to take part in the interview. All interviews were audio-recorded and the recordings professionally transcribed.

Four interviews were excluded from the analysis. One interview was withdrawn because the participant was acutely psychotic and the data that was provided did not relate to consumer participation. The other three were withdrawn because these participants were distracted during their interviews; they provided no data related to consumer participation, giving responses such as *"I don't know"*, *"I don't care"*, *"when is this going to finish"* and *"when do I get my voucher"*.

## **Formation of a consumer action group and action stages**

The meetings were documented through minutes written by various group members, and audio recordings from meeting 13 onwards, as this latter method required additional ethics approval. After each meeting, I recorded my impressions of the proceedings and the dynamics that transpired between members in a reflective journal. In addition, I transcribed sections of the audio recordings that were relevant to the study objectives and my personal reflections.

## Evaluation and withdrawal stage

The CAG was evaluated through CAG-related questions in the 2016 MSIC client satisfaction survey and structured interviews with consumers in the group and MSIC staff members in and outside of the group.

### 2016/17 MSIC client satisfaction survey

As a quality improvement exercise, MSIC's research coordinator assigned a staff member to update the client satisfaction survey. Therefore, some of the questions in the 2016/17 survey are written differently to those in the 2015 survey. Table 8 outlines the consumer participation-related questions in the 2016/17 survey. Between October and January 2017, MSIC staff encouraged 100 consumers to complete the survey in the aftercare and referrals stage. The same procedures that were used to collect and record the 2015 satisfaction survey were utilised.

**Table 8. Consumer participation questions 2016/17 MSIC client satisfaction survey**

Question number	Question	Type of question
28	How often are you consulted about your ideas on how the service provided by the Injecting Centre could improve?	4-point Likert Scale: Never, rarely, sometimes, often, don't know/unsure
29	Would you like to make any comments about providing your ideas on how the Injecting Centre's services could improve?	Written response
30	Have you ever completed an Injecting Centre client suggestion form?	Yes, No or Don't Know/Unsure
31	Did you receive a response about your suggestion?	Yes, No or Don't Know/Unsure
32	Did you feel that your suggestion was taken seriously?	Yes, No or Don't Know/Unsure
33	Would you like to make any comments about your experience of the Injecting Centre's client suggestion mechanisms?	Written response
34	Have you ever made a complaint about the Injecting Centre's service?	Yes, No or Don't Know/Unsure
35	Did you receive a response about your complaint?	Yes, No or Don't Know/Unsure
36	Did you feel that your complaint was taken seriously?	Yes, No or Don't Know/Unsure

37	Would you like to make any comments about your experience of the Injecting Centre's complaint mechanisms?	Written response
48	Are you aware of the Injecting Centre's Consumer Action Group (CAG)? This is an advisory group made up of Injecting Centre clients who advise the staff about how to improve the service for its clients	Yes, No or Don't Know/Unsure
49	Can you write down some things you know about the Injecting Centre's Consumer Action Group?	Written response
50	If a place became available on the Injecting Centre's Consumer Action Group, would you be interested in joining?	Yes, No or Don't Know/Unsure
51	Why or why not would you be interested in joining the Consumer Action Group?	Written response

### Structured interviews

To allow a more detailed evaluation of the CAG, I conducted structured interviews with CAG members and MSIC staff members from July to December 2016. I formulated the interview schedule and all questions were approved by the CAG members. The following is the interview schedule for the CAG members:

- How has the group helped MSIC's clients?
- What has the CAG achieved?
- How has the group helped you on a personal/professional level?
- What challenges have you experienced in the group?
- What are some barriers that have prevented the group achieving their goals?
- What suggestions do you have to improve the group?

The following is the interview schedule for staff members not in the group:

- How did you find out about the CAG?
- Are you aware what the CAG does and what they have achieved?

- Would you be interested in joining the CAG if a place becomes available and what are your reasons for joining or not joining?
- What suggestions do you have for improving the CAG?

All interviews were audio-recorded and professionally transcribed.

### **Withdrawal**

My withdrawal from this study involved a reflective account of the process of leaving the research. It was facilitated by my resignation from full-time work at MSIC to concentrate on writing up my research. My reflections documented how this process affected the CAG.

## **Data analysis**

Content analysis was employed to explore and make sense of the data collected during the brainstorming exercise, CAG meetings and the survey data. Raw percentages were also used to report on the closed-ended survey questions. To assist the analysis of the satisfaction surveys, the results were typed into Survey Monkey and raw percentages automatically calculated in this program were used to report on the closed ended survey questions. Template analysis was used to analyse the assessment and evaluation structured interview data. The following provides examples of how I employed content analysis to analyses the CAG meeting data (minutes, reflective journal and audio recordings) and framework analysis to analyses the structured interviews.

## **Content analysis**

Content analysis is a method used to examine verbal, written or visual communication and can be approached in either an inductive or deductive manner (Elo & Kyngas 2008). If there is little prior knowledge about a phenomenon or if knowledge is fragmented, an inductive analysis is warranted; a deductive analysis is employed when prior knowledge is available or if the purpose of the study is theory testing (Elo & Kyngas 2008). Content analysis was a useful method to arrange the CAG meeting data into categories that related to the formation of the group and action research cycles.

The first two stages of the three-stage (preparation, organising and reporting) content analysis process were used to examine the meeting data. Another stage was added that involved reflection on the formation of the group and action cycles. Table 9. outlines the stages of the CAG meeting data analysis.

**Table 9. Analysis of CAG meeting data**

<b>Preparation Stage</b>	<ul style="list-style-type: none"> <li>• Making sense of the data</li> <li>• Units of analysis and meaning units were decided</li> </ul>
<b>Organising Stage</b>	<ul style="list-style-type: none"> <li>• Using NVIVO the data were arranged into categories relating to the formation of the group and each cycles' planning, action and observing cycles (deductive approach)</li> <li>• Data were coded and then grouped into categories (inductive approach)</li> </ul>
<b>Reflecting Stage</b>	<ul style="list-style-type: none"> <li>• Reflection of the action cycle and future directions for the CAG</li> </ul>

## **Preparation stage of content analysis**

The preparation stage began as I familiarised myself with the data by reading it several times in order to make sense of the data as a whole and ascertain its meaning (Bengtsson 2016; Elo & Kyngas 2008). This stage also involved selecting a unit of analysis, for example, an objective of the study, and a meaning unit, "the smallest unit that contains some of the insights the researcher needs" to establish the study's aims (Bengtsson 2016 p. 11). Units of analysis comprised the meetings journal, minutes and audio recordings, and meaning units consisted of phrases, sentences or paragraphs that related to the formation of the group and the PAR cycles used to achieve their goals to improve MSIC service delivery. The formation of the group and cycles are outlined in the middle row of Figure 7. Figure 7 outlines how data related to the CAG meetings were arranged in NVivo 11, a software program that assists with the management and analysis of qualitative data (NVIVO for Windows 2015).

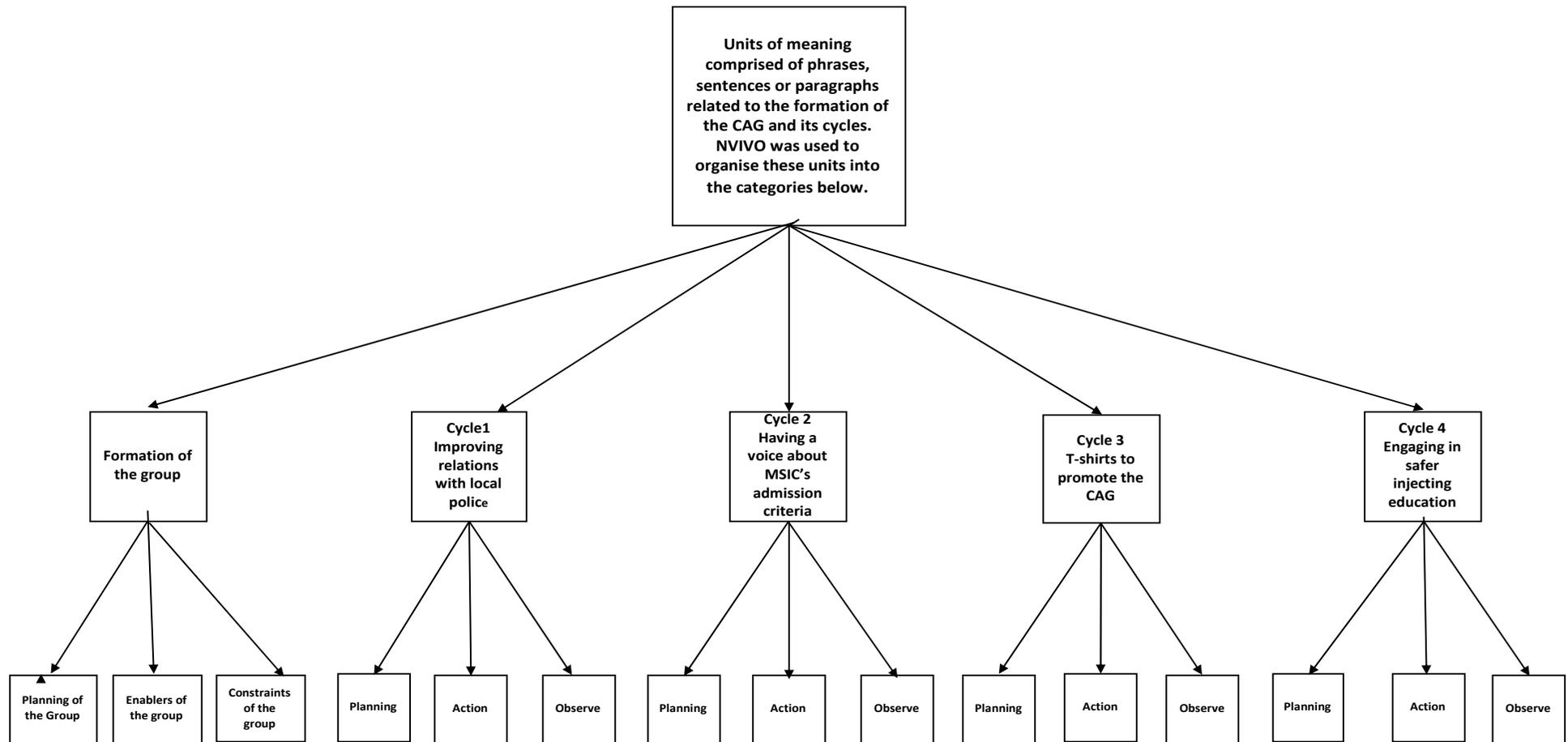


Figure 7. Organisation of units of meaning in NVIVO

## Organising stage of content analysis

The main aim of content analysis is to organise and reduce data into fewer content-related categories (Elo & Kyngas 2008). The organising stage began by using NVivo to sort the meaning units into categories that related to the formation of the CAG or the action cycles the group undertook. Figure 7 illustrates how these meaning units were arranged into categories. This part of the analysis was deductive, because the organisation of data was informed by the formation of the group or the PAR action cycles.

Data were coded once they were all inputted to NVivo. Coding involved labelling passages of data within the 'formation of the group' and 'action' cycles based on my interpretation of it (Bazeley 2013). After coding was completed, the codes were arranged into categories, subcategories and sub-subcategories. A category is a group of codes that have phenomena in common (Bengtsson 2016). Figure 8 is an example of how data that related to the planning of the CAG was organised into categories. This part of the analysis was inductive, because the data were fragmented.

It took time to determine which data belonged to which category. Therefore, up to five episodes of coding and recoding occurred until the final categories were established. These coding episodes were interdependent, although not sequential, and involved rearranging and renaming codes and combining those codes that were similar in nature until all related codes were captured within a category.

Tables 10 and 11 illustrate how the sub-codes for the CAG structure category were reduced from eight to four. Table 10 lists the codes that were developed in the first episode of coding and the number of passages of data that were coded. The codes with an asterisk were eventually merged within other, similar codes. For example, because the 'roles' code had low counts, it was merged into the 'membership' code, because they represent similar concepts. Table 11 lists the final subcategories for the CAG structure category and includes examples of the data within them.



**Table 10. First phase of coding for CAG structure sub categories**

<b>Code</b>	<b>Number of passages of data that were coded</b>
Rules	23
Processes	19
Objectives*	14
Membership	8
Philosophy*	4
Roles*	4
Associations with user groups*	2
Subgroups*	3

### **Reflecting stage of content analysis**

The reflecting stage was an opportunity for me to critically contemplate the process and outcomes of the 'formation of the group' and 'action' cycles to gain insight into what happened and what possible future directions the group could take. These insights were taken back to the CAG for discussion and planning for new goals and action cycles.

**Table 11: Final subcategories for CAG structure**

<b>Subcategories for the CAG structure category</b>	<b>Number of coded data items within this category</b>	<b>Examples of data included in this category</b>
<b>Philosophy, Aim and Objectives</b>	13	<p><i>List of goals, including – to improve the MSIC service for the members of the Participation group and for other clients; group members to be representatives for other service users (minutes meeting one, 30/06/15).</i></p> <p><i>I explained that we will democratically make decisions on what issues we will focus on, what interventions we will implement and how these will be measured (journal meeting one, 30/06/15).</i></p>
<b>Membership</b>	15	<p><i>Mark would be the mediator for the group dynamics, but asked should there also be a chairperson each meeting? There was general agreement all around. Barry suggested we take turn to be speaker/chair (minutes meeting one, 30/06/15).</i></p> <p><i>Susan proposed that Paul join the group, as he wants to revise the MSIC consumer rights and responsibility pamphlet into a comic book (journal meeting five, 22/09/2015).</i></p>
<b>Processes</b>	23	<p><i>Arthur emailed me today about having a consumer group subcommittee that focuses on the Statuary Review. I spoke with Arthur about this, and he expressed his frustration with the amount of time the group has taken on deciding on a T-shirt design and the slow progress of the group (journal meeting 10, 05/01/2016).</i></p> <p><i>Barry suggested that we each get a manila folder to keep minutes and notes in and that they could be kept in stage 1 (minutes meeting two, 22/07/15).</i></p>
<b>Rules</b>	27	<p><i>Barry put forward the idea that what is said in this room stays in this room (minutes meeting one, 30/06/15).</i></p> <p><i>The group decided that conditions of leaving early should be the similar as when members miss three consecutive groups (journal meeting four, 01/09/15).</i></p>

## Template analysis

Template analysis was employed to analyse the assessment and evaluation structured interviews, because the interviews in this study had specific questions. Template analysis is a type of thematic analysis that involves a hierarchical coding system which is flexible and adaptable to the needs of a specific study (Brooks et al. 2015). Unlike some other thematic analytical methods, template analysis does not dictate a set sequence of coding levels, but encourages the researcher to develop themes according to “where the richest data in relation to the research question are found” (Brooks et al. 2015, p. 203).

Like other qualitative analytical methods, the start of a template analysis involves familiarisation of the data through reading and re-reading the transcripts (Brooks et al. 2015). With small studies all of the transcripts are read, but for larger studies only a few transcripts that have data that are highly associated with the topic guide are read (Brooks et al. 2015). I read and reread six of the consumer interview transcripts and four of the staff member interview transcripts, and from these I wrote notes about key ideas and themes that related to the interview’s topic guide.

From my notes I developed “the initial template that is applied in order to analyse the text through the process of coding, but is itself revised in the light of the ongoing analysis” (King 2004, p. 259). Table 12 shows the initial template for the evaluation structured interviews. The first row contains the highest-order codes that relate to a *priori* themes from the interviews topic guide, and below them are the second-level codes that are associated with the highest-order codes (King 2004) .

The codes in Table 12 were then arranged into NVivo as nodes and sub-nodes. Nodes in NVivo “are folders for organising data about similar ideas or themes” (Maddern 2016, p. 13). Data from the interview transcripts were transferred into the nodes, but the nodes were tentative, as when the analysis progressed some were removed or redefined as they were not related to the analysis at hand (Brooks et al. 2015). With template analysis, the analysis is not considered finished until all data that is relevant to the research question is coded (King 2004). Table 13 is the final template for the assessment structured interviews.

**Table 12. Initial template for the post structure interviews**

<b>One: Barriers</b>	<b>Two: Group's achievements</b>	<b>Three: Suggestions to improve group</b>	<b>Four: How the group helped MSIC consumers</b>	<b>Five: How has the group help you personally or professionally</b>	<b>Six: What challenges did the group encounter</b>	<b>Seven: Staff interest in joining group</b>
1.1 Drug laws and consumer incarceration	2.1 Changed MSIC culture	3.1 More time	4.1 Decreased the consumer/provider divide	5.1 Helped me to develop better relationships with consumers	6.1 Drug dependence and marginalised lifestyle	7.1 Yes
1.2 Management	2.2 Consumers have learned new skills and knowledge	3.2 Peer leadership roles at MSIC	4.2 Provides consumers with a voice	5.2 Provided me with hope of new directions and a brighter future	6.2 Group dynamics	7.2 No
1.3 Group dynamics	2.3 Formed an advisory group and promoted its purpose	3.3 Better promotion of the group and include consumers outside of the group	4.3 Triggered consumers to improve their lives	5.3 Improved my communication style	6.3 Intoxicated clients	
1.4 MSIC admission criteria and medical focus	2.4 Safer injecting course and teaching peers safer injecting	3.4 Change MSIC policies	4.4 Provides consumers with a sense of belonging and social support	5.4 It has been good to help others	6.4 Jealously from other clients	
1.5 Time factors	2.5 Police Liaison Officer	3.5 Increase MSIC's capacity to allow consumers to interact	4.5 Provides consumers with a better service	5.5 Made friends and enhanced existing friendships	6.5 Moving too fast	
1.6 Staff/consumer power differences	2.6 Statutory review	3.6 Members be more open in groups		5.6 Triggered recovery or reduced drug use	6.6 Police	
1.7 Consumers unaware of group	2.7 Suggestion box	3.7 Better group facilitation			6.7 Staff (not in the group) not being on board	
	2.8 Has long term members	3.8 Training for consumers				

**Table 13. Final template**

One: Group achievements	Two: How has it helped MSIC clients and staff	Three: Suggestions for improvement	Four: Challenges the group faced	Five: Staff's interest in joining group
1.1 Formed an advisory group and promoted its purpose	2.1 Improved relationships between consumers and staff	3.1 Links with other peer organisations and peer leadership roles at MSIC	4.1 Group dynamics	5.1 Yes
1.2 Safer injecting course and teaching peers safer injecting	2.2 Provides consumers with a voice	3.2 Better promotion of the group and include consumers who are not in the group	4.2 Promotion of the group	5.2 No
1.3 Police liaison officer	2.3 Consumers have improved their lives, enhanced friendship or stopped drug use	3.3 Better group facilitation and adherence to the rules	4.3 Time factors	
1.4 Statutory Review		3.4 Training for consumers	4.4 Drug dependence, marginalised lifestyles and drug laws	
			4.5 MSIC's medical model	

## Reflexivity

During this project it was essential that I was conscious of my beliefs, values, life experiences, social and professional background, and epistemological position. This is because human observations are never neutral; people do not interact without their own personal perspectives, beliefs and assumptions (Cruz, 2015). To reduce the risk of my PhD project being overshadowed by my personal and professional values and beliefs, I constantly reflected upon my place within this research project. This involved taking responsibility for my own position within the study by considering how my actions were affecting the choice of setting, the behaviour of the research participants, how questions were asked and data was collected and how the analysis was undertaken (Berger 2013).

Having an older brother who died from a heroin overdose 25 years ago, being gay and growing up in a working-class family has provided me with insight into what it is like to be vilified and discriminated against. These factors have shaped my personal beliefs, values and career choice. Consequently, I empathise with the disadvantaged and marginalised, support political parties that promote social justice and equality, and have pursued a career in a caring profession. While it was important to me that this project succeeded, I was cautious that my beliefs did not blind me to a possible lack of success.

To reduce the risk of my personal and professional values and beliefs affecting my interactions with the study participants and the interpretation of the study's data, I regularly reflected on my interactions with the participants and decisions I made throughout the research. Reflection was achieved by recording my thoughts and feeling about my study in my journal and attending regular supervision with my academic supervisors. Through these processes I realised that my anxiety and professional status could potentially impede the success of the study.

At the start of the project I was anxious that the study might fail, because of my lack of experience as a researcher and the consumers' chaotic lifestyles. The regular reflections that I recorded in my journal enabled me to realise that my anxiety could endanger the integrity of this study. My anxiety could have prompted me to use my professional status to control the CAG so that the desired outcomes could be achieved. I realised that if I had been unaware of this and allowed my actions to unfold unchecked, I may have prevented the consumers from determining their own path. Therefore, I decided that the CAG staff and I needed to cede our professional power and allow the consumers' ideas to predominately shape the formation of the CAG. Nonetheless, I also realised the study would be more authentic if the CAG staff and I shared our professional knowledge to enable the consumers to learn skills that would help them achieve service delivery outcomes.

My experience as a mental health nurse has helped me to appreciate that mental health care consumers are much more than their psychopathology; like all humans, they have inherent strengths. A strengths-based approach aligns with the principles of PAR, but at the same time the authority afforded to me as a nurse was incongruent with my position as a PAR researcher because of the traditional power divisions that exist between nurses and consumers.

Reflexivity enabled me to recognise that my tendency to focus on consumer's strengths rather than on their limitations may impact on my analysis of the data. This focus could have led to a lack of recognitions of certain challenges including the ways in which consumers could have also constrained the project. To ensure a genuine and balanced view of the actions of the group my primary supervisor examined my reflective journal and some of the interview transcripts. In supervision, I also discussed my interpretations of the data with both supervisors and showed them how I categorised data into NVivo. In addition, I had some of the CAG consumers and staff read the results of the study. This feedback helped the analysis to have more authenticity, as the CAG members could confirm or provide alternative insights about the results.

Overall, the success of this study was important to me not only because of a PhD, but also because I value social justice and believe that MSIC consumers' lives can be enriched when you focus on their strengths instead of their deficits. Therefore, I had to constantly monitor my actions and analysis so as to not let these values and beliefs cloud my judgement. Reflection also prevented me from 'fooling' myself into pretending that I had no power and authority and realise that my position as a researcher and MSIC staff member could hamper the authenticity of this study. Therefore, continuous reflection was essential to this project so I could reduce the chance of my values, beliefs and authority influencing the outcome of the study.

## **Summary**

I employed social capital as a theoretical concept because it highlights the importance of supportive and trusting relationships, and as a result is considered an important aspect of an individual's health and health care service delivery. A social capital approach aligned well with PAR, the methodology I chose to use, because it also centres on collaborative and equal relationships between researchers and participants. PAR is philosophically aligned with the concept of consumer participation in health care service delivery, as both aim to reduce power imbalances, value laypeople's expertise and empower them.

This study consisted of 'assessment', 'formation of a CAG', 'action', and 'evaluation and withdrawal' stages. Ethical principles and procedures of voluntary participation, informed consent and confidentiality were strictly adhered to, as MSIC consumers are

considered to be some of Australian society's most vulnerable and disadvantaged people.

Assessment and evaluation structured interviews, pre and post satisfaction surveys, a brainstorming exercise, my reflective journal, the CAG's meeting minutes, and audio recordings were used to gather data to answer the study's questions. I employed NVivo to organise the data, and a content analysis and a template analysis to analyse and interpret meaning. I also used reflexivity to understand the influence of my own personal experiences and beliefs and my clinical role at MSIC in this study. The next four chapters present the results of my study.

## CHAPTER FIVE: ASSESSMENT STAGE

This chapter focuses on the project's 'assessment' stage, which established MSIC consumers' and staff perceptions about consumer participation and participatory activities at baseline. Figure nine illustrates the 'assessment' stage of the research process.

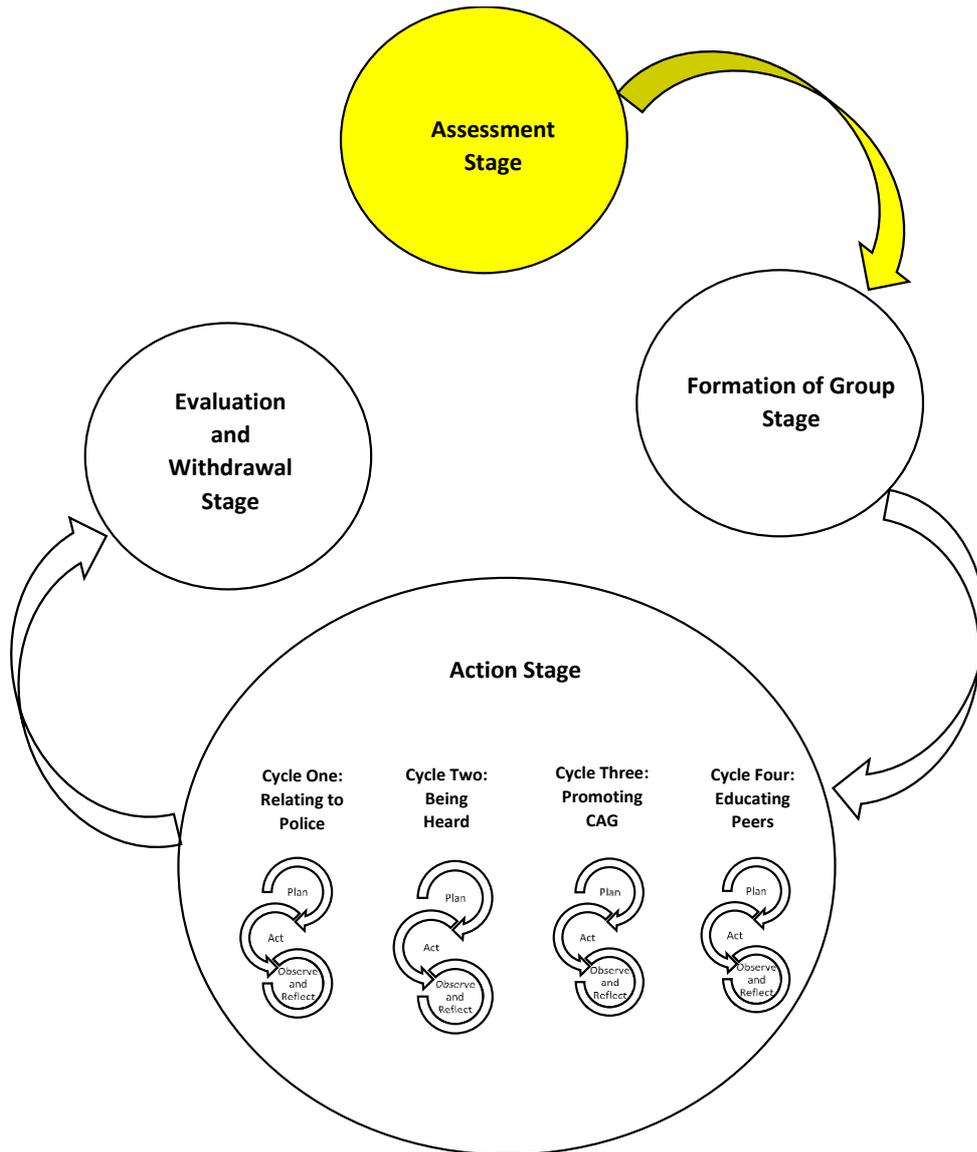


Figure 9. 'Assessment' stage of research process

In the 'assessment' stage, data were collected using structured interviews, a brainstorming exercise at the MSIC staff training day, and consumer-related questions in the 2015 MSIC client satisfaction survey.

I interviewed 13 MSIC consumers (five woman and seven men) and seven staff members (five women and two men). Thirty-three staff members and three security guards participated in the brainstorming exercise. One hundred consumers (25 woman, 69 men, one transgender and five of unknown gender) participated in the client satisfaction survey.

## **Current participatory activities at MSIC**

Interviewees reported that consumer participation at MSIC, before the establishment of the CAG in June 2015, consisted mainly of lower-level activities, some mid-level activities and no higher-level activities.

### **Lower-level activities**

The consumer satisfaction survey included items related to three participatory activities: consumer consultation, suggestion and complaints procedures. Interview data revealed further comments related to these activities.

#### **Consumer consultation**

Of consumer satisfaction survey respondents, 26% (n=25) stated that they were often consulted about their ideas; 40% (n=38) said they were consulted sometimes; 18% (n=17) were consulted rarely and 17% (n=16) were never consulted. Some written responses mentioned partaking in surveys, and others included that clients felt listened to: *"I felt that my input is taken on board and what I have to say is important"*. Some responses focused on not being consulted enough: *"I think I have participated in two surveys, but I have never been asked for any ideas or opinion"*, and others reported that it depends on the staff member: *"different staff have different personality traits and some are more outgoing and personable than others"*. Other respondents said that they were not consulted, as they had not been coming to MSIC for long or they did not like giving ideas or complaining.

## **Suggestion procedure**

Thirty-seven per cent of survey respondents (n=36) reported they had completed a suggestion form. Of those who completed a form, 67% (n=24) received a response. Some clients indicated that their suggestion was implemented: *"I have made comments and ideas in the past and am happy to see they were heard and put into action"*, and others reported they were happy with the response: *"the service let me know that my advice was good"*. One client reported that they received no response, and another that they did not check their email.

Eighty percent (n=31) of clients who made a suggestion believed staff had taken it seriously. One respondent wrote: *"other places we are not taken seriously because we inject drugs, but here staff listen to us"* and another *"felt that my suggestion was taken on board, but staff lack the power to make the change."*

In the interviews, consumers reported that they had made suggestions to improve MSIC service delivery. These included placing a microwave oven in stage three, starting a group in which older consumers could teach younger consumers how to inject with better technique, a writing group, extending operating hours later into the evening, and a chilled water dispenser for stage one.

The consumer who suggested the microwave felt that the staff member who helped her write her suggestion liked her idea, but it was not acted upon. Similarly, the proposed injecting technique group did not happen and operating hours were not extended; however, the writing group occurred, and a chilled water dispenser was installed in stage one within three weeks of the suggestion being made.

## **Complaint procedure**

In the satisfaction survey, 14% of MSIC consumers (n=13) reported that they had made a complaint. Of those, 70% (n=9) received a response. One wrote *"handled professionally (naturally)"*, and another that *"staff were very approachable, which made it easier to air my suggestion"*.

Sixty per cent (n=8) thought their complaint had not been taken seriously by staff, and their written responses included:

*"It would have been good if staff [had] formally written my complaint"*.

*“I think everyone is backing each other instead of truly thinking of the person at hand. I feel it is a most important issue to listen seriously and help no matter what !!!”*

Three consumers in the interviews reported that they had made complaints about staff. The first consumer reported that a staff member in stage one said, *“hurry up because there’s twenty people out there who’ll hit you over the head if you don’t hurry up”* (Sebastian, consumer). He told another staff member about this incident and was happy with the outcome, because he received an apology from the staff member who was brash with him.

The second consumer complained to a staff member who talked down to him. He said *“she wasn’t very pleased. She tried to walk out of it (the confrontation). And basically, just um [I] didn’t really like it.”* (Jack, consumer)

The third consumer spoke about how he became angry with a staff member who threw his fentanyl<sup>7</sup> patch into the sharps disposal bin when he was talking to another consumer. He considered writing a formal complaint, but he changed his mind because he realised he would never get his patch back and because:

*“I was angry at the time and so I probably said some things I shouldn’t have said to make her feel bad about what she had done and she did, she felt bad about what she’d done, um, yeah. I think that next time, because of that, she may actually um double-check to make sure that everything’s sorted, you know.”* (David, consumer)

Two consumers and one staff member reported that some consumers were wary of making complaints against staff because they were worried about the consequences.

*“I don’t want to get singled out. That I’ll be singled out and that, you know, I’d be victimised when I came in here.”* (Wesley, consumer)

*“It would fall back on me – the consequences.”* (Ruth, consumer)

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<sup>7</sup> Fentanyl is an opioid which is 80-100 times more powerful than morphine and is used to control chronic/cancer pain (Alcohol and Drug Foundation 2018). Accessed from: <https://adf.org.au/drug-facts/fentanyl/> Some MSIC consumers using citric acid to extract fentanyl from transdermal patches so it can be injected intravenously.

*“I guess only that it would... could potentially escalate the situation between that person and, let’s say, a staff member, and just to let it go is the easiest option.” (Kylie, staff member).*

### **Staff members’ views about suggestions and complaints**

Three staff members reported that they regularly encouraged and helped consumers write formal suggestions and complaints about service delivery and pass them on to MSIC management for consideration. Below is one of the responses:

*“if a client mentions something which they’re not happy about at MSIC or a suggestion, I will say to them: ‘We have a complaint form, or a suggestion form, would you like to do that so you can actually, you know, so your opinion can be heard by management?’ And then if they want to, then it will be, for me, negotiating with them whether they want to write or if they want me to put into words what they’re saying and I check with them that I’ve written what they would like and then I pass it onto management.” (Kate, staff member)*

A staff member believed that MSIC has a “solid basis” for expanding consumer participation because staff and management are receptive to consumers’ suggestions and complaints. He said:

*“MSIC is able to take advice on board given by clients, although it is through an informal mechanism which is clients talking to staff and staff taking it up the ladder, but it’s still... certainly it’s... certainly there is a level of consumer participation, or whatever you’d like to call it, going on already. But generally speaking I think MSIC does consumer engagement and participation quite well. But it’s only the low level.” (Andrew, staff member)*

On the other hand, two staff members reported that MSIC management do not take consumers’ suggestions and complaints seriously. The first staff member said:

*“They tick the box that complaints are received, but there is no evidence that the complaints process has changed the nature of the service. I think the tone of the letter and response is generally to kind of shut the person up that wrote the complaint.” (Amber, staff member)*

The second staff member (Angela) reported that she suggested a noticeboard be put in stage three to allow consumers to write suggestions for service improvements. She

said that management thought the noticeboard was a good idea, but they never provided the resources or support to make her idea a reality.

## Mid-level activities

Interview data revealed two mid-level activities. Two consumers reported that they had informally taught their peers injecting techniques at MSIC, and one consumer and two staff members reported that MSIC consumers had received formal education about tablet filtration<sup>8</sup>.

Informally, consumers reported that they taught their peers to inject fentanyl and gave their peers information on safer injecting techniques.

*“Well I’d um just stand back or sit next to them, but you know, not... And um, I’d just um, show them, well I wouldn’t show them, I’d tell them what to do. If I was having fentanyl at the time myself, I’d actually get them to watch me and see what I was doing, so I could show them, you know? Like, I’d go to my booth and do that bit and then go over there and you know and watch them do it and just oversee. And if they were about to do something wrong or something like that I could correct them. And yeah, the conversations are pretty easy to start.”*

(David, consumer)

*“And I find when you start talking about something like that, other people like to join the conversation because it’s stuff that people feel they know a lot about. You know if someone’s giving misinformation it’s great to be able to steer it and say, ‘Well actually you know these days we do a one-way swipe with a swab, or, you know’... .”* (Darren, consumer)

One consumer said she attended a tablet filtration education session at MSIC that was conducted by NUAA, and two staff members spoke about a tablet filtration workshop that MSIC consumers and staff members attended in 2011. At this workshop, researchers who were conducting studies of tablet filtration, clinicians and PWID discussed and shared their knowledge about filters that reduce the harms associated with injecting tablets. The MSIC staff members felt that the workshop removed barriers

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<sup>8</sup> Tablet filtration techniques can be used to reduce the chance of bacterial infections, embolism, ischemia, and pulmonary difficulties from crushing and injecting tablets such as oxycodone (Peacock, de Graff and Bruno 2014). Accessed from: <https://ndarc.med.unsw.edu.au/sites/default/files/ndarc/resources/IDRSApril014.pdf>

that usually impede equal alliances between consumers and clinicians, and that this legitimised consumers' knowledge. Below are the staff's responses.

*“Because I had worked a long time in methadone behind a barred window, not to say that I’m doing that here, but I had worked a long time there – and what this thing did physically felt like: we’re all in the same room together, we’re all sitting around a table together, and we were all experts. And that was acknowledged, that was the core of the whole damn thing: we were all experts coming together to discuss these things. Nice one.”* (Kylie, staff member)

*“It really changed the dynamic from the normal situation where a client is a client and they are a consumer of the service as opposed to a client who is giving or who is teaching – who is actually imparting something.”* (Peter, staff member).

## **Suggestions for improved consumer participation**

The interviewees and participants in the staff brainstorming exercise suggested that consumer participation at MSIC would improve with the formation of a consumer representative group, consumers running activities and consumers' involvement in service management.

### **Consumer representative group**

Through exploring ideas for a MSIC consumer group, two consumers suggested that the group should have rules and realistic goals, meet on a regular basis, and represent and advocate for MSIC consumers.

*“So, whereas I guess if there was an hour taken out of the day, maybe like you said, Group guidelines included members attend meetings sober, group members are nominated by their peers and the group have realistic and achievable goals once a month or something, where a selected group of people that wanted to get on board and I guess represent our side of the fence sat down with staff.”* (Gary, consumer)

*“That’s why it would be good to have a group... a consumer group that could advocate for everybody, take everybody’s ideas on board. And put them into like a vote or something to have it done you know.”* (Wesley, consumer)

In the staff brainstorming exercise, it was agreed that the group should have realistic and achievable goals, consumer members be nominated by their peers, consumers should attend meetings sober and mechanisms be in place so that consumer participation activities are ongoing and sustainable in the long term.

Staff members in the interviews suggested that a consumer group should challenge MSIC’s service delivery and provide advice on research projects. One staff member proposed the group could rally for MSIC’s admission criteria to be changed so consumers could work on their paintings (for an art project that took place in stage three), watch TV, use a computer, or access clean injecting equipment or information about hepatitis C treatment without having to inject.

A consumer asserted that a consumer group should be more than a representative group and assist MSIC consumers with practical matters, such as *“helping them getting their fines fixed or making it to a legal appointment”* (Ruth, consumer).

A consumer and staff member stated that not all consumers could participate in a group, so there needed to be other mechanisms that allow voices outside of the group to have their ideas heard.

*“And that’s where, I guess, the box (suggestion box) will come in handy, you know what I mean, where other people (not in the group) can write down if they’re not happy with something.”* (Gary, consumer)

*“Because not everyone can come to a meeting. Can we have, like, an internet forum where you can just discuss stuff on the internet? And then of course the homeless people aren’t necessarily going to have access to the internet, so maybe we can have um, you know, like, just a message book even where you can scribble stuff in. Again, you know, it doesn’t have to be high-tech, but just lots of different strategies for different input from different people. Including just those little talks that you have with just two or three people in Stage one or three, you know.”* (Angela, staff member)

Because many MSIC consumers have complex psychosocial problems, two staff members suggested the consumers in a group would require considerable support from staff and management. The first staff member reflected on his experiences working on consumer participation projects in other drug and alcohol services. He said the main downfall of the projects was the *“high expectations of the consumers becoming ‘empowered’”*, without considering that the consumers *“have a whole range of complex psychosocial problems going on”*; consequently, *“there is a lot more work to be done than is anticipated”* (Peter, staff member). Therefore, this staff member thought if the MSIC consumer group was going to work the consumers in the group would require a lot of support from staff.

Similarly, the second staff member suggested that the group should:

*“not have these high expectations that you can just say to a person: ‘We’ve had this meeting and we’ve got all these actions now everybody go off and do the jobs they’ve been given...’ Now we’re workers, we’re used to operating that way and going off and do it, but, but consumers aren’t, you know? This might be a bit new to them... So I think, you know, our expectations can be a bit high and we actually need to have that support to help them go through and follow up those actions and that takes time, money and resources.”* (Angela, staff member).

## **Consumer-run activities**

A consumer suggested that he would like to co-facilitate two consumer education groups with a staff member. These proposed groups included a conflict resolution group in which consumers could enhance their communication skills and a writing group to help improve MSIC consumers’ literacy. Another consumer said that she would be interested in helping to run a consumer art and crafts group.

Several of the consumers suggested that consumer participation could be enhanced through consumers teaching each other safer injecting techniques and educating staff about their lived experience of drug use.

*“I’d like to see older addicts come and put all their input, all their knowledge that they’ve gained, because most of us didn’t gain our knowledge from MSIC, most of us have gained our knowledge through previous experience. And like, vein*

*care, and, summer's here, how to keep your body hydrated so you're getting maximum use of the right veins."* (Ann, consumer)

*"The only thing that I would like sometimes is to be able to help people who are having a hard time finding a vein."* (Darren, consumer)

*"I think that, you know, responsible consumers here should be able to help other people in guiding things, you know."* (David, consumer)

*"I think staff need, really need to know how people really do feel when they come in, but I think they've either forgotten, as you can, or they've never had any contact with drugs whatsoever, so they just will never have that understanding."* (Ruth, consumer)

Three of the staff members in the interviews and staff in the brainstorming exercise suggested that consumers should be involved in health promotion at MSIC. Their reasoning was that that would make displays more meaningful for consumers, health promotion is not just from the staff's perspective, and health promotion does not take a top-down approach (Kylie, staff member).

## **Consumer involvement in service management**

At the staff brainstorming exercise, it was suggested that MSIC involve consumers in the running of the service, reviewing policies, hiring staff and running projects.

Two staff members in the interviews suggested that consumers should be involved in higher-level activities such as attending staff meetings, sitting on recruitment panels and being involved in staff performance appraisals. Another staff member said she would support the first two activities, but she would not support consumers involvement in staff appraisals, because staff are responsible for enforcing rules and consumers may rate staff unfairly if they must discipline consumers. She said, *"if you pulled up Mr X a certain amount of times because he keeps dealing and everything, well you're going to get a bum rap from them aren't you?"* (Elizabeth, staff member).

One of the consumers also thought having consumers on a recruitment panel was not feasible because:

*"I don't see how, what, um, how it could make it any better by having a bunch of users fucking decide who's going to be working here, watching over them. I*

*mean, I think the staff here are all really awesome, you know, they are the right type of people... .” (David, consumer)*

## **Facilitators and benefits of consumer participation**

Respondents in the interview agreed that caring staff and positive consumer/professional alliances and consumers who have their drug use under control were facilitators of consumer participation. Another facilitator was that the majority of respondents in the interviews and satisfaction survey reported that they would be interested in being involved in consumer participation at MSIC.

Consumers’ lives being enriched and improved MSIC service delivery were factors that the interviewees and staff brainstorming exercise participants described as potential benefits of enhanced consumer participation at MSIC.

### **Facilitators**

#### **Caring staff**

Staff members and consumers reported that MSIC has caring staff members who are able to create positive consumer/professional alliances, which are conducive to consumer participation. Some of the consumer responses were:

*“The staff, are so caring and non-judgemental and helpful and just beautiful.”*  
(Rita, consumer)

*“I’ve gotten to know various staff members well enough that they can see when something’s on my mind without me opening my mouth, you know?”* (Gary, consumer)

*“I think the staff here are all really awesome, you know, they are the right type of people.”* (David, consumer)

*“I haven’t got a family, I haven’t got many friends and youse treat me respectfully; I like youse”* (Jack, consumer).

*“I see people work here who I know advocate and feel passionately about what they do, and that means a lot to me as a user, you know?”* (Darren, consumer)

One of the staff members felt that some MSIC staff members were open to the idea of regarding consumers as experts and that this attitude had the potential to boost their personal and professional development. Another staff member believed that developing “*good, humanistic and trusting relationships*” with consumers made her work more “*enriching*” (Kate, staff member).

Two staff members asserted that consumers being educated about the services’ rules and consumers teaching staff could foster improved relationships between consumers and staff members. A staff member stated that when she was a consumer representative in a methadone clinic, she conducted an educational session about the clinic’s rules to improve the consumers’ understanding of why staff had to enforce rules.

### **Stable consumers**

Three consumers and one staff member stated that consumers who were ‘stable’ through having their drug use under control or being prescribed an opioid replacement therapy were more suited to being members of the consumer group and would help the group function better. Responses include:

*“I think you need a clear head to know what you kinda need and stability and then to be making, yeah, choices.”* (Rita, consumer)

*“Somebody that, I suppose, got to have their habit under control, I suppose they would have to be on the program or something at least... or at least, you know, have their habit under control, you know, they can’t be actively addicted without being on a program, because otherwise they’re too unreliable.”* (David, consumer)

*“But the barrier is the drugs, but when I’m on the methadone program I’m sure all that will go away and all I’ve got to concentrate is me turning up, being motivated, and looking after the group.”* (Sally, consumer)

*“An opiate replacement therapy which can help alleviate their drug seeking behaviour.”* (Elizabeth, staff member)

## Interest in enhancing consumer participation

Two thirds of the consumers in the satisfaction survey and two thirds of the consumers and two thirds of the staff in the interviews reported that they would be interested in being involved in enhancing consumer participation at MSIC. One of the consumers and two of the staff members in the interviews reported that they were in two minds about participating and three consumers reported that they were not interested.

In the satisfaction survey, 68% (n=56) reported that they would be interested in a consumer action group. Around half of the consumers suggested that the advisory group could help themselves as individuals, and others (MISC consumers, staff and community) through passing on information, *“being productive”, “being involved in the process and giving back to the [drug] using community”, “learning”, “focusing on a brighter and better future”* and *“doing something different than injecting”*. One respondent said they would like to help because *“it is my service”*, and another said that they would be *“interested in being employed at MSIC”*. The following response highlights that a person with a lived experience of injecting drugs could be effective in helping MSIC’s consumers:

*“I would enjoy having a say/helping and speaking for those who cannot find the words or have trouble expressing their opinions to people in authority. A lot of MSIC clients are quick to snap, but if another person of a similar background can help or listen to them they would be more likely to get involved”.*

Just under a quarter of consumers suggested that their *“input”, “knowledge”, “ideas”, “opinions”, “skills”, “concerns”, or “observations”* could make a valuable contribution to the proposed CAG: *“I believe I possess the necessary skills, communication, knowledge base to contribute effectively”.*

Some consumers argued that they should have a say in MSIC service delivery and get their point across, because they are the ones who use its services: *“I think we should have every say in changes, because we are the main instigators in this organisation”.* In addition, clients also reported they should be involved in service delivery through *“getting things such as [injecting equipment] not already provided”, “help workers improve”, “help improve networking between services”* and have more *“staff and clients working together”.*

The consumers in the interviews reported that they were interested in enhancing consumer participation at MSIC because they wanted to share their views, represent MSIC consumers, help their peers, help conduct activity groups, teach other consumers safer injecting, educate staff about their lived experience, and because they like the staff. One consumer said that contributing to service delivery would encourage her to *“get to into a routine, have something to look forward to, get up every morning, feel that I’m worth something, and that I can contribute”* (Sally, consumer). Another consumer told me that he would love to contribute because he felt that improved consumer participation would foster a sense of community and belonging amongst the MSIC consumers. This is because – through being HIV positive, a former sex worker, and a person who injects drugs – he knew what it was like to be isolated, and:

*“if it weren’t for members of the community who got together and decided to come out and educate us and start needle exchanges and hand out condoms and stuff, you know, I would have felt sure that no one cared.”* (Darren, consumer)

Two staff members who had a lived experience of injecting drugs were interested in being involved, because they belonged to the drug user community and felt that enhanced consumer participation could empower MSIC consumers. One of them said:

*“I suppose my motivation is personal, um, you know I am a part of the community, I see myself as part of the community, so, you know, I suppose for it’s just about seeing my own community getting empowered more and taking control of their own futures, it’s just again, you know, all about that: we can do it for ourselves, you don’t have to keep doing it to us!”* (Angela, staff member)

The other staff members said they were interested because:

*“consumer involvement in service delivery ‘builds a ‘richer and equal service’ that allows more humanistic interactions between staff and consumers.”* (Kate, staff member)

*“I would like to have the consumers more involved in health promotion.”* (Kylie, staff member)

*“Consumer participation is the future direction for drug and alcohol and harm reduction services.” (Peter, staff member)*

## **Benefits**

### **For consumers**

The staff brainstorming exercise produced the idea that consumers having more input into service delivery would empower and enrich their lives through the development of new skills and a chance to develop a service that is more relevant to their needs.

Both consumer and staff interviewees believed that consumers’ lives could be enriched through being involved in service delivery, because it could help them realise their skills, give back to their community, increase their self-esteem, have a safe space to be themselves and have something to do other than drug use.

A consumer who was involved in judging the MSIC art project (described earlier) reported that his involvement helped him to realise that he had not lost the skills that he gained when he was employed. Another consumer felt that she was articulate and a good listener, and that being involved in service delivery would allow her to pay back to her community. A staff member reported that being involved in service delivery would allow MSIC consumers to feel useful in their community and that this would provide them with a sense of pride.

A staff member felt that a consumer group would benefit MSIC consumers, because it would give them a safe space to speak about their drug use without judgement. Another thought that it would provide consumers with other activities besides drug use and possibly a stepping stone to future study and employment. She said:

*“I also think that would be a good thing for the consumers, because it gives them something other to do than injecting drugs and sex work all day, it gives them a bit of self-esteem, it gives them a bit of empowerment, that they are a worthy person, that they do have something to contribute. And who knows, that could lead on to perhaps maybe some of them going into study, or you know, working at NUAA, or working at a [Needle and Syringe Program] or something like that, just changing their life, you know, and to make them feel worthwhile that their word is actually relevant, you know.” (Elizabeth, staff member)*

## **For the service**

In the staff brainstorming exercise, it was agreed that consumer participation could benefit MSIC because it is an investment in a better service. It would broaden MSIC's capacity to deliver more services, look good to the outside world, and help MSIC to respond to drug trends as consumers would be more open about their drug use.

Two of the consumers in the interviews reported that consumer participation could benefit MSIC, because it would enable the service to hear and learn things from their perspective. For example:

*"Like, you know, it would be good to have, you know, a user's perspective thing to help you understand and to see it from that perspective as well, yeah definitely it would help."* (David, consumer)

*"Well you learn a whole different side. The benefits are you're hearing it right from the person's mouth, what they feel about the place, what they think, where it could improve."* (Ruth, consumer)

A staff member reported that she would be receptive to hearing the consumers' perspective because:

*"I would feel honoured for them to show me what they thought would be the best thing that would work for them, instead of having some theoretical approach, you know, ground roots, grass roots sort of approach from the consumers to the health education, uh, to the nurses."* (Elizabeth, staff member)

## **Barriers to consumer participation at MSIC**

Research participants reported substantially more barriers than facilitators of consumer participation. The following were identified as factors that could constrain consumer participation at MSIC: consumers' substance dependence, and lifestyles; societal stigma; consumers not wanting to participate; MSIC's managerial structures; staff members' attitudes, disinterest and professional status; and confusion about the concept of consumer participation. These issues are explored in turn below.

## Consumer-related barriers

### Drug dependence, mental health problems and marginalised lifestyles

In the brainstorming exercise, staff members agreed that consumers' lack of reliability, commitment and confidence, and their intoxication and cognitive impairment, were barriers to consumer participation at MSIC. Similarly, five consumer interviewees stated that substance dependence was a barrier for MSIC consumers participating in service delivery, because it makes them chaotic, irresponsible and self-centred, and this could prevent them from attending meetings. In addition, avoiding withdrawals is often a primary concern for MSIC consumers, because:

*"your priority is to feed your demon [your drug craving] and this has the ability to, you know, make you do things that you otherwise would not normally do to stop yourself from being sick."* (Gary, consumer).

Four staff interviewees agreed that the consumers' substance dependence, mental health problems, cognitive deficits and marginalised lifestyles could be a barrier to participating in service delivery at MSIC.

*"Um, well I suppose there is the barriers that would be involved within anyone who, you know, is in a disadvantaged sort of group of people – homeless, mental health, addiction issues, dependence issues – um, when you're dealing with all that on a day-to-day basis, you know, being involved in a group can be very, very difficult. All the best intentions in the world, but on a given day it might be hard to turn up at three o'clock for the meeting because you're waiting for your dealer at that time, and that's always going to be difficult."* (Angela, staff member)

*"Well, you know, it's a busy lifestyle. Goodness know what you have to do to be homeless with all your stuff and packing up and getting a site and there's a whole building a nest at night, there's packing up properly in the morning, there's getting through the night, there's being tired, there's now you've gotta score and get whatever, you've got to get your money, you've got to get to the doctor... ."* (Kylie, staff member)

*"A barrier for them would be not understanding the questions that were being asked of them or the services that they could help contribute to; but also, erratic*

*lifestyles and having cognitive impairment and that sort of thing would certainly stop them from being involved.” (Elizabeth, staff member)*

### **Societal stigma**

A consumer interviewee reported that she had been conditioned by society and her family’s stigmatising views about drug dependence to believe that drug users are undeserving of having their voices heard, because *“your views are not valid when you are intoxicated on drugs”* (Rita, consumer). Two other consumers also thought that drug users were often silenced by society, and that is why many MSIC consumers did not know that they were able to make suggestions or complaints about service delivery. A consumer said that he would not join the advisory group as he did not want to be seen with other drug users, because *“all it takes is the police to walk along and see you associating with someone, whoever it is, and then that’s when I’m saying guilty by association”* (Gary, consumer).

A staff member (Andrew) who has a previous lived experience of injecting drugs and worked on various consumer participation projects in drug and alcohol services stated that service providers’ stigmatising views were a barrier to the projects’ success. He asserted that many staff members felt that the consumers were *“lazy, thieves and roting the system”* because they injected drugs. He also mentioned that it took a director of a service two years to realise that he was a:

*“hardworking member of the sector and I just kept on, I knew that he had reservations about me, but I just kept on working and doing my thing and eventually he came around and we’re great friends now.” (Andrew, staff member)*

Another staff member reported that stigmatisation occurred within MSIC because it had created a culture in which consumers are perceived as *“one-dimensional people”* who do not have equal status to non-consumers, and this notion was reinforced by the display of:

*“material around the place that makes it look like all drug users are victims, drug users don’t have any choice, you know, drug users have got mental health issues, yeah... .” (Amber, staff member)*

## Consumers not wanting to participate

Around one third of the respondents from the MSIC consumer satisfaction survey and two of 13 consumer interviewees reported that they did not want to be involved in a consumer group. Survey respondents did not want to be involved due to being “shy”, they “dislike working in groups”, prefer “to learn drug safety with my own common sense” or “personally I mostly come in to inject and leave quickly”. The two consumer interviewees said they were not interested in participating in service delivery because they were satisfied with the staff’s work.

*“I really, really am happy with the job that you guys do.”* (David, consumer)

*“I can’t see how they can improve it, though; they already give you everything you need.”* (Anderson, consumer)

## Service-related barriers

### MSIC’s managerial structures

Six staff interviewees and staff who participated in the brainstorming exercise regarded MSIC’s managerial structures as barriers to consumer participation at MSIC, because MSIC predominately operates via a medical model. In a medical model, the patient’s expertise is rarely taken into consideration, physical complaints are considered more important than personal concerns, and there are clear power divides between patients and health professionals<sup>9</sup>.

Two staff interviewees reported that MSIC’s medical model did not align with consumer empowerment. The first thought the model “*belittles, silences, and dehumanises drug users*” (Amber, staff member). Instead of consumer participation, this staff member suggested that MSIC should adopt a peer-led model, because consumer participation still encourages “*the power dynamic of the difference between staff and management and the people who use the service*” (Amber, staff member). The other staff member thought that the medical model was not compatible with consumer participation because it:

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<sup>9</sup> This medical model definition is by Sillars (2015) and can be accessed at: [https://www.aging.ca.gov/ProgramsProviders/ADHC-CBAS/HCB\\_Settings\\_Stakeholder\\_Activities/Workgroups/Docs/Medical\\_Model.pdf](https://www.aging.ca.gov/ProgramsProviders/ADHC-CBAS/HCB_Settings_Stakeholder_Activities/Workgroups/Docs/Medical_Model.pdf)

*“underestimates the whole consumer and in this field, we have fairly complex people, and they have a whole range of psychosocial mechanisms and factors going on that mean that they don’t always fit neatly into the boxes that sort of normal organisations and services operate with.”* (Peter, staff member)

One staff interviewee reported that some consumers’ requests for service improvements were not feasible. She gave an example about a consumer who suggested that the bathroom in stage three should be divided into two because consumers regularly had to wait for the toilet. She believed the consumer did not realise that extra space was needed for staff to intervene if someone overdosed.

Another staff member felt that MSIC’s top-down organisational structure prevented the consumers being involved in health promotion, because consumers were not consulted to determine the topics, they were interested in. Another staff member expressed concern that the MSIC managers would pay lip service to the consumer participation project, because everyday issues overshadowed her previous attempt to improve consumer participation at MSIC five years ago. She said management:

*“pay lip service to it, they say oh yes, yes, yes, this is important but then day-to-day stuff takes over – the database has failed, uh, there’s always something more important to do, and that’s where, you know, I suppose a lot of issues get dropped to onto the backburner for that reason, but we can’t keep backburnering this issue because it’s just ridiculous.”* (Angela, staff member)

In the staff brainstorming exercise, it was also suggested that management was not supportive of consumer participation because they had other organisational priorities and might not provide time and space to conduct consumer meetings.

Some staff in the interviews thought that the organisation overseeing MSIC’s operations was a barrier to consumer participation. One staff member felt that the organisation did not have any consumer participation guidelines in place and two others with a lived experience of injecting drug use expressed concerns that the organisation’s staff disclosure policy prevented them from being positive role models for MSIC consumers by showing them that recovery is possible. Below is one of the staff members’ concerns.

*“You know, my biggest issue I suppose is I often hear clients say things like, ‘Show me one person who’s ever succeeded on methadone’, and I feel like I have succeeded on methadone! I have a mortgage and everything, you know. Um, but I’m not allowed – I don’t feel like I’m allowed to say, ‘Well I have actually’. It would just be nice, I suppose, to have an official policy saying that and talk about it a bit more, because, yeah, I do feel like we’re a resource that we do have a lot to offer and it’s being a bit wasted and it’s a bit of a shame, you know, that that, um, we can’t talk about our personal stuff.” (Angela, staff member)*

### **Staffs’ attitudes, disinterest and professional status**

It was reported that there are caring MSIC staff who have attributes that could facilitate consumer participation, but the opposite was also true, with respondents stating that some staff’s negative attitudes, disinterest and professional status would constrain consumers’ involvement in service delivery.

In the staff brainstorming exercise, it was suggested that MSIC staff’s poor attitudes and lack of acceptance of and commitment to participatory activities and consumers contributing in service delivery were barriers to consumer participation at MSIC.

Six consumer and four staff interviewees said that MSIC staff members who are disinterested in their job, avoid contact with consumers, rush consumers out of the service and look down on consumers destroy the consumer/professional alliance, which is an essential element of successful consumer participation. Some of their responses are given below.

*“And yeah, so they need to be able to communicate like that, you know, they need to be able to, because I have had a... had someone in here that shouldn’t have been in here, I mean, she just looked down on everybody, like, yeah, cause you did drugs she was so much better than you and you could tell, it oozed out of her.” (David, consumer)*

*“You’ve asked for help, but they’ll be doing, like, well one occasion one was not wanting to talk to me and telling me to wait and I looked down and he was filling in his time sheet, you know? Or when they just seem to have a little bit of an*

*aloofness when you might try to talk to them and you get the impression, they don't really want to talk to you, but it's been very rare.” (Rita, consumer)*

*“I find a couple are a little bit not really – ‘it's just a job’; they're not really invested in you or making sure you're not taking too much or... it's almost like if you go up and ask for another it, it's a bit of an eye roll, that type of thing. It's only with a couple of people.” (Ruth, consumer)*

*“I personally feel though I am rushed through the system after I've had a shot of ice. I've cried a couple of times, but, nothing worse than being forced out into the street when you're homeless, you know? I don't have a home to go to and yeah... .” (Wesley, consumer)*

*“The TV [in stage three] isn't to be used, and essentially that was because clients would stay around for hours and hours and hours and that was the fear, so what I'm trying to say is... There seems to be, some people at least in management, who for them the priority is keep people moving through.” (Andrew, staff member)*

*“There is a culture of silencing and ignoring consumers. There seems to be a celebratory environment amongst staff when the place is empty.” (Amber, staff member)*

Three staff members also reported that staff members' professional status could weaken consumer participation, because it gave them power to enforce organisational rules and use terminology that consumers do not understand.

*“We tend to use a lot of terminology here, we use a lot of language and lingo, and not everyone's familiar with that language and lingo, and all of a sudden someone's getting in trouble because they haven't obeyed a directive from a staff member, and it turns out they didn't even understand what the staff member was talking about!” (Angela, staff member)*

*“You know, people get really pissed off in stage two because they've been accused of, usually, not using, um, and um, or, being, um talking... fuck... spoken to by staff in sort of a brash way or an off-handed way or not listening or accused of something which may or may not have happened.” (Kylie, staff member)*

*“We can’t get over the power imbalance because the bottom line is that we’re employed, we earn X amount of dollars per year, and therefore we, you know, it’s power imbalance. You know, they’re sleeping on the streets, they’ve got no food, they’ve got to do jobs to get drugs, all that sort of stuff, so there will always be a power imbalance.”* (Elizabeth, staff member)

### **Confusion about consumer participation**

In the staff brainstorming exercise, it was decided that the consumers’ lack of understanding of the concept of consumer participation was a barrier to consumer participation at MSIC.

One of the staff interviewees who had been involved in consumer participation projects in other drug and alcohol services said: *“a lot of people don’t even know what consumer participation is. It’s like you have to educate and inform people about all this stuff”* (Angela, staff member). This confusion was apparent in the interviews. Four consumers were confused when I asked if they had been involved in consumer participation at MSIC. Two said that they had no idea about what I was talking about, and the others thought that receiving a voucher for participating in a research project was consumer participation. Two staff members were also confused; one said, *“there isn’t any consumer participation happening at this service”* (Amber), and the second said *“I don’t think they’re involved at all actually, if I think about it”* (Elizabeth). These staff members did not consider MSIC’s suggestion and complaint mechanisms to be forms of consumer participation.

## **Conclusions**

The findings from the ‘assessment’ stage revealed that consumer participatory activities at MSIC before the formation of the CAG mainly consisted of lower-level activities such as suggestions and complaint procedures. Respondents also cited more barriers than facilitators to enhancing consumer participation at MSIC, mostly related to the consumers’ substance dependence and lifestyles. Service-related barriers were predominantly associated with the medical model, because respondents felt that this model was not compatible with consumer empowerment.

Despite reported barriers, most of the respondents were interested in and supported enhancing consumer participation at MSIC. They suggested that enhanced MSIC

consumer participation should entail a consumer representative group that has realistic goals, consumers helping to run activity groups and health promotion, and consumers being involved in staff meetings, recruitment panels and staff appraisals. It was also recommended that staff should support the consumers who are involved in the project, because many have complex psychosocial problems.

## CHAPTER SIX: FORMATION OF A CONSUMER GROUP

This chapter presents the findings from the formation of the MSIC CAG. Figure 10 illustrates the 'formation of a consumer group' stage of the research process.

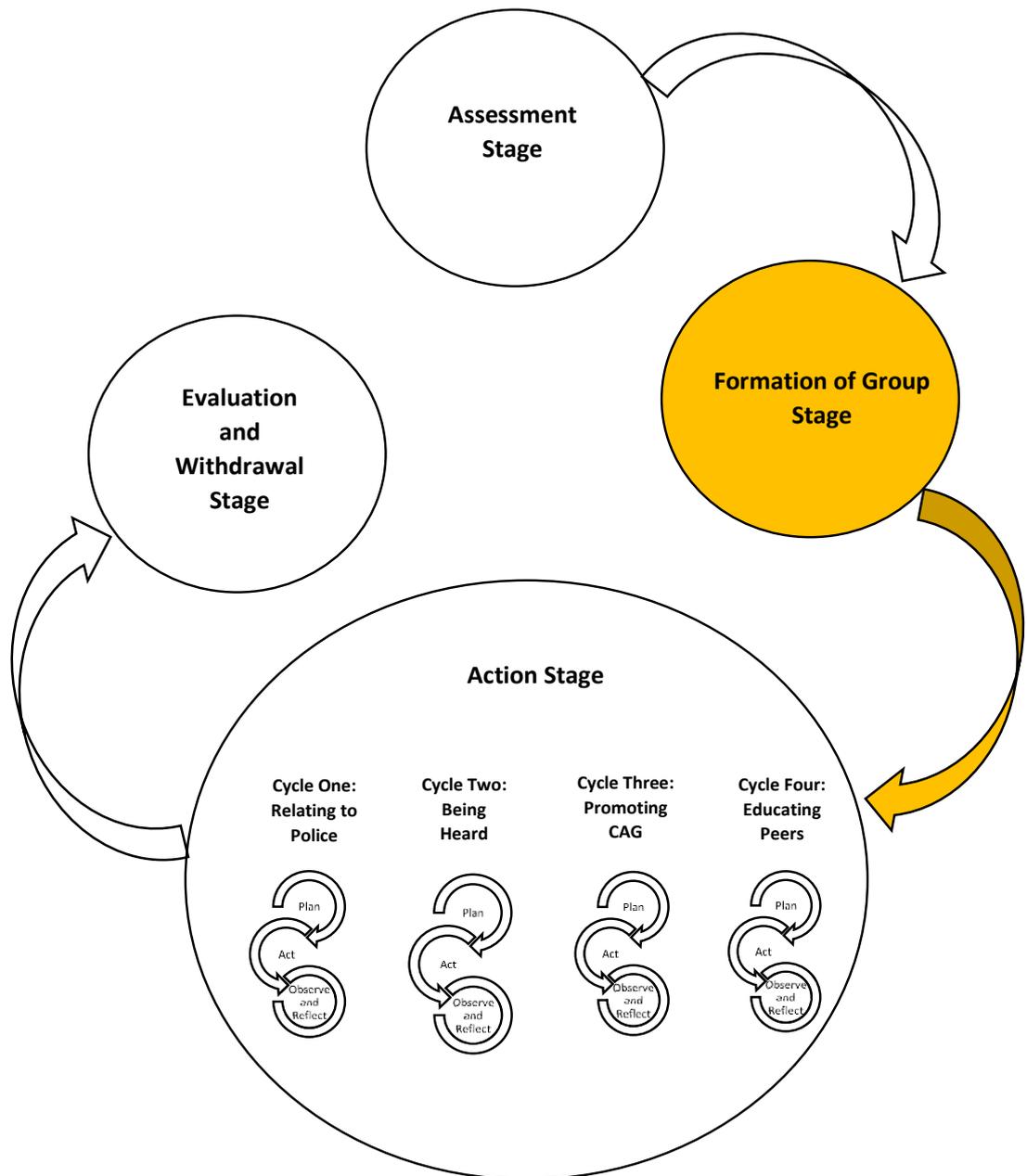


Figure 10. 'Formation of a group' stage of research process.

During the project, 13 consumers (five woman and eight men) joined the CAG. Two consumers never attended a meeting, and four others resigned from the group for various reasons. Five staff members – one registered nurse (woman) and four HEOs (two women and two men) – enrolled, and one of the HEOs resigned.

The first part of this chapter explains how the CAG members planned and negotiated strategies to form, promote and sustain a group representing MSIC consumers. The second part of the chapter focuses on my observations of and reflections on the factors that enabled and constrained the functioning of the group.

## **The planning of the CAG**

The planning of the CAG involved the members negotiating, planning and developing group structures for function and performance. Table 14 outlines the group’s terms of reference, which were formulated and altered throughout the life of the research project. Planning also involved the group determining and implementing goals and strategies to transform MSIC service delivery and promote and sustain the CAG’s longevity.

**Table 14. CAG’s terms of reference**

<b>Terms of Reference for Uniting Sydney Medically Supervised Injecting Centre’s (MSIC) Consumer Action Group (CAG)</b>	
<b>Purpose</b>	
<ul style="list-style-type: none"> <li>• The current purpose of the CAG is to represent consumers’ views about MSIC service delivery and inform management of ways to make MSIC services more reflective of consumers' needs.</li> <li>• The CAG’s longer-term goal is to expand MSIC consumer participation by creating mechanisms with the management team to establish consumer voluntary and paid positions.</li> </ul>	
<b>Membership</b>	
<ul style="list-style-type: none"> <li>• The MSIC Mental Health Coordinator will facilitate meetings.</li> <li>• Group members will consist of eight MSIC consumers and four staff who are interested in contributing to MSIC service delivery.</li> <li>• Two consumer members are female and one Aboriginal or Torres Strait Islander person to reflect MSIC’s consumer population.</li> <li>• There is a waiting list for consumers who are not in the group and who are interested in joining.</li> <li>• Three consumer members form the group’s quorum; therefore, three consumers must be present for votes to be passed.</li> </ul>	

<ul style="list-style-type: none"> <li>• If a consumer member has not attended two consecutive meetings and is not able to provide a reason (e.g. sickness or hardship) they should resign to allow a consumer on the waiting to join.</li> <li>• Consumer members who are incarcerated will be able to return to the group when released, as the group supports drug law reform.</li> <li>• To acknowledge consumer members' contributions to service delivery they will receive \$40.00 cash and refreshments each meeting they attend.</li> </ul>
<p><b>Facilitator's Role</b></p>
<ul style="list-style-type: none"> <li>• Monitor Group dynamics and rules</li> <li>• Prepare meeting agenda</li> <li>• Provide necessary documents</li> <li>• Disseminate minutes a week before the next meeting</li> <li>• Remind consumer members of upcoming meetings via text messages or messages on the MSIC database when a member does not have a mobile phone.</li> <li>• Be available for consumers who need support outside of meetings.</li> <li>• Present the group's suggestions and ideas at MSIC management meetings for discussion and approval.</li> <li>• Coordinate the annual MSIC consumer satisfaction survey and collect responses form suggestion box and present to MSIC's Service Manager.</li> </ul>
<p><b>CAG Member's Role</b></p>
<ul style="list-style-type: none"> <li>• Attend meetings to represent MSIC consumers and discuss ideas to improve MSIC service delivery.</li> <li>• Rotating chair and recording meeting's minutes - only if members feel comfortable.</li> <li>• Promote the CAG to MSIC consumers and staff so they are aware of the group's purpose and ways that consumers can be involved in the development of MSIC service delivery and planning.</li> <li>• Promote the group to other services and researches by presenting at conferences – only if members feel comfortable.</li> <li>• Create partnerships with other drug user groups, consumer groups, researchers and any other interested organisations to generate support and ideas to enhance consumer participation at MSIC.</li> <li>• Foster positive relationships with MSIC management and staff so we can work in partnership to improve MSIC services</li> </ul>
<p><b>Rules and Code of Conduct</b></p>
<ul style="list-style-type: none"> <li>• Consumers will not be able to attend the group if their intoxication is impairing their concentration and is disrupting the group.</li> <li>• Members are to be considerate by attempting not to interrupt each other.</li> <li>• If consumers become frustrated during the meeting, they are to express their frustration in a respectful manner.</li> <li>• Group members are to be mindful that personal details discussed in the group are confidential and are not to be discussed outside the group.</li> <li>• Consumer group members who are going to be late to meetings are to ring MSIC and inform that they will be late.</li> <li>• Members who know they will not be able to make two or more meetings must discuss their circumstances with the group facilitator.</li> </ul>

<ul style="list-style-type: none"> <li>• Consumers who arrive or leave half way through the group will only receive half pay and those who arrive after half time will not be paid.</li> <li>• If conflict occurs between members, the facilitator will mediate and attempt to resolve the dispute.</li> </ul>
<b>Duration and Frequency of Meetings</b>
<ul style="list-style-type: none"> <li>• Ninety minutes every four weeks on Tuesdays at 4:30 pm when MSIC closes for staff education/meetings and public tours</li> </ul>
<b>Commencement of Meeting: Acknowledgement to Country</b>
<ul style="list-style-type: none"> <li>• All CAG Meetings will commence with 'Acknowledgement to Country' using the following example: <b>'I acknowledge the local Custodians, the people of the Gadigal Nations, past and present, the Elders and the Ancestral Spirits. And I honour the land upon which I live and work.'</b></li> </ul>
<b>Location</b>
<ul style="list-style-type: none"> <li>• Sydney MSIC in stage 3 or mezzanine level when public tours are occurring.</li> </ul>
<b>Review of Terms of Reference</b>
<ul style="list-style-type: none"> <li>• The terms of reference will be reviewed as necessary.</li> </ul>

## CAG structure

The CAG structure included the development of the group's philosophy, main aim, and objectives; membership, the group's meeting formalities, and group norms/rules.

### Groups' philosophy, main aim, and objectives

During the first meeting, the research project's methodological approach (PAR) was explained and its democratic and egalitarian nature – with each member considered to be both participant and researcher – emphasised (as noted in my reflective journal meeting one, 30/06/15). It was also explained that decisions about the direction of the group's actions would be achieved through a majority vote. Because of PAR's democratic approach, it was decided that the group's main aims were to represent consumers' views about MSIC and give management suggestions of ways to make MSIC services more reflective of consumers' needs (minutes meeting one, 30/06/15). After the first meeting, a CAG Structure and Rules document was created to guide the group, with the view that revisions could be made when changes occurred (see Appendix D). The following objectives were developed to achieve the group's aims; to:

- Create a CAG that will give MSIC consumers a voice and a sense of empowerment.
- Promote the CAG to MSIC consumers and staff, so they are aware of the group's aims and the ways consumers can be involved in the development of MSIC service delivery and planning.
- Promote the group to researchers by presenting at academic conferences.
- Create partnerships with other user groups, consumer groups, researchers and any other interested groups to generate support and ideas to enhance consumer participation at MSIC.
- Foster positive relationships with MSIC management and staff so we can work in partnership to improve MSIC services.

## **Membership**

The CAG initially consisted of eight consumers, four staff members, and me as both a member and monitor of the group's rules and dynamics. Because 25% of MSIC consumers are female and 16% identify as Aboriginal or Torres Strait Islanders, it was decided that at least two members should be female, and one should be someone who identified as an Australian Indigenous person.

The group decided to have a rotating chair, and because it was a consumer group there was discussion about whether it was appropriate that staff members chair meetings (minutes, meeting one, 30/06/15). The consumers decided they were happy for staff members to chair meetings, because they trusted the staff and did not feel confident chairing meetings themselves (journal meeting one, 30/06/15).

I suggested that a member of the management team be invited to meetings to speed up approval of goals the group wanted to achieve. Ellen (consumer) expressed some reservations about this, as managers *“have too much power and prevent the action from occurring”* (journal meeting two, 22/07/15). The group decided the manager *‘can be asked to meetings when the group feels it is appropriate. For example, if the group has developed an idea to pitch to her’* (minutes meeting two, 22/07/15).

A waiting list was created for new members to join because, throughout the study, members left the group and others expressed interested in joining. Consumers left

because they went into drug rehabilitation (journal meeting five, 22/09/2015), moved interstate to reconnect with family and give up drugs (journal meeting 14, 29/03/2016), decided that the group was not for her (journal meeting six, 13/10/2015), or resigned due to dislike of the other consumer members (journal meeting 20, 28/06/2016). A staff member also left because of a change in employment.

When members left the group, selection of new members from the waiting list became the CAG's priority. However, many of the consumer members were worried about the consumers on the list as they worried that their marginalised lifestyles would prevent attendance, and/or they would attend meetings grossly intoxicated or only because of the \$40 cash (journal meeting seven, 03/11/2015). The staff group members said that before the group began they had similar worries, but were pleasantly surprised at how well the group functioned and that the consumers rarely came to meetings while intoxicated (journal meeting five, 22/09/2015). The staff also stressed that it would be unfair to deny consumers membership because of preconceived ideas about their capacity. Therefore, it was decided that everyone on the waiting list should be allowed to join when membership became open and the consumer at the top of the waiting list should be invited first (minutes meeting eight, 25/11/2015).

There was also some positive talk about consumers on the waiting list. The consumers and staff liked the idea of Paul joining, as he is a talented cartoonist and had the idea of making the MSIC consumers' rights and responsibility book into a cartoon booklet (journal meeting five, 22/09/2015). They also liked the idea of Kathy joining because she is an Aboriginal woman and could represent MSIC's Indigenous consumers (journal meeting three, 11/08/15). They also liked how she was active in placing notes in the suggestion box.

### **Meeting formalities**

The meeting formalities that were discussed included reminders of meetings, minutes, location of meetings, voting procedures, homework, subgroups, and communication with management.

### ***Reminders of meetings***

It was agreed that group members with mobile phones would be sent reminder texts about meetings, and member without mobiles would receive a reminder when they registered to use MSIC's services via the MSIC database (journal meeting one, 30/06/15). The consumers said that these messages helped them to remember and attend meetings (journal meeting two, 22/07/15).

### ***Minutes***

The group decided that minutes should be available prior to the next meeting (minutes meeting one, 30/06/15). All consumers were given folders in which to store their meeting documents at MSIC (minutes meeting two, 22/07/15), because homeless members had no suitable space (journal meeting two, 22/07/15). Consumer group members who were confident in doing so were encouraged to keep the meeting minutes, and staff members typed them up.

### ***Location of meetings***

The groups were mostly held in stage three on Tuesday afternoons when the service was closed for staff training and public tours. When public tours were occurring, the management team requested we hold our meetings on the mezzanine level used for staff meetings and education. Some staff members were concerned that holding CAG meetings on the mezzanine level would pose a security risk, because the consumers would have access to the upper level where staff kept their belongings (journal, prior to commencement of groups). However, several meetings were held on the mezzanine level, and no security problems were reported.

### ***Voting procedures***

In group 12, Andrew (staff) suggested that the group decide on a method for voting, because some consumers were still arguing about whether the group should support the 'Ditch the Dogs' petition (that supports the removal of drug detection dogs), despite the group voting to support this petition in the previous meeting (journal meeting 12, 23/02/2016). Andrew said that members were not always going to be happy with the outcome of a vote, but they must be final. Andrew stated that he had been in user organisation meetings where he was unhappy with the result of a vote, but he just had to accept it. The group decided that there had to be at least three consumers at the

group for a vote to pass (minutes meeting 13, 01/03/2016). They also agreed that staff could vote, but only if there was a quorum present.

### ***Homework and sub-groups***

As the study progressed, both staff and consumer members were concerned about time limitations; meetings only occurred every three weeks and lasted 90 minutes. They were also concerned that the group was not achieving its goals, and that time in the group meetings was wasted on unproductive talk that was not related to the group's goals and agenda. To speed progress, homework tasks were allocated to the consumers, and Arthur (staff) suggested that we create subcommittees that would focus on particular goals (journal meeting 10, 05/01/2016). Eventually, the group decided through a majority vote that subcommittees would not be formed because not all CAG members would be involved in decisions and having subcommittees would make the group too complicated (journal meeting 13, 01/03/2016).

It was realised that consumers were not completing their homework tasks because they did not have access to computers and other helpful resources. To resolve this issue, time and space at MSIC was organised for consumers to work on their homework, but consumers rarely took advantage of this. As time progressed, the group realised it was possible to achieve their goals within the group time, and patience was more important for group success than homework and subcommittees (journal meeting 13, 01/03/2016).

### ***Communication with MSIC management team***

I regularly attended MSIC management team meetings through my roles as mental health coordinator. Therefore, the CAG decided that I would present issues or goals that needed approval from the management team.

### ***Group norms/rules***

The rules were decided within the first CAG meeting and were revised on several occasions throughout the study, especially when conflict occurred. The rules concentrated on not interrupting others, maintaining confidentiality, being in attendance and leaving the group early.

### ***Not interrupting others***

The standard group norms of raising a hand when wanting to speak and not interrupting members who are talking were adopted quickly. Alice suggested that if there were too many interruptions, we should use a talking stick (minutes meeting one, 30/06/15). When a person is holding the talking stick, everyone else has to listen attentively and unable to speak until they have the stick in their hand. The talking stick did not become a group norm, as members found it to be an unnatural way of communicating.

### ***Confidentiality***

The importance of confidentiality, and that group members should not disclose any personal details about members outside the group, was discussed on several occasions. I explained that the group was part of my PhD project, and aspects of group members may be written about in my thesis and journal articles and presented at conferences, as per informed consent (journal meeting one, 30/06/15). I reassured the members that group member identity would be kept confidential through the process of deidentification in my written work.

### ***Attendance***

There were discussions about the consequences of poor attendance. It was decided that if a consumer had missed more than three groups consecutively and could not provide a valid reason (e.g. sickness, hardship, sleep rough) they would have to resign from the group and relinquish their place to someone on the waiting list (minutes meeting four, 01/09/2015). Incarceration was also considered a valid reason for missing groups (journal meeting five, 22/09/2015), because many MSIC consumers are jailed for drug possession.

Some of the consumers said the rule should be strictly enforced and members should not give weak excuses for not attending group meetings. I pointed out that the group should not be too punitive about non-attendance, and understand that MSIC consumers are highly marginalised and disadvantaged people (journal meeting two, 22/07/15). Ellen (consumer) agreed, and said people who use drugs often find it a challenge to keep time and turn up to appointments.

### ***Leaving the meeting early***

During the first few groups, I expressed my concern about some consumers leaving halfway through the meeting and reminded them of the study selection criteria of an interest in consumer participation and a commitment to attending groups over 12 to 18 months (journal meeting five, 22/09/2015). I said that leaving halfway through a meeting does not display interest or commitment and suggested that if a consumer member leaves halfway they should only be paid \$20 (minutes meeting five, 22/09/2015). The group agreed, and consumers rarely left early after this rule was implemented.

## **Transforming MSIC**

The CAG raised issues, ideas and goals that were negotiated and voted on to help make MSIC services more reflective of consumers' needs. In the following sections I describe the issues and ideas the group debated, and then the goals that the group decided to pursue and how they transpired.

### **Issues and ideas**

The group discussed the following issues and ideas to make MSIC services more reflective of consumers' needs:

- consumers' negative encounters with the local police;
- the need for more sturdy and discrete takeaway injecting equipment;
- consumers' desire to attend MSIC without injecting;
- consumers' ability to formally teach each other how to inject;
- the need for a new consumer rights and responsibility document;
- consumer input into MSIC's health promotion; and
- use of the available MSIC property for a commercial endeavour.

### ***Consumers' negative encounters with local police***

There were many discussions throughout the project about consumers' negative encounters with police. The main concern was that the police often search consumers for drugs in close proximity of MSIC, and this prevents some consumers from using MSIC's services because they fear arrest (journal meeting one, 30/06/15).

Furthermore, MSIC consumers were often unaware of their legal rights when being searched and/or arrested by the police. Consequently, Ellen (consumer) suggested that we write a legal rights information pamphlet for MSIC consumers (journal meeting two, 22/07/15), and that the group invites a lawyer from the homeless health legal service to educate MSIC clients about their legal rights (minutes meeting three, 11/08/15), as ways of addressing this issue.

### ***Sturdy and discreet takeaway injecting equipment bags***

The CAG discussed how the takeaway injecting equipment paper bags at MSIC were flimsy and the police often associate them with injecting drug use and that this increases the risk of being searched. This issue was highlighted by Alice (consumer), who said: *“the police know that injecting equipment comes in these paper bags and they often break open and are difficult to carry around as they have no handles”* (journal meeting two, 22/07/15). Susan (staff member) also pointed out that the staff bring in their old shopping bags from home for consumers to disguise the paper bags, but she feels this practice is unhygienic (minutes meeting three, 11/08/15). To resolve this problem, Alice suggested that the group contact NUAA because they offer stronger and cleaner bags that look like department store shopping bags, and the police might not associate them with injecting equipment (minutes meeting two, 22/07/15).

### ***Attending MSIC without injecting***

In group one, Alice (consumer) commented on how Kings Cross had changed over the past 15 years and how MSIC needed to adapt to these changes. She said there were a lot more homeless PWID in the area (minutes meeting one, 30/06/15) and staff who work in homelessness services often have stigmatising views about them (journal meeting eight, 25/11/2015). She also said that MSIC was the only place where they felt welcomed, because they were often excluded from other services when suspected of using drugs.

Therefore, the CAG discussed changing part of MSIC’s admission criteria so consumers could be admitted if they are not intending to inject. The CAG thought that this change would increase consumers’ (especially those who are homeless) capacity to socialise, work on their painting for the MSIC Art project, and work on CAG-related activities (minutes meeting 14, 29/03/2016). The group also suggested that they should have a computer in stage three, so they can record minutes and work on other CAG activities.

### ***Consumers formally teaching each other how to inject***

In group three Kevin (consumer) and Susan (staff) suggested that MSIC should formally allow clients to engage with others to learn about preparing and using drugs in stage two (minutes meeting three, 11/08/15). This is because *'MSIC consumers often show each other how to inject and prepare pills when they share a booth, but they often do not teach each other the safest or evidence-based techniques.'* (journal meeting three, 11/08/15)

### ***New consumer rights and responsibility document***

There was discussion about the group reminding consumers about their rights and responsibilities when attending MSIC, because not adhering to their responsibilities can have serious consequences for the service. In group two, Kevin (consumer) and Barry (consumer):

*'became protective of MSIC and explained how they dislike clients dealing within MSIC and how this could jeopardise MSIC's licensing conditions. Kevin also suggested that clients should be given the rights and responsibility document to review on a six-monthly basis to remind them of the rules.'* (journal meeting two, 22/07/15)

There was also discussion about consumers not reading the rights and responsibilities document when they registered at MSIC. Paul proposed transforming the MSIC consumer rights and responsibility document into a comic book, *"so it would have more street credibility and increase the chance [of] people reading it"* (minutes meeting five, 22/09/2015).

### ***Input into health promotion***

In the meetings, there was debate about whether MSIC consumers should drive health promotion activities instead of staff. The group decided that staff should continue to lead this activity, but also felt they should contribute by using a space in stage 3 that would display CAG health promotion (minutes meeting 14, 29/03/2016). The group discussed creating health promotion displays about safer injecting and newly emerging illegal drugs, new hepatitis C treatments and raising awareness of domestic violence.

### ***Use of available property for a commercial endeavour***

In group one, I mentioned that Uniting Care owns a property above MSIC, and that MSIC management was thinking about ways to use it (journal meeting one, 30/06/15). I suggested that the group brainstorm commercially viable ideas, such as setting up a café in the property. Monica (staff) suggested that we write to Richard Branson to ask for funding to make our ideas a reality, because he is supportive of MSIC and planning to visit (minutes meeting one, 30/06/15).

The group thought setting up a café or other business was a good idea, but it was decided it was too big an undertaking for a new group. Nevertheless, several months later hope about a café resurfaced, when a manager informed me that a wealthy benefactor had visited MSIC and donated some money, and that this might be used to transform the upstairs property (journal meeting eight, 25/11/2015). However, this hope was short-lived because the existing tenants signed another long-term lease, thus the space was not available.

### **Ideas the group decided to pursue**

In order to accomplish a sense of achievement and not lose hope, the group decided to transform ideas into goals that were simple and achievable. The following goals, except for improving relations with the police, were decided in group six. Addressing negative encounters with the police was a goal eventually decided in group nine; the CAG debated it constantly and found it difficult to let go. The seven agreed-upon goals were to:

1. Improve relations with King Cross Police by the creating a police liaison officer position;
2. Write a submission for the MSIC statutory review that will focus on allowing consumers to engage in activities without injecting;
3. Conduct a safer injecting workshop, so consumers can teach others safer injecting techniques;
4. Promote the group and sustain its future;
5. Rewrite the consumer rights and responsibilities into cartoon format;
6. Obtain a computer for consumer use in MSIC stage 3; and

7. Provide discreet and sturdier bags for takeaway injecting equipment.

The group achieved the first three goals; chapter seven outlines the actions that were undertaken to achieve them. Paul (consumer) made a start on the cartoon booklet, but never finished it; a laptop was acquired for the consumers in stage three, but there were technical problems with internet connection, and the managers did not approve the new injecting equipment bags due to the cost.

## **Promoting the group and sustaining its future**

Since the main aim of the CAG was to represent MSIC consumers, it was realised the group needed to be promoted to consumers who were not group members. It was also noticed that some consumers outside of the CAG were unhappy about the group.

According to Alice and Barry (consumers), some consumers were jealous, *'as we can come into MSIC when it is closed, have pizza and get paid \$40 cash'* (journal meeting seven, 03/11/2015). To increase awareness of the CAG and decrease animosity, it was decided that part of the group's role was to promote its aims.

T-shirts were designed for CAG members to wear and spark conversations with other consumer about the group so its aim and purpose could be promoted. (The creation of these t-shirts is described and discussed in the next chapter.) In addition to designing t-shirts, I suggested we create an MSIC paper/newsletter to inform other MSIC consumers and staff about what was happening in the CAG (journal meeting one, 30/06/15). I took this idea to the MSIC management team, who did not approve it because:

*"they were concerned about a member of the public getting hold of the newsletter and taking it to the press. The management team suggested a notice board as an alternative way of advertising the CAG."* (journal meeting two, 22/07/15)

So, rather than distribute newsletters, one was prepared for display on a noticeboard. In order to reduce misunderstanding and resentment from those not in the group, it was decided that the first newsletter should explain the aims and objectives of the CAG and how and why members were chosen (minutes meeting four, 01/09/2015). For the second newsletter the group suggested focusing on the fact that the comment book (in which consumers could provide feedback about MSIC) had gone missing in the hope it would be returned (minutes meeting seven, 03/11/2015). Barry suggested that we use

jail-like language like 'shit off' (an alternative way to tell someone to 'f... off') to grab the consumers' attention about the missing book. However, Susan (staff) said "*MSIC is not a jail and we should not allow prison culture to filtrate into the consumer group*" (journal meeting eight, 25/11/2015).

After the creation of two CAG newsletters it was decided that they would no longer be displayed, because the second newsletter was defaced with derogatory remarks about the CAG consumers. Therefore,

*'the group decided they 'had no control over the newsletter being vandalised and that they would stop promoting the group in this way, because the insulting comments dampened the member's spirits.'* (journal meeting nine, 15/12/2015)

Not only did the group need to be promoted with other consumers, but the staff needed to become aware of the CAG. To increase staff's awareness of consumer participation and update them about the CAG, I presented the results of the 2015 MSIC consumer satisfaction survey at a staff training day (journal meeting five, 22/09/2015). At another staff training day, Paul (consumer) and Sebastian (consumer) presented their experiences in the group (journal meeting 15, 19/04/2016).

The group also decided that they wanted to promote the CAG outside MSIC, and this was achieved by the following:

- a member of the NSW Parliament reported, in parliament, that she met with the CAG when she visited MSIC (minutes meeting 16, 26/04/2016);
- the CAG developed a submission to the MSIC statutory review that was debated in NSW Parliament;
- three members (one consumer and two staff) promoted the CAG at The Consumer Led Research Network Forum (Sydney, 04/11/2015), which involved consumers and academics interested in consumer-led mental health and drug and alcohol research (journal meeting six, 13/10/2015);
- Sebastian (consumer) and I gave a presentation about the group at an academic conference (journal meeting 14, 29/03/2016);
- Sebastian (consumer) promoted the group when he attended a NUAA advocacy course (journal meeting 17, 17/05/2016); and

- Alice (consumer) said that she promoted the group to other inmates in jail and that they were interested in the group's activities (journal meeting 17, 17/05/2016).

In addition to promoting the CAG, the group realised the importance of making the group sustainable. In the first group, Andrew (staff) said *“we need to keep in mind that not all things we discuss or want to change, or implement will be possible”* (minutes meeting one, 30/06/15). This helped the CAG to have a realistic outlook and realise *‘if the group became too disappointed it would be hard to sustain the group’s enthusiasm and this may fuel the group’s demise’* (journal meeting one, 30/06/15). Andrew (staff) also suggested that when management did not approve the group's suggestions, the group ask for the rationale behind the decisions (minutes meeting one, 30/06/15).

## **Reflections on the formation of the CAG**

Upon reflection, I identified several factors that enabled the group to progress and function, as well as factors that constrained the group.

### **Factors that enabled CAG**

The factors that enabled the CAG to function and achieve its goals were the consumers' enthusiasm, consumers having a voice, an atmosphere of encouragement and support, consumers learning how groups function, staff and management consulting with the CAG, and management support.

#### **Consumers' enthusiasm**

At the outset, I observed how the consumers' enthusiasm and eagerness enabled the functioning of the group. In the first meeting, the first 30 minutes were set aside for socialising and sharing food to help members gradually ease into the agenda items. Instead, the consumers were eager to speak about issues that affected MSIC consumers, and therefore the discussion started 15 minutes early (journal meeting one, 30/06/15). The consumers' enthusiasm continued throughout the project, and halfway through consumer members *“showed their commitment by forfeiting their 10-minute break to concentrate on agenda items because they realised time was precious”* (journal meeting 11, 19/01/2016).

Some consumers displayed enthusiasm by volunteering for group tasks. Michael offered to chair a session (journal meeting one, 30/06/15) and write the minutes (journal meeting five, 22/09/2015), and Barry asked to chair a session (journal meeting two, 22/07/15). Throughout the project, Kevin expressed his passion for the CAG and MSIC by saying that they were important aspects of his life (journal meeting two, 22/07/15).

I noticed excited new members could reignite the group's passion when progress and momentum slowed, and the group's enthusiasm naturally declined. In group 14, "*Sally attended for the first time and brought a cheerful and enthusiastic vibe to the group*" (journal meeting 14, 29/03/2016).

### **Having a voice**

On reflection, I realised it was counterproductive to focus on CAG consumers completing homework tasks during the first half of the project. This was because the consumer's marginalised lifestyles often inhibited them from completing designated tasks. I eventually realised that raising the consumers' voice was more important to the group's success than completing homework tasks, because the CAG provided a new platform for the MSIC consumers' voice to be heard (journal meeting nine, 15/12/2015). This voice was often political in nature and related to drug law reform and harm minimisation. Sebastian (consumer) said that:

*"everyone's individual's voice is valuable, and an individual can achieve anything, and I am talking about drug law reform, anything to do with drugs, spreading information and collective voices can move mountains. So, that gets back to lobbying and all of that sort of carry-on."* (audio recording meeting 17, 17/05/2016)

The CAG was mentioned in the NSW Legislative Assembly by Jo Haylen, a member of the NSW Parliament who visited MSIC and met the CAG. She announced to the assembly that she "had the privilege of hearing from drug consumers about what it means to have harm minimisation on the political agenda"<sup>10</sup>. Alice and Paul were keen to voice their views about the law and drug use in *Bar News*, a publication for lawyers, but unfortunately, the journalist was unable to arrange a time to interview them (journal

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<sup>10</sup> NSW Parliament, Legislative Assembly, 11<sup>th</sup> May 2016, accessed from: <http://www.parliament.nsw.gov.au/hansard/Documents/LA20160511.pdf>

meeting 10, 05/01/2016). Andrew (CAG staff member) observed that Alice's new-found voice enabled her to speak to police assertively and educate them about the importance of MSIC's harm minimisation approach.

*“Andrew gave an account of a conversation he heard on the street, and it was Alice and the police. Andrew said that Alice was being hassled by the police, but she calmly told them that it was not good that they were bothering clients near MSIC, as MSIC saves lives.”* (journal meeting nine, 15/12/2015)

Paul and Sebastian (consumer CAG members) presented at an MSIC staff training day about their experiences in the CAG. This presentation provided staff with a new voice and fresh perspectives – consumers had never presented previously. Monica (staff) asked Paul about how the group affected him personally, and Paul:

*“spoke from the heart and about how the CAG meant a lot to him. He explained how the CAG meetings triggered him to stop drinking because his extremely high alcohol consumption prevented him from effectively participating in the group and not drinking allows him to be more efficient and enables him to draw cartoons for the consumers' rights and responsibility pamphlet.”* (journal meeting 16, 26/04/2016)

Kate (staff) asked Sebastian how the CAG assisted him to help other MSIC clients. Sebastian:

*“gave an example of how he has educated other consumers on using pill filters. He said that he used his lived experience to deliver this education and explained how his breathing has improved as the particles from the pills are no longer going to his lungs, because the filter has removed them.”* (journal meeting 16, 26/04/2016)

Paul and Sebastian's presentations were well received. Of the 22 staff who provided feedback, 96% rated their talk as 'excellent' or 'very good'. The written feedback was also positive, and included: *“good to hear the clients' perspective”*; *“brilliant presentation by Paul and Sebastian”*; and *“bring clients again – well done”* (evaluation of CAG presentation at MSIC staff training day, May 2016).

## Encouragement and support

On occasion the CAG staff members and I felt frustrated when consumer members missed meetings, arrived late, left meetings early and did not complete their homework tasks. However, I realised that it was more productive to encourage and support consumers than to chastise them. Such encouragement and support probably increased consumers' confidence, triggered some consumers to address their substance dependence, influenced consumer members to support each other, and reduced power differentials between consumers and staff members.

Examples of encouragement included Monica (staff) giving Robyn a warm welcome because she was only 10 minutes late, when in previous meetings she was much later (journal meeting 16, 26/04/2016);, and Ellen (consumer) being congratulated for attending the meeting, considering she was going through difficult circumstances (journal meeting three, 11/08/15). I also contacted (either face to face or by telephone) consumers who missed meetings, so I could offer support and encourage them to attend the next session. My frustration usually dissipated when I discovered the consumer's reason for non-attendance:

*"I spoke with Alice about missing the group. She said that she was experiencing excruciating pain because of osteoarthritis. She also reported that the doctors are reluctant to do a knee replacement because she is only 40 years old. Alice said she has been taking up to 24 non-steroidal anti-inflammatory tablets and injecting fentanyl patches to cope with the pain. She also said that the pain is controlling all aspects of her life and she is finding it difficult to cope." (journal meeting eight, 25/11/2015)*

I noticed that the encouragement and support that the staff members provided in meetings was infectious; I observed the consumers were becoming more supportive and encouraging of each other. An example was when Barry phoned the group to inform of his abstinence and to encourage everyone that recovery is possible. Barry said:

*"so, I got up here and was on the methadone for about twenty days, and then I said to my brother I am done and then I jumped off one-fifty milligrams cold turkey – no other drugs. I have had twenty-two days fucking clean and have come through the worse shit in my fucking life. (There was a loud applause and*

*cheer from the group). I want to tell you something if you do not believe in yourself I believe in each every single one of you, because you have more strength, because you can draw strength from each other, because all you have to do is believe in yourself and take that one step and let faith do the rest and you will come out smelling pretty.”* (audio recording meeting 15, 19/04/2016).

In addition, Kevin comforted Barry during the phone call when Barry spoke about his traumatic childhood. Kevin said to Barry:

*“you are one of my best mates, and I love you to death, my brother. And if I can help you I will. You and I have been through a lot together over the years.”*  
(audio recording meeting 15, 19/04/2016)

Another example of consumers supporting each other occurred when the group was debating whether people under the age of 18 should be allowed to access MSIC's services. I noticed that Michael *“was looking upset. I pointed out that we should be mindful that this subject is hard for Michael because he recently lost his 13-year-old daughter who overdosed on heroin”* (journal meeting 16, 26/04/2016). Despite most members agreeing that MSIC should admit underaged people, everyone could see Michael's distress and supported him and did not continue the debate.

### ***Increased consumer confidence***

I noticed that the group's encouraging and supportive environment lifted the consumers' confidence. Barry and Alice (consumers) said that attending CAG meetings boosted their self-esteem and self-respect, and Kevin (consumer) stated that the meetings made him feel more human again (minutes meeting nine, 15/12/2015). These self-affirming transformations triggered consumers to have the confidence to help themselves and consider new life directions. The CAG prompted Kevin to see more possibilities in life, gave Alice *“a stepping stone and confidence to do other things like volunteer at NUAA”*. Michael (consumer) stated that the CAG had *“given me the courage to start improving my life”* (minutes meeting nine, 15/12/2015). Two other consumers stated that being a member of a supportive group triggered them to address their substance and alcohol dependence. Paul said he stopped drinking so he could be a more effective CAG member. Barry said the support he received from the CAG increased his self-esteem, thus influencing him to reconnect with his family and detox from drugs (journal meeting 15, 19/04/2016).

### ***More equal relationships between consumers and staff***

I observed that the CAG meetings' supportive atmosphere removed some of the unequal power dynamics that usually occur in the MSIC clinical environment. Barry and Alice said that *"we are treated as equals, and we're listened to here"* (minutes meeting nine, 15/12/2015). I said I enjoyed that the meetings *"removed a barrier between staff and clients, and this help me to get to know the consumers outside of the clinical environment"* (minutes meeting nine, 15/12/2015). Arthur (staff) said he became more *"inspired to do more for MSIC and the clients, and to take the feeling of equality between staff and clients from the group into my regular work at MSIC"* (minutes meeting nine, 15/12/2015).

### **Developing interpersonal skills**

The CAG meetings gradually enabled the consumers to learn how to appropriately interact within a formal meeting. At first the consumers struggled with chairing the meetings. I realised that the consumers had probably not chaired a meeting before or attended formal meetings. Therefore, I created chairing guidelines (Appendix E) and paired the consumers who were chairing with a staff member who could provide guidance if they were struggling. The guidelines and staff support proved helpful, because *"the meeting appeared to run a lot smoother and kept us on track"* (journal meeting 14, 29/03/2016).

In group 20, the consumers learned about the importance of expressing frustration in a respectful manner and listening to others in the group. I said that *"groups can be frustrating and demanding at times and can bring out the best and worst of our characteristics and uncomfortable feelings"* (audio recording meeting 20, 28/06/2016), and Arthur highlighted the importance of respecting other group members by giving them your undivided attention:

*"you don't need to hear your own voice all the time, you just think, keep it in here and let others, give others respect by giving other people your attention and your silence and listening. That's respect and, umm and I think that we all make mistakes and we all get excited or frustrated – that's okay. But you know, how we can have this conversation when the things we are criticising and the things we are trying to overcome are happening right now. And umm, I think that's umm (pause) you know I don't know the answer to that and we are all guilty of it, but just say, let other people talk and let it go, just let the situation*

*happen, and talk when it is necessary.” (audio recording meeting 20, 28/06/2016)*

I also pointed out that Arthur was a role model for the group in relation to respectful expression of frustration:

*“Arthur is really fantastic at expressing his frustration, but in a really respectful sort of manner [pause] of listening to people, listening to their point of view, not putting people down, but at the same time expressing his frustration. And sometimes when I have been listening back (to the recording of the groups) Arthur has helped the group, umm, go forward with his frustration. Frustration is not a bad thing, but it is the way that we express it – in a respectful way.” (audio recording meeting 20, 28/06/2016)*

The CAG discovered that discussing issues outside of meetings was counterproductive and it was better to address grievances internally. This realisation transpired through two issues. The first issue involved a consumer who found it difficult to like the other consumer members, and the second involved consumers resenting a member coming to the safer injecting workshop highly intoxicated.

In group 14, Susan (staff) stressed the importance of CAG members putting aside their own personal views. Sebastian responded by saying, *“putting aside your prejudices is something that I think, or I found in the past is umm, quite a hard to do’* (audio recording meeting 14, 29/03/2016). He said he found it difficult to respect the other consumer members because they:

*“remind him of the MSIC consumers who have betrayed him over the years. He said that he does not want to soften his attitude because last year he befriended a MSIC consumer who stayed at his place for over six months. This person did not pay rent and constantly hounded Sebastian for his MS Contin<sup>11</sup> tablets. Sebastian eventually refused to give him tablets and his guest became verbally threatening towards him. The next day Sebastian found his dog dead and he suspects that his guest killed him.” (journal meeting 14, 29/03/2016)*

I empathised with Sebastian and asked him:

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<sup>11</sup> MS Contin is a tablet that is used to control severe chronic pain. Some MSIC consumers crush, dissolve, and inject MS Contin tablets.

*“if there were any consumers in the group that have hassled him and he said no. I said it is important that he try to resolve his resentment towards the other consumers, as his anger is disrupting the group’s dynamics. I suggested he engage in counselling with Arthur (staff) who he has a good therapeutic relationship with to discuss his anger towards the other consumers, as a way of processing it.”* (journal meeting 14, 29/03/2016)

Susan (staff) also had discussions with Sebastian outside the group about his behaviour in the meetings, because she was worried it would destroy the group’s cohesiveness (journal meeting 14, 29/03/2016). She also spoke with Kevin.

*“Kevin (consumer) complained to Susan (staff) about another consumers’ drunkenness and how he was angry, as he tries very hard to reduce his drug-taking on the day of the group, so he does not come to the group too smashed.”* (journal meeting 10, 05/01/2016)

My academic supervisor strongly advised that group issues should not be discussed outside of the group meetings, as these conversations increase the chance of group dysfunction (journal meeting 19, 21/06/2016). At first, I was reluctant to address Sebastian’s behaviour in the group, because I feared that consumers would deal with him in a physically aggressive manner. Eventually, I accepted that matters were not going to improve if I did not confront the dysfunction in the group and decided to address Sebastian’s behaviour in group 20. So he was not singled out, I decided to also address Sally’s intoxication in the safer injecting workshop, as this was also causing tension between group members.

My fears that the consumers would become aggressive toward Sebastian did not transpire. In group 20, Alice (consumer) spoke calmly about how she was aware of Sebastian’s behaviour and how she found it disrespectful. She said:

*“a certain person has been mumbling under his breath negatively and showing negative body language. If we have a problem, we put up our hand and we say I don’t agree with you. Not to sit there grumbling and griping to themselves for the next half an hour or through the whole meeting. If you have a problem, raise your hand and verbalise it. Don’t sit there and grumble about it please, because we respect each other.”* (audio recording meeting 20, 28/06/2016)

Sally was emotional when I addressed her intoxication and gave a heartfelt apology and the group forgave her (journal meeting 20, 28/06/2016). On the other hand, Sebastian was void of emotion during the meeting and did not mention or acknowledge his behaviour during the meetings. The next day Sebastian called and:

*“apologised for his behaviour in the groups. I thanked him for his apology and told him that he should also apologise towards the group and how the consumers in the group would appreciate his apology. Sebastian agreed to apologise in the next group.”* (journal meeting 20, 28/06/2016)

Even though Sebastian agreed to apologise in the next group, there were reports that he continued to express his disdain about the other consumers outside of meetings. Consequently, I thought that Sebastian was not going to change his view about the other consumers and would find it hard to apologise to the group (journal meeting 20, 28/06/2016). I did not have to worry about Sebastian’s apology, because he *“wrote a resignation letter stating that he could no longer be in the group, as he felt that he is unable to represent the views of MSIC clients”* (journal meeting 20, 28/06/2016).

When Sebastian’s behaviour and Sally’s intoxication were finally addressed, the majority of the group realised that addressing issues within the group was a healthier way of resolving conflict than discussing resentments outside of meetings (journal meeting 20, 28/06/2016). I hope that this will continue into future groups.

### **Consulting with consumers**

During the project, the MSIC management team and MSIC staff members (inside and outside the group) sought feedback from the CAG about their suggestions to improve MSIC service delivery or upcoming MSIC events. This helped the group to feel useful and important. The following are some of the proposals that were brought to the CAG meetings for consideration.

Uniting Care gave the MSIC management team money to buy Christmas gifts for the MSIC consumers. The management team consulted with the CAG regarding their ideas for Christmas presents. Kevin suggested that train travel cards would be appreciated, as this *“may help clients avoid nuisance and harassment they experience from police when they try to skip the train station barrier”* (minutes meeting four, 01/09/2015).

The MSIC management team also consulted with the CAG about a complaint regarding MSIC staff who worked the evening shift. The consumer members responded that the:

*'staff in the evening are often on the computers in stage two instead of focusing on clients, the booths are not always cleaned well, staff often ignore clients in stage three, clients are often rushed in the evening especially towards the end of the night, and some staff are still strict with the one-hour limit in stage two even when it is very quiet.'* (journal meeting four, 01/09/15)

This feedback enabled the management team to see the complaint from a consumer's viewpoint and how it affects their care.

In group 14, several ideas about upcoming MSIC events were raised for the consumer members to consider. Susan presented a staff member's idea about having a party and prize to celebrate MSIC's millionth visitor (minutes meeting 14, 29/03/2016). The consumers liked this idea and endorsed it. A staff member who coordinates an annual drug overdose memorial ceremony came to a meeting to ask for ideas for the event and to see if anyone wanted to be involved (minutes meeting 14, 29/03/2016). Sebastian (consumer) volunteered to be on the memorial's organisational committee.

A staff member who coordinates MSIC's counselling came to a meeting to ask if any of the consumers wanted to help her design a new counselling pamphlet (minutes meeting 16, 26/04/2016) and Paul agreed to help with the artwork (minutes meeting 16, 26/04/2016). Arthur (staff) also asked the consumers for their ideas for a prize for a health promotion he was running (minutes meeting 19, 21/06/2016).

### **Management support**

The management team showed their support for the CAG by approving most of their goals to improve service delivery. The management team also supported the group financially by paying \$40 for consumers to attend meetings, refreshments for the meetings, the cost of the t-shirts (journal meeting 11, 19/01/2016) and fees for Sebastian and me to attend and present at a conference (minutes meeting nine, 15/12/2015). Financial support continued after the research project ended, because the management team could appreciate what the CAG added to MSIC service delivery.

## **Factors that constrained the CAG**

Factors that constrained the functioning of the CAG were the consumer's lifestyles, frustration, and consumer members being focused on their personal views. They are discussed below.

### **Consumers' lifestyles**

It was observed that consumers' marginalised lifestyles sometimes prevented them from attending meetings and fully contributing to the CAG. Chronic illegal drug use often leads to high levels of intoxication and incurs harsh penalties. In addition, many of the consumers in the group have unstable accommodation and serious health problems.

### ***Intoxication***

One of the conditions of enrolling in the project was that consumers agreed not to attend while intoxicated, so they could focus and contribute and not disrupt the meetings. Four consumers did not adhere to this condition and this impaired their ability to concentrate and contribute to the group. Except for Sally disrupting the safer injecting workshop in group 16, I did not observe that consumers' intoxication affected the running of meetings. For example:

*"A consumer was pressured in speech and visibly intoxicated with methamphetamine. Despite this she did not disrupt the group, adhered to the rules and participated in the meeting."* (journal meeting three, 11/08/15)

*"A consumer was falling asleep because he was drunk, but he was not disrupting the group and he only fell asleep for a few seconds."* (journal meeting 10, 05/01/2016)

*"In the second half of the group a consumer stood away from the group and was staring at her phone, and I think this was related to her ice use. Despite this she did not disrupt the meeting."* (journal meeting 10, 05/01/2016)

*"A consumer was very intoxicated with meth and was restless, moving around the room and was unable to concentrate on the group. No other group members pointed out Sally's intoxication and she did not upset the meeting."* (journal meeting 15, 19/04/2016)

### ***Legal issues***

Because of the current penalties for illegal drug use, MSIC consumers are often in contact with the law and many have been incarcerated. Ellen and Alice missed numerous groups because they were occasionally imprisoned during the study. In addition, Robyn was keen on enrolling in the CAG project before the meetings began, but then went to jail and consequently was unable to enrol until halfway through the project (journal meeting 10, 05/01/2016).

Even when Ellen was realised from jail, her bail conditions continued to prevent her from attending meetings, as *'she was living in Newcastle and could not come to Sydney, as it would break her bail conditions'* (journal meeting 12, 23/02/2016). Sally was also worried about attending meetings because her good behaviour bond stipulated that she was not allowed in the Kings Cross area (journal meeting 14, 29/03/2016). Therefore, attending meetings meant she could possibly be returned to jail. The consumers' encounters with the law also prevented them from presenting at the MSIC staff training day and conferences. Michael was unable to attend the training day because he was detained by police (journal meeting 16, 26/04/2016), and Alice missed out on presenting at a conference because she was incarcerated (journal meeting 14, 29/03/2016).

### ***Homelessness and health problems***

Most CAG consumers had slept rough in the past, and two were sleeping in a park during much of their involvement in the project. Two others slept on friends' couches and occasionally slept rough. Due to sleeping rough, one consumer needed a hip replacement; another needed a knee replacement due to osteoarthritis that was exacerbated by sleep rough and therefore missed group eight (journal meeting eight, 25/11/2015). The consumers' health problems prevented them having their Christmas party in a park, because some found the 10-minute walk to the park strenuous (journal meeting eight, 25/11/2015). Also, unstable accommodation meant some consumers had to leave meetings early to collect their belongings before the train station's lockers closed for the evening (journal meeting three, 11/08/15). Homelessness also prevented the consumers from engaging in homework, as many did not have space or equipment (such as a computer) to complete it (journal meeting eight, 25/11/2015).

## Frustration

The atmosphere was harmonious during the first few meetings, because *“no power imbalances were apparent, and all group members were focused, attentive and no consumers appeared to be overtly intoxicated”* (journal meeting one, 30/06/15) and *“the group members appeared to be working harmoniously and respectfully together”* (journal meeting two, 22/07/15). However, this harmony did not last; as the project progressed, the potential for frustration and conflict grew.

In group four (01/09/2015), the staff and I became frustrated that the consumers were not completing their homework tasks and worried that this would prevent the group from achieving its goals (journal meeting four, 01/09/15). Tension also increased because the group had not come to consensus on group norms about coming late and leaving early (journal meeting five, 22/09/2015) and the conditions for consumers returning to the group after a long absence. Arthur (staff) became particularly frustrated by the returning member issue, because the group previously voted on this and some members remained dissatisfied with the outcome (journal meeting 14, 29/03/2016). Arthur said, *“how can we stop talking about this and will another vote put it to bed?”* (audio recording meeting 14, 29/03/16).

Annoyance also surfaced because of dominating personalities in the group. A staff member and consumer thought that the more vocal consumer members in the group prevented the quieter ones from speaking. Monica (staff) thought that the group needed more structure and balance. She said:

*“the people that we don’t hear from need to be allowed to speak. It’s not their fault that they are not speaking and that’s not what I am saying. I am saying I think they find it hard to speak; we need more structure that when we have a topic we go around the room and let every single person say what they need to say and even if you have nothing to say and actually I don’t have anything to say.”* (audio recording meeting 20, 28/06/2016)

In group eight, I was becoming increasingly aware and frustrated of the limited time the group had to achieve its goals and how my work responsibilities prevented me from devoting more time to the CAG.

*“As the project progresses, I am becoming more aware of the limited time the group has to meet its objectives. The group only meets for 90 minutes every*

*three weeks and this time goes very fast, as the consumers have a lot to say because they rarely have a voice in our society and therefore, are very keen to provide ideas about MSIC service delivery. I am also concerned that I am very busy with my mental health coordinator position and have limited time to commit to the project.”* (journal meeting eight, 25/11/2015).

There were also concerns that time was being wasted because some members were going off on tangents and not attending to the meeting’s agenda. This caused frustration, because some members felt it could prevent the group from achieving their goals. Some examples are given below.

*“Barry talked about his ideas for transforming the property upstairs when it was not a goal or an item on the agenda.”* (journal meeting seven, 03/11/2015)

*“The group kept coming back to the issue of the police, which was not on the agenda.”* (journal meeting nine, 15/12/2016)

*“Sebastian spoke at length about some consumers’ distasteful behaviour in stage two, when we were supposed to be discussing issues related to confidentiality.”* (journal meeting 12, 23/02/2016)

In group 15, Sebastian expressed his annoyance about Barry (a consumer who left the group) phoning the group during the meeting. He said:

*“the call was intrusive to the group’s time and disconcerting to some group members and perhaps no more surprised phone calls, but if someone wants to talk it should done at a separate time.”* (audio recording meeting 16, 26/04/2016)

I was surprised that most of the consumers agreed that the phone call was not appropriate during group time, because when the call occurred, they appeared overjoyed to hear from Barry. Paul said, *“we don’t have enough time as it is”* (audio recording meeting 15, 19/04/2016) and Michael said the call does not need to *“eat into the group’s time and we don’t have enough time as it is to do want we want to do”* (audio recording meeting 15, 19/04/2016).

The staff in the group felt differently about the call. I said *“most of you were happy to hear from him and I don’t know. The way I would like to see this group ... sure we have some formalities, but we have some flexibility, as well”* (audio recording meeting

15, 19/04/2016). Kate agreed and said, “*you know there are traditions and formal ways of doing things, but that does not necessarily mean we have to do them with every group*” (audio recording meeting 15, 19/04/2016).

As time progressed, it became clear that Sebastian’s concerns about the phone call were more a result of his personal views and experiences than being worried that Barry’s call was taking up the group’s time. Other consumers’ personal views and experiences sometimes prevented the group from achieving its main aim of representing MSIC consumers.

### **Personal views and experiences**

Even though the CAG members decided to support drug law reform, some were more focused on how drug-related issues affected them personally. Consequently, they found it difficult to let go of certain decisions the group made democratically. This dilemma became apparent when Susan (staff) asked members if the CAG should support the ‘ditch the dogs’ petition, which advocates ending police use of drug detection dogs in public places. The majority voted in favour of having MSIC consumers sign this petition in group 11, but in group 12:

*“Sebastian passionately said that he is still is against the petition, as some dogs are trained to detect explosives and getting rid of the dogs makes him feel unsafe. Michael also said that 90% of people would feel safer having the dogs. I asked if anyone knew if the petition was specifically about the dogs that detect drugs and Andrew (staff) said it was and it had nothing to do with dogs that identify explosives. Despite this Sebastian and Michael were still against the petition. I checked the ditch the dogs’ website and it does not mention dogs that detect explosives. The website explains that the petition is to end police use of drug detection dogs in public places and points out that the poor are much more likely to be searched by the drug dogs than the rich, therefore this petition is very relative to MSIC consumers.”* (journal meeting 12, 23/02/2016)

In group 13, I informed everyone that I had reviewed the ‘ditch the dogs’ website ([https://www.unharm.org/ditch\\_the\\_dogs](https://www.unharm.org/ditch_the_dogs)), which highlights that marginalised people like MSIC consumers are very much at risk of being searched. I also mentioned that the website mentioned nothing about explosive detection dogs. Despite my explanations, some consumers were still opposed. Michael (consumer) said, “*I actually*

*like the sniffer dogs – it gets rid of the shitkickers<sup>12</sup> in my building and I don't want fucking drug dealers in my building*" (audio recording meeting 13, 01/03/2016), and Sebastian said *"it is your risk if you want to carry drugs and I therefore don't give a stuff about the petition"* (audio recording meeting 13, 01/03/2016). Despite this, Kevin and Michael continued to voice concerns that getting rid of the dogs would increase the risk of terrorism (journal meeting 13, 01/03/2016).

Arthur (staff) and I reminded the consumers that the main aim of the group was to represent the majority views of consumers. Arthur said *"we are not discussing if we disagree with the sniffer dogs or not. We are discussing if we should put a petition in stage three for other consumers to consider"*, and I said:

*"the group should not be focusing on their own personal opinions when deciding about whether or not we should have a petition in stage three but looking at how the petition can help the larger MSIC consumer community"* (journal meeting 13, 01/03/2016).

Some consumer members were also ambivalent about allowing consumers who went to jail back into the CAG, despite the group voting that they could return (minutes meeting five, 22/09/2015). Because Alice and Ellen were recently released from jail, Kevin was concerned about them returning to the group, because he had always been careful to avoid being arrested, and said *"I have never done a day's jail in my life"* (audio recording meeting 14, 29/03/2016). Sebastian said:

*"I am a little uncomfortable when I hear that you know, that so and so did not have any choice that they ended up in jail. But you know, we all have decisions about the behaviours we chose to follow and umm, if people want to you know, commit a crime and know what the risks involve if they get caught and ramifications are if you miss more than three meetings."* (audio recording meeting 14, 29/03/2016)

Susan (staff) challenged the consumers about their personal views, and said:

*"you need to be less judgemental about MSIC clients going to jail because of their drug use, and if you are unable to control your judgment, they maybe you*

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<sup>12</sup> 'Shitkickers is Australian slang for a person that performs menial tasks and is an unskilled labourer. Retrieved from: <https://greensdictofslang.com/entry/4vkxbdy>

*need to reconsider if you should be in the group” (audio recording meeting 14, 29/03/2016).*

In the end, despite some consumers expressing their strong personal views about the petition and consumers who were in jail returning to the CAG, the group voted in favour of both supporting the petition and allowing CAG members to return after imprisonment.

## **Conclusions**

Despite the consumers in the group being dependent on drugs, living chaotic lifestyles, and having no prior experience of working in a formalised group, the CAG succeeded in achieving its primary aims and most of its goals. I think the major factor that helped the group succeed is that, with support from the staff and me, the consumers used their voices and ideas to create the aim, goals, and structure of the CAG. However, like all groups, the CAG faced several challenges.

Some of the CAG members were more vocal than others, some did not adhere to the agenda, some came to meetings grossly intoxicated, some left meetings early and some did not complete homework tasks; these factors at times caused disharmony amongst members. Conflict also occurred because some members were focused on how issues affected them personally instead of considering their impact on MSIC consumers collectively. In addition, one of the consumers found it difficult to like the other consumers in the group, and consequently resigned because he realised he was unable to represent MSIC consumers.

It was only towards the end of this project that I realised that the discussions of group problems outside of meetings were counterproductive. These discussions occurred because I was fearful of addressing conflict in the group, having often observed MSIC consumers dealing with conflict belligerently. However, the opposite occurred when issues were finally addressed in meetings: the consumers expressed their grievances civilly and they forgave Sally for attending the safer injecting workshop grossly intoxicated.

To further enrich the CAG’s cohesiveness, the members need education about representing others; this could be provided by a drug user organisation, such as NUAA and AIVL. This learning will enable members to put aside their personal beliefs and

make decisions that benefit the majority of MSIC consumers. The group also needs to interview new members to determine how they perceive MSIC consumers, because if new members view their peers negatively, they will be unable to represent them.

The results in this chapter provide hope that group dynamics and relationships in the CAG will continue to improve, as the CAG staff members and I have helped to create encouraging and supportive meeting environments focused on the consumers' strengths instead of their deficits. This environment has helped the consumers to feel valued, find their voice, reduce or stop alcohol and drug use, address health problems and have more hope for the future. I firmly believe that the staff and I have also been good role models for the consumers on how to appropriately and effectively interact in meetings, and our continue involvement will help the group members to learn skills and grow personally.

## CHAPTER SEVEN: ACTION STAGE

The 'action' stage of this PAR project involved four cycles that focused on improving service delivery for MSIC consumers. Cycle one involved improving relations with the police; cycle two involved being heard; cycle three centred on promoting the CAG; and cycle four was about educating peers. Figure 11 illustrates the 'action' stage of the research process.

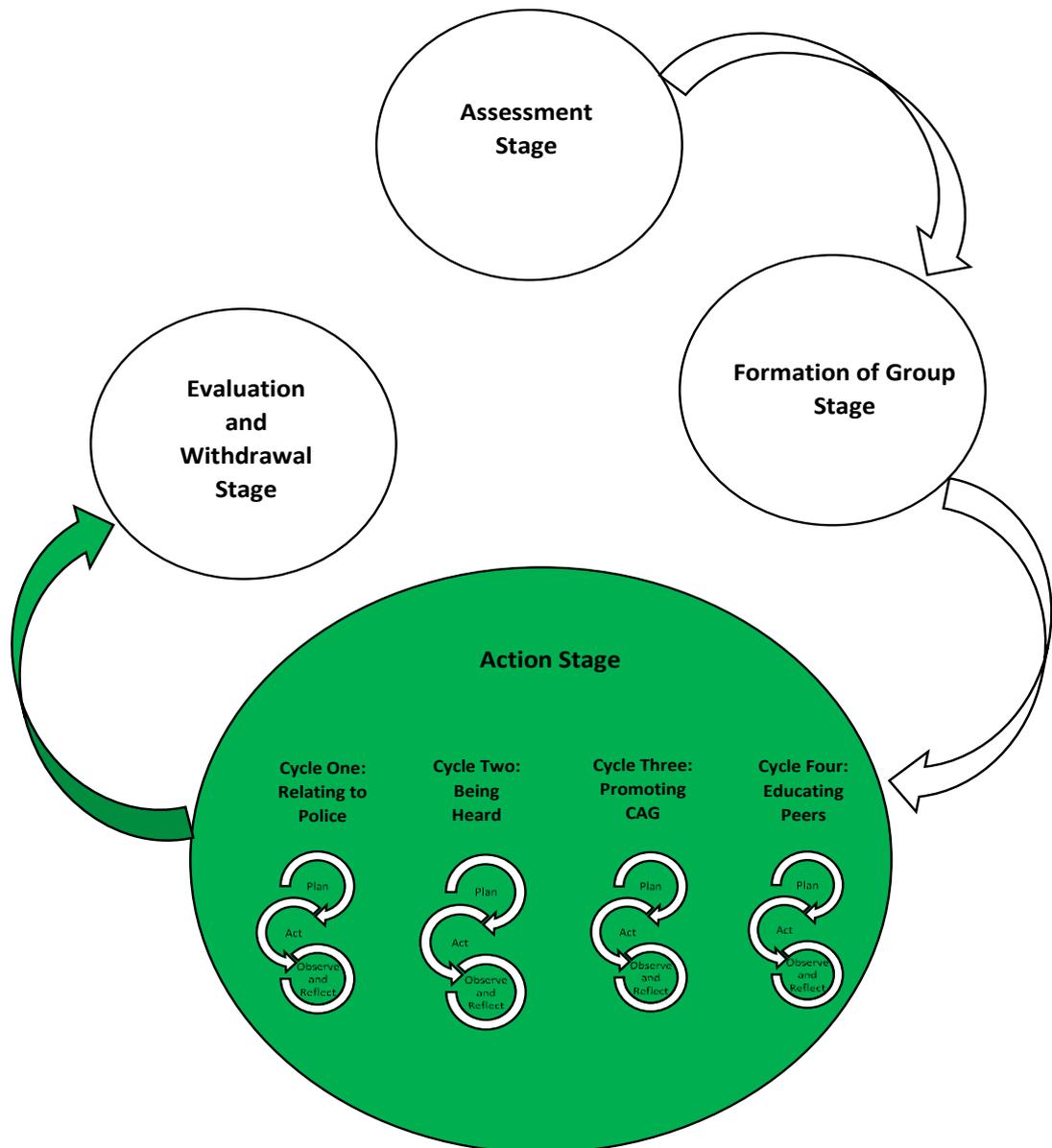


Figure 11. 'Action' stage of the research process

## Cycle one: improving relations with the police

Cycle one involved the CAG discussing issues they had with the local police. The group took action by having a meeting with a newly created police liaison officer (see the **Informing management** section below), and through respectful dialogue it was shown that improved relations with the police are possible. However, the group realised that patience is required before relations with police could significantly improve. Figure 12 outlines the planning, action, observing and reflecting stages of the improving relations with local police, cycle one.

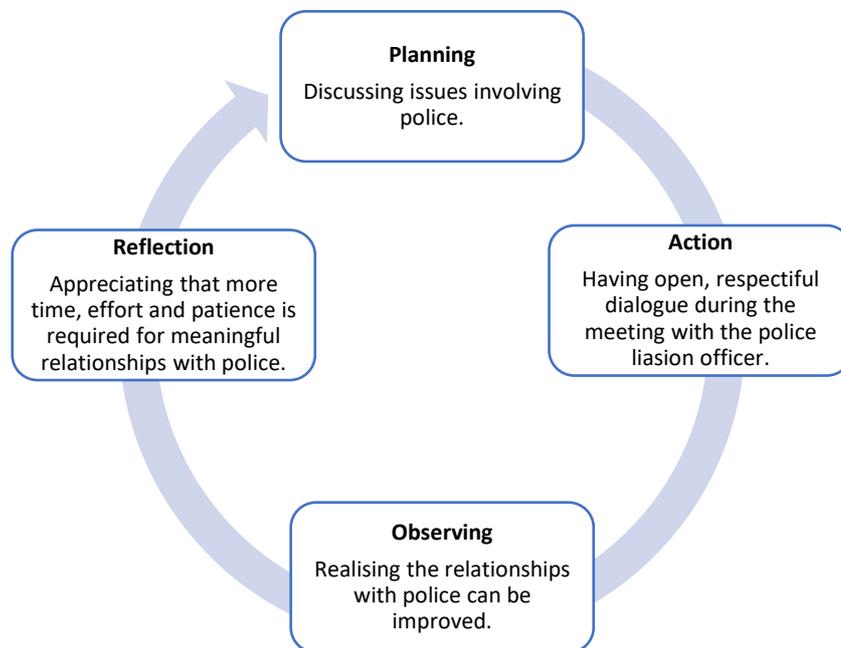


Figure 12. Cycle one: improving relations with police

### Planning

The planning stage involved the members discussing the issues MSIC consumers have with the police and discussing ways to resolve them.

### Issues consumers have with the police

The consumer members voiced their frustration about police searches occurring near MSIC and how this encourages consumers to inject in less safe places because of the fear of arrest (journal meeting one, 30/06/15). The consumer members also reported that they perceived some police officers to be rude, aggressive and unprofessional; for

example, covering their name badges to conceal their identity. Overall, the consumers described the searches to which they were subjected as ‘harassment’:

*“Barry said that police often harass and target clients at or near MSIC’s front and back entrances.”* (minutes meeting one, 30/06/15)

*“Alice said the police harass MSIC clients who carry paper bags that contain clean injecting equipment.”* (journal meeting two, 22/07/15)

*“Kevin mentioned that he had been harassed by police because he carries around his medication for epilepsy and sometimes, they take it off him.”* (journal meeting two, 22/07/15)

There was discussion about the existence of an exclusion zone in which police could not search MSIC clients. The consumers said that many MSIC clients are under the impression that when MSIC opened, the police and MSIC agreed on such a zone. Andrew (staff) said we need to find out if there is any truth about this agreement – *“is it written, verbal or non-existent?”* (minutes meeting one, 30/06/15).

### **Suggestions to reduce searches and improve relations with police**

The suggestion that the group contact the local member of parliament about the searches was met with pessimism; a member of the group stated that *“this had been tried before, and there is nothing we can do, as the police are acting within the law”* (journal meeting one, 30/06/15). There was a further suggestion that the group contact and work with Law Enforcement Against Prohibition, an international non-for-profit organisation comprising of former and current police who are opposed to policies related to the ‘war on drugs’ (minutes meeting one, 30/06/15). A suggested strategy was to collect information on the time, place and circumstances of the police searches so that this could be used to present data to senior police officers (journal meeting one, 30/06/15). I suggested inviting MSIC’s medical director to a meeting, as she has regular meetings with the police local area commander and could convey the CAG’s concerns (journal meeting 10, 05/01/2016).

It was also noted that MSIC consumers are often unaware of their legal rights. I suggested creating a poster that outlines an individual’s rights when being questioned by the police (journal meeting two, 22/07/15). A further suggestion from one of the

consumer group members was to develop a legal rights pamphlet for consumers and to invite the homeless health legal team, which provides legal advice to homeless people, to conduct information sessions about the law and legal rights (journal meeting two, 22/07/15).

An MSIC identification card to show to police officers was also considered as a possible way of reducing police searches near MSIC. Aaron suggested:

*“that MSIC should provide clients with a card stating that they are an MSIC client and show this card when they are confronted by the police. It is hoped that this card may prevent some police from being so punitive and allow clients to proceed to MSIC.”* (journal meeting two, 22/07/15)

The group also discussed the need to improve their relationships with the police and how organising a face-to-face meeting would be a good place to start. The group:

*“spoke about some strategies to improve our relationship with them [police] and show them that MSIC does more than just allowing clients to inject (e.g. referring clients to treatment and welfare services). The group discussed the possibility of inviting a senior police officer from the local area command to attend a meeting and learn more about MSIC and its client.”* (journal meeting nine, 15/12/2015)

## **Action**

The CAG took action to improve their relationships with police by:

- investigating the existence of an exclusion zone where police cannot search MSIC consumers;
- informing MSIC management of their concerns about the police;
- preparing for the meeting by writing a summary of issues and;
- developing a MSIC ID card to enable police to use their discretion.

## **Exclusion zone**

I investigated the existence of the hypothesised exclusion zone in which police are unable to search MSIC clients by speaking with MSIC management. My colleague said that the zone was a myth, and:

*“police can lawfully search clients anywhere outside and inside of MSIC, and the amendment to the drug misuse act only stops clients from being prosecuted for injecting a personal quantity of drugs inside MSIC. Overall, the group members appeared to be quite accepting of this, and that stopping police from searching and arresting MSIC clients near MSIC will be a difficult goal to achieve.”* (journal meeting two, 22/07/15)

I also reviewed the Needle and Syringe Program (NSP) policy for NSW police<sup>13</sup>, which contains information about the principles of harm minimisation and encourages police to develop positive views about NSPs. I distributed the guidelines to the group, and they learned that police could use their discretion near services that provide clean injecting equipment. The guidelines explain that discretionary judgements by police can prevent unwarranted searches that discourage people from receiving equipment and services that minimise harms associated with injecting drugs (journal meeting three, 11/08/15). The group felt that the NSP guidelines could also apply to MSIC, because its main aim was also to reduce the risks of injecting drug use.

### **Informing management**

I informed the management team about the consumers' concerns about the police, and MSIC's medical director contacted the local area commander. Through the director's contact, a MSIC police liaison officer position was created. The position involves an officer liaising with MSIC consumers and management to reduce conflict and enhance communication between MSIC and the police (journal meeting 12, 23/02/2016). The CAG then invited the newly appointed MSIC police liaison officer and the community police liaison officer to a meeting to discuss their concerns.

### **Preparing for meeting**

I coached the consumer members for the meeting with the police liaison officer so that we presented a professional and well-organised approach. I acknowledged that, *“some members are angry about the police, but it is important this anger is not expressed aggressively, as it could negatively cloud the officers' attitudes about us”* (journal meeting 19, 21/06/2016). Also, to keep the meeting organised we developed and gave the police a summary of the issues and a proposal to work in partnership (Table 15).

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<sup>13</sup> NSW Police Force. (2013). NSW Police Needle Syringe Program Policy. Retrived from <http://www.health.nsw.gov.au/csm/Documents/nsp-police-policy.pdf>

**Table 15. The CAG's issues with the police and proposals for working in partnership**

Issue	Consequence	Potential solution
Police searching clients in close proximity to MSIC	Clients feel harassed, affecting their ability to access MSIC and therefore inject in a safe place. This conflicts with the goals and purposes of this health service and may harm MSIC clients.	MSIC and police create an MSIC ID card. This will allow police to identify MSIC clients and therefore enable access to MSIC safe injecting facilities rather than inhibit them
Some police being unprofessional towards MSIC clients by using stigmatising, discriminating and foul language, covering up their ID so clients cannot make complaints, and being violent.	This behaviour fuels animosity between MSIC clients and police.  The covering of IDs makes it difficult for clients to make complaints.	The police liaison officer position can be an avenue of redress when clients encounter problems with the police.  CAG members educate the police about how MSIC saves lives and makes Kings Cross a safer place.

### **MSIC ID card**

In the meeting, the consumers suggested creating an MSIC ID card that could be shown to police, thus enabling police to exercise their discretion when encountering consumers in close proximity to MSIC (Figure 13 is the front and back of the card eventually developed). It was also proposed that new police recruits undertake a tour of MSIC, allowing CAG consumer members to educate them about the service and harm reduction. One of the members of the CAG agreed to speak during the next tour. It was also suggested that this tour would be useful to promote the MSIC ID card. The tour transpired, but unfortunately the consumer who agreed to speak did not attend, so one of the MSIC managers spoke instead.



**THINKING OF VISITING MSIC? Please use the Medically Supervised Injecting Centre because it:**

- ✓ is a safer place to inject drugs
- ✓ prevents deaths from drug overdose
- ✓ reduces infections like Hep B & C and HIV/AIDS
- ✓ puts people in touch with treatment and support services
- ✓ reduces unsafe disposal of needles and syringes
- ✓ makes the neighbourhood more comfortable and safe for everyone

**Please do not use the Injecting Centre to:**

- ✗ deal in drugs
- ✗ evade Police



**BEEN STOPPED BY THE POLICE? Show them this information:**

Section 36N of the Drug Misuse and Trafficking Act creates specific exemptions from criminal liability for users of MSIC. These include that a police officer can exercise a discretion not to charge for possession of a small quantity of a prohibited drug if a person is “travelling to or from” MSIC, or is “In the vicinity of” MSIC (see s36N(4)).

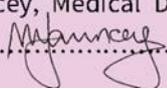


Drug use is otherwise illegal in the Kings Cross area, so police will actively pursue the supply of drugs and will seek to prosecute suppliers of drugs in all circumstances in the Kings Cross Area.




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**Card issued by**  
 Dr Marianne Jauncey, Medical Director, Uniting Medically Supervised Injecting Centre .....



**Figure 13. Front and back of MSIC ID Card**

After the meeting, a follow-up meeting with Paul (consumer member), the police and MSIC executive management was arranged to discuss the meeting’s outcome. The MSIC police liaison office could not attend, but the community liaison officer came in his place. In this meeting, the ID card and MSIC clients educating the police were discussed. The MSIC’s medical director stressed that the ID card should not contain the client’s name and personal details, so their anonymity is protected, and the officer said that clients would only be able to use the card close to MSIC. Everyone agreed the card should contain both MSIC’s and the police’s logos and that it should first be

approved by the police and then the CAG (minutes, police liaison officer follow up meeting). Regrettably, the local area commander did not authorise the police logo being printed on the card.

## **Observations and reflections**

Four key ideas emerged from the meeting with the police liaison and community liaison officers:

- the MSIC consumer/police relationship is complex, and interactions are not going improve overnight;
- the meeting enabled the consumers and police to see each other's humanity;
- MSIC consumers and police need to communicate differently and perceive each other in a different light; and
- there is hope that MSIC consumers and police can work in partnership.

## **Complexity of relationships**

The police liaison officer explained his role as being a "*conduit for communication between the police and MSIC*" and enabling a more efficient way for MSIC clients to voice their concerns about the police, noting that formal complaint procedures are complex and convoluted (minutes meeting 19, 21/06/2016). He also said that he plans to educate officers about MSIC's life-saving work, and that they can use discretion when deciding to search or arrest MSIC clients. Furthermore, he has rewritten policies to reflect an officer's powers of discretion. He stressed that relations between MSIC consumers and the police are not going to change overnight. This is because it is hard to influence 152 officers' attitudes, and public and government expectations are that illicit drugs are seized and that monthly drug search targets are met (minutes meeting 19, 21/06/2016).

The consumers mentioned some other policing practices that create tensions between police and MSIC clients. One instance was related to the 'move-on' orders that allow police to direct people to vacate public places, a law that was initially promoted as an anti-gang strategy but was expanded in 2001 to allow police to move on suspected

drug dealers and purchasers<sup>14</sup>. Barry expressed his frustration regarding an incident in which he was waiting at a bus stop when a police officer instructed him to move on and said that he would be charged with trespass if he refused to do so (journal meeting 19, 21/06/2016). Another instance was related to the perceived hassling of MSIC clients about previous legal charges. Michael said, “*when you are being searched some police officers look up your criminal record and hassle you about crimes committed 10 years ago*” (journal meeting 19, 21/06/2016).

### **Seeing each other’s humanity**

The meeting with the police liaison officer began with Barry retelling his story about his recovery journey. Barry’s story was a useful way to commence the meeting, as this enabled the police to see beyond the consumer’s hostility and appreciate their humanity and that recovery is possible for MSIC consumers (journal meeting 19, 21/06/2016). In addition, the group’s preparation for the meeting paid off, as CAG members were polite and respectful, and this showed their desire to work in partnership. Overall, Barry’s story and the CAG members’ calm behaviour helped the police see MSIC consumers in a new light.

The meeting also helped the consumer members to regard the police in a different light and realise that some are willing to listen and change the status quo. Michael said:

*“I like how the officers said that we could be invited to the police training days and how this could build the relationship between the younger officers and MSIC. I think this is really proactive and I think we could go a long way with this.”* (audio recording meeting 20, 28/06/2016)

### **Changing communication patterns**

During the meeting, it was discussed that MSIC consumers were often belligerent when they interact with police. Kevin said that many MSIC clients *‘dig their own hole by the way they speak to the police’* (journal meeting 19, 21/06/2016). Consequently, the consumer members realised that they needed to change their communication style if relations with police were going to evolve. An example of this new way of communicating arose when Paul was searched by the police about six months after the

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<sup>14</sup> Shop Front Youth Legal Centre. (2011). Police move-on orders. Retrieved from [http://www.theshopfront.org/documents/Police\\_move-on\\_directions.pdf](http://www.theshopfront.org/documents/Police_move-on_directions.pdf)

CAG started. Instead of being combative, Paul explained the importance of MSIC to a group of officers. Paul told them:

*“how searching clients close to MSIC can be dangerous as it puts them off using the service and then they have to inject somewhere else. He also explained that the police’s job in Kings Cross was a lot harder in the days before MSIC, as they were often called to overdoses. Paul said that a younger officer just called him a junkie, but a lot of the older police agreed with Paul, and one liked the idea of an ID card that clients could show police in the close vicinity of MSIC.”* (journal meeting 10, 05/01/2016)

Alice’s reflection on being a CAG member also highlights how she developed the confidence to interact with the police in a calm manner and how this helped an officer to view MSIC and its clients in a different light.

*“Through being a CAG member, I have gained the confidence to communicate with the police in a more constructive and less aggressive manner. About a year ago, I heard a young police officer on the street saying ‘I do not like the injecting centre because it is keeping the junkies alive longer’. Instead of aggressively responding, I calmly told him that there has never been a death at the centre and explained that the centre does more than just letting people inject, as it refers clients to drug treatment and other health services. He appeared surprised about this. Through being calm, I could help this officer see MSIC in a different light, and I am hoping that our encounter will help him treat MSIC clients with more compassion and respect.”* (Alice’s reflections for APSAD conference presentation)

### **Hope for effective relationships**

The meeting with the police liaison officers ended in an atmosphere of goodwill and hope that improved relations between MSIC consumers and police were possible (Figure 14 is a photo of the CAG members and community liaison officer after the meeting). The police agreed with all of the CAG’s concerns, with the exception of the move on orders, as they are lawful. The officers liked the ideas of an MSIC ID card and consumer members training the police about MSIC and harm reduction. The police were also happy to amend alerts regarding previous crimes if they were no longer relevant (journal meeting 19, 21/06/2016).

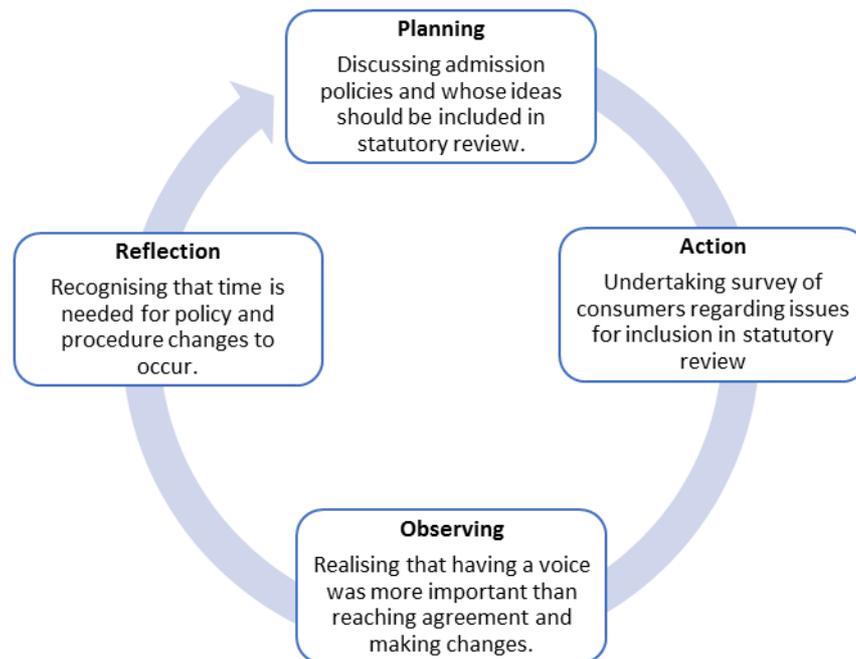


**Figure 14. CAG members and community police officer after meeting**

It was decided that consumer complaints about the police would go to the MSIC service manager, who would then pass them on the police liaison officer. Also, the community liaison officer said if any consumers had concerns, he was happy to chat with them on the street, or they were welcome to come into the station and talk to him there. The police agreed to attend another meeting in six months to see if relations were improving (journal, meeting19, 21/06/2016).

## **Cycle two: being heard**

Cycle two involved the group discussing policies about consumers' admission to MSIC and whose ideas should be included in the MSIC statutory review. The group took action by designing a survey about MSIC's admission criteria; they had 70 consumers complete it and submitted the results to the MSIC Statutory Review. The consumers realised that having a voice was more important than having their suggestions implemented, and recognised that time was needed for policy and procedure changes to occur. Figure 15 outlines the planning, action, observing and reflecting stages of cycle two – being heard about MSIC's admission criteria and statutory review.



**Figure 15. Cycle Two: being heard**

## **Planning**

The planning stage involved members of the group discussing how the MSIC's admission criteria prevented clients from engaging in non-injecting activities at MSIC (such as the art project or socialising with other clients) when they were not injecting drugs. Members also decided on the admission criteria issues on which they should concentrate and whether the voices of consumers outside of the CAG should be included in a submission to the NSW Parliament Statutory Review of MSIC's licensing conditions and internal protocol requirements.

### **Consumers' concerns about MSIC's admission criteria and policies**

The consumer members expressed a desire to attend MSIC without injecting, so they could use a computer to work on CAG-related tasks that included writing up minutes, designing the t-shirts, and creating cartoons for the MSIC's rights and responsibility pamphlet (journal meeting 10, 05/01/2016). The group discussed how MSIC consumers sometimes like to engage in non-injecting activities at the centre as they do not feel judged there, unlike at other services in the area (journal meeting seven, 03/11/2015). One of the members suggested that MSIC could attract more clients by providing a drop-in service in stage three that allows clients to partake in activities and engage with staff without injecting (journal meeting one, 30/06/15). However, MSIC

policy was that consumers cannot access any services without injecting (Sydney MSIC 2012).

The group also felt that some of MSIC's policies, such as excluding intoxicated clients (journal meeting 10, 05/01/2016) and not allowing clients to inject in their necks or inject each other (journal meeting 16, 26/04/2016), contradict the principles of harm reduction. In addition, the policies pose a danger because clients will still inject, but in a less safe place. Arthur's quote highlights the group's concerns about excluding some MSIC clients:

*"... with neck injecting and intoxicated people there are so many things and rules that to me fundamentally that go against the concept of this building [MSIC]. And as much I might cause us more problems, or it might cause more arguments or more work for staff, well that's why we are here for. And I truly believe that we are here not to tell them to go out on the street, because when I hear that it breaks my heart."* (audio recording meeting 16, 26/04/2016)

In addition, it was also thought that the intoxication policy prevents consumers from:

*"truthfully reporting their drug use, as they are worried that they will not be admitted. They also feel if this policy was changed consumers would be more forthright about the substance intake and this would help staff better monitor those who are at risk of overdose."* (journal meeting 10, 05/01/2016)

### **Issues for submission to statutory review**

An opportunity arose for consumers to address their concerns by preparing a written submission to the Statutory Review of Part 2A of the *Drug Misuse and Trafficking Act 1985*. This law provides the statutory basis for the operation of MSIC and shapes its internal management protocols and admission criteria. The Responsible Authorities of MSIC, which include the Ministry of Health, Office for Police and NSW Police, conduct the review approximately every five years to ensure MSIC is meeting its objectives and the review's report is tabled in the NSW Parliament.

The group members debated whether the submission should include the voices of consumers outside of the CAG and whether we should concentrate on issues different to those of the MSIC management team. Andrew (staff) suggested that an independent body like NUAA could help the group write the submission, because he was worried

that the consumers' voice would not be fully reflected if the MSIC management team edited the submission (journal meeting seven, 03/11/2015). NUAA's CEO was contacted and expressed interest in assisting with the review, but we had only two weeks to respond, and time was too short.

## **Action**

The CAG decided to conduct a survey at MSIC regarding the statutory review. As noted earlier, 70 MSIC consumers completed this survey, which contained multiple-choice questions (yes, no or unsure) and written responses. Survey questions about neck injecting and consumers being able to inject each other were originally in the survey, but MSIC's management team asked for these items to be removed, because a neck injecting project was about to start at MSIC and injecting another person is illegal. The team approved the other questions. The final questions were:

- Do you think that pregnant women should be able to access MSIC services?
- Do you think that people under 18 years should be able to access MSIC services?
- Do you think that highly intoxicated clients should be admitted to MSIC?
- Do you think that MSIC should change their opening hours?
- Do you think you should be able to access injecting equipment in Stage 1?
- Do you think that clients should be allowed to engage in MSIC activities, such as the art project and writing group without injecting?

I analysed the data from the 70 surveys and the results were included in the CAG's submission to the MSIC statutory review. The submission can be found in Appendix F.

## **Observations and reflections**

Through observing the CAG's involvement in its submission to the statutory review, several issues became apparent:

- frustration and anxiety about limited time;
- members have differing views about some of MSIC's admission criteria;
- consumers can take action; and

- having a voice is more important than winning.

### **Time constraints**

The group was frustrated and anxious about the slow progress of their submission to MSIC's statutory review. To increase productivity, Arthur suggested that the group should consider creating a statutory review subcommittee that meets outside of the main meetings (journal meeting 10, 05/01/2016). The group arranged a meeting time to form a subcommittee (minutes meeting 10, 15/01/2016), but it was cancelled because no consumers attended the meeting.

The group's frustration and the subcommittee not eventuating made me anxious. As a result, I drafted a survey and sought advice from MSIC's research coordinator (journal meeting 11, 19/01/2016). The coordinator advised me to rewrite the survey once the review's terms of reference were released. The advice helped me to realise:

*“rushing is counterproductive, as if we went ahead with the survey, we could have wasted a lot of time because we did not know the terms of reference of the review.”* (journal meeting 11, 19/01/2016)

The CAG was given only two weeks' notice of the review (minutes meeting 16, 26/04,2016), but the members constructively used the time in group 16 to discuss and formulate survey questions and within a week had 70 consumers complete it, as mentioned earlier. When debating the questions for the review, it was observed that some of the consumer members had polarised views about some of MSIC's admission criteria, as discussed below.

### **Views about MSIC's admission criteria**

The group unanimously agreed on most of the statutory review survey questions, but disagreed about some questions. All agreed that pregnant women should be admitted to MSIC because they are highly vulnerable and will be able to engage with medical staff and be referred to drug treatment and antenatal services (journal meeting 16, 26/04/2016). It was also agreed that intoxicated clients and those who inject in the neck should be admitted for safety reasons, that injecting equipment should be available in stage one because needle exchanges in the area are not always open, and that MSIC should extend opening hours (especially open earlier) because many consumers experience mild withdrawal symptoms in the morning.

On the other hand, the CAG had differing views about people under the age of 18 attending MSIC. Some felt that underage people attending MSIC sends the ‘wrong message’, and Michael was against it because his 13-year-old daughter had recently died from a heroin overdose (journal meeting 16, 26/04/2016). Alternatively, Robyn pointed out that we should allow those who are under 18 to access the service because *“we were using when we were kids, I was”* (audio recording meeting 16, 26/04/2016) and Monica (staff member) stressed that *“on registration many MSIC clients report that they started injecting at 13, 14 or 15 years of age”* (audio recording meeting 16, 26/04/2016).

Some consumers were against the idea of allowing consumers to inject each other because *“it can cause fights between clients’, ‘you can feel responsible about it,’ and it can increase the risk of blood-borne virus transmission”* (audio recording meeting 16, 26/04/2016). Arthur’s quote highlights why some members were in favour of allowing clients to inject each other.

*“.....there is more to it than it causes problems. Like because it happens anyway, so we are timing people out for it and that means those people are no longer able to use the service. That’s not harm reduction.”* (audio recording meeting 16, 26/04/2016)

Despite the differing opinions, it was unanimously agreed that questions about admitting under-aged people and clients injecting each other should be in the survey so consumers outside of the group could voice their thoughts about these issues.

### **Consumers taking action**

Before the consumers were involved in the statutory review, they rarely contributed to MSIC service delivery beyond attending CAG meetings. However, in group 16 several MSIC consumers agreed to help with the statutory review survey outside of meetings by encouraging other clients to participate (minutes meeting 16, 26/04/2016). MSIC management team allowed CAG members to collect survey responses in stage three without injecting and Paul and Michael spent several afternoons persuading clients to use their voice via the survey. Paul and Michael were successful at convincing clients to complete the surveys and explaining the survey’s questions and purpose. Michael also took further action by helping stage three staff with their work and disrupted power dynamics between him and a staff member. Michael was:

*“cleaning the floor and stocking the tea and coffee supplies. He even called out to one of the staff to provide Narcan<sup>15</sup> training to a consumer. This baffled the staff member as she thought Michael was stepping out of line”* (journal meeting 16, 26/04/2016).

### **Having a voice is more important than winning**

There was concern that the CAG’s submission to the statutory review would not alter the status quo, because some staff members were resistant to things changing at MSIC. Monica pointed out that some staff members would be unhappy about consumers engaging:

*“in other activities besides injecting, as they feel MSIC’s focus is harm reduction and saving lives and not clients’ social situations. They also feel there are other services in the Cross that concentrate on social problems”* (journal meeting seven, 03/11/2015).

Also, Andrew remarked the group might not ‘win’ (i.e. have the regulations changed) through the submission, because some staff would not support a change in policy that allows intoxicated clients to be admitted (journal meeting 11, 19/01/2016). I stressed to the group that the purpose of writing the submission was more about MSIC consumer’s voice being heard than winning or having our suggestions implemented (journal meeting 11, 19/01/2016).

In the end, the CAG’s recommendations to change MSIC service delivery were not accepted, and the submission did not change MSIC’s admission criteria or internal operation policies. However, the submission was not in vain, as this was the first time that MSIC consumers had voiced their concerns in a MSIC statutory review. I believe that the submission was one of the factors that helped in the development of a culture at MSIC in which the consumers’ voice is considered important.

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<sup>15</sup> Narcan (Naloxone) is a medication that is administered intramuscularly, intravenously or via a nasal spray and is used to reverse opioid related overdoses. MSIC consumers and PWIDs internationally are being trained to administer Narcan, so they save the lives of their peers. Retrieved from: <https://www.drugabuse.gov/related-topics/opioid-overdose-reversal-naloxone-narcan-evzio>

## **Cycle three: promoting CAG**

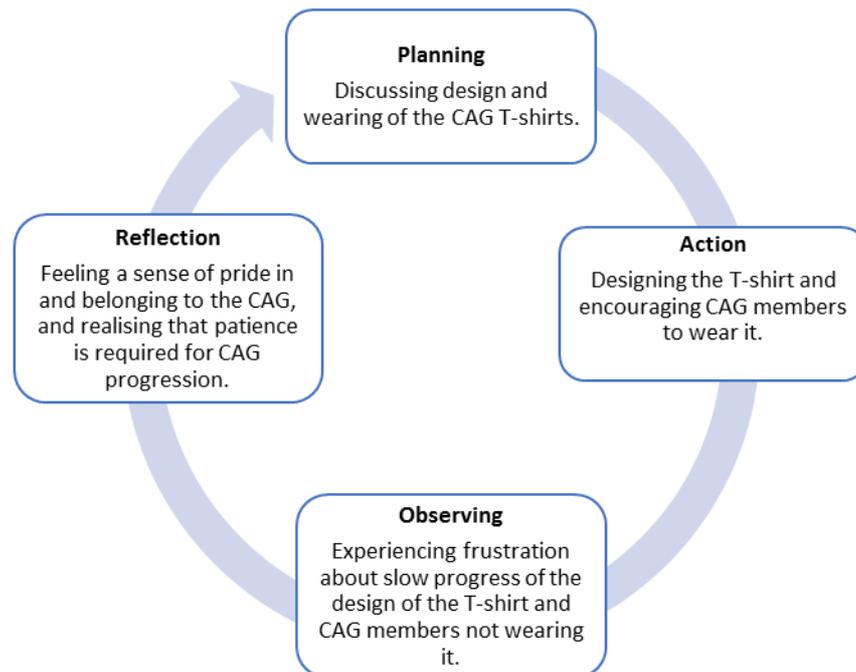
The CAG designed t-shirts in order to promote the group and to encourage discussion with consumers outside of the group. The consumers were enthusiastic about the t-shirts but played little part in the design; consequently, there was frustration among the CAG members about the progress of the t-shirts. The t-shirts were not widely worn, and therefore did not successfully promote the CAG. However, the t-shirts did provide the CAG members with a sense of pride and helped the group realise that patience is required for the group's progression. Figure 16 outlines the planning, action, observing and reflecting stages of producing t-shirts to promote the CAG.

### **Planning**

The planning for cycle four involved two stages: determining the purpose of the t-shirt and discussing its design.

#### **The purpose of the t-shirt**

Members of the CAG suggested that they design a t-shirt so that they would be identifiable to other MSIC consumers, thus enabling those outside of the group to highlight ideas that could be brought to meetings for discussion (minutes meeting three, 11/08/15). The group also discussed whether staff group members could wear the t-shirt. The group determined that this was appropriate because doing so had the potential to break down barriers between consumers and staff and increase solidarity and the visibility of the group (journal meeting seven, 03/11/2015).



**Figure 16. Cycle Three: Promoting CAG**

### **The t-shirt's design**

The group decided that the consumers would design the t-shirts, working on this endeavour outside of the scheduled meetings. Some of the ideas for the t-shirt design included:

- having the same text and slogan, but containing individualised graphic designs (journal meeting seven, 03/11/2015);
- having a hood to keep members warm in winter (minutes meeting nine, 15/12/2015);
- containing the slogan, 'nothing about us without us' (minutes meeting 12, 23/02/2016); and
- having long sleeves, as some members are self-conscious about displaying their track marks (minutes meeting 12, 23/02/2016).

However, due to cost restraints, the final shirt did not have a hood and was not long-sleeved.

## Action

Susan (staff member) designed the t-shirt, as the consumers did not have time to work on their designs outside of meetings. The group approved Susan's design (journal meeting 13, 01/03/2016). Figures 17 and 18 are photos of the front and back designs of the t-shirt. I received quotes from online t-shirt companies and had the t-shirt design and costs approved by MSIC management team. I also organised sizes and placed the order. CAG members were encouraged to wear the t-shirt when they attended MSIC in order to generate conversations with consumers about the CAG and encourage them to share their ideas in relation to how MSIC can improve its services to be focused on consumer needs and wants (minutes meeting 13, 01/03/2016).



Figure 17. Front of CAG t-shirt



Figure 18. Back of the CAG t-shirt

## Observations and reflections

It was observed that the CAG members were frustrated with the slow progress in the production and the impact the t-shirt had in promoting the group. It took over a year to design the t-shirt and not many members wore their t-shirt once it was produced. However, those who wore the t-shirt did so with a sense of pride.

### Frustration

Both consumer and staff members expressed frustration with the slow progress of the t-shirts design. Sebastian expressed his impatience with the process (journal meeting 10, 05/01/2016) and I felt disappointed that consumers were not working on their own designs (journal meeting nine, 15/12/2015). Sebastian (consumer) was also frustrated with consumers wanting to have individualised graphic designs on the t-shirts, feeling some of their ideas were childlike and unprofessional (journal meeting 10, 05/01/2016).

### Feedback

After group members received their t-shirts, I observed that few were wearing them and was concerned that the purpose of the t-shirt was not made clear or understood by the consumers (journal meeting 14, 29/03/2016). In the next group, I expressed my concerns and reinforced the rationale behind the t-shirts (journal meeting 15, 19/04/2016). The consumers said that they were not wearing their t-shirts because they were in the laundry; therefore, a second t-shirt was ordered for all the members.

Kevin and Michael reported they had been wearing their t-shirts, which enabled them to promote the group. Michael said that a MSIC staff member and two clients had asked him about the t-shirts, and he explained the purpose of the group (journal meeting 15, 19/04/2016). On another occasion, when Michael was wearing his t-shirt, a client asked him for advice on injecting methadone. In response, he provided guidance and informed him of the safer injecting course that the group was planning to conduct (journal meeting 15, 19/04/2016). Kevin said that two clients were so impressed with the t-shirt they asked him if they could have one, but the group decided that the t-shirts should only be worn by CAG members as the purpose was to promote the activities of the group (journal meeting 15, 19/04/2016).

A few consumers asked me questions when I wore the t-shirt and I explained the purpose of the group and how we were successful in creating a police liaison officer position. This provided an opportunity for them to express their anger about police searches seemingly conducted because they were carrying an MSIC styrofoam coffee cup. They explained that after injecting they usually make a cup of coffee and walk out on the street, and the police associate the cup with MSIC. I said I would bring this issue to the Police Liaison Officer (journal meeting 14, 29/03/2016).

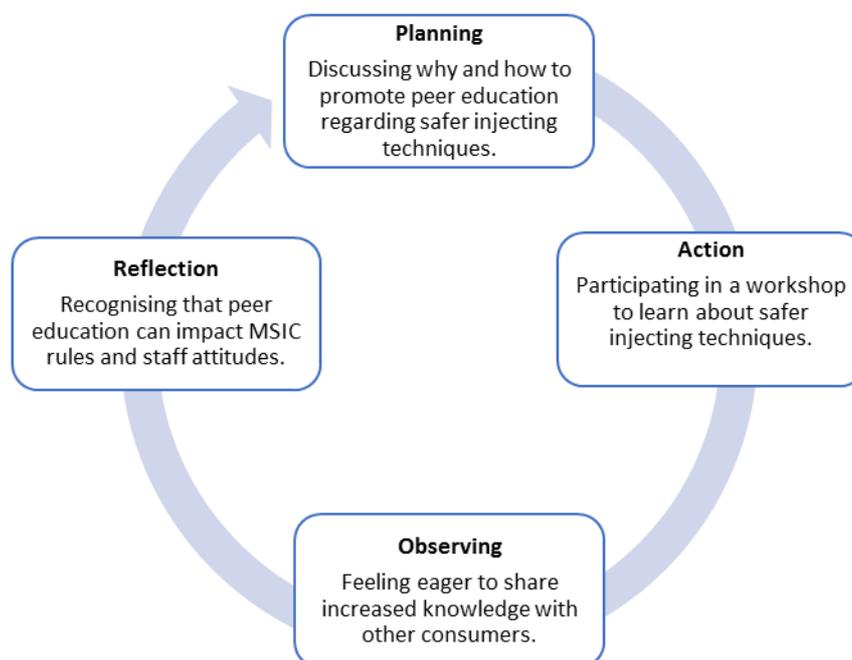
### **Sense of pride and belonging**

Even though the t-shirts did not promote the CAG to many consumers outside of the group, I did notice that they gave the CAG members a sense of pride and belonging. I remember how proudly the members wore their t-shirts during the meeting with the police, when they were helping with the statutory review survey in stage three, and while presenting at academic conferences. Also, the t-shirts helped the consumers belong to a group, and this feeling of belonging is rare for MSIC consumers, who are often excluded because of their marginalised position in society.

## **Cycle four: educating peers**

The group discussed why and how to teach their peers safer injecting techniques, and took action by completing safer injecting and pill filtering workshops. After the workshops, the consumers were eager to share the knowledge they had learned with their peers. On reflection, the CAG members wished that they considered MSIC rules and staff attitudes, because these prevented them from teaching all aspects of safer injecting to other MSIC consumers. Figure 19 outlines the planning, action, observing

and reflecting stages of engaging in safer injecting education and teaching peers to inject.



**Figure 19. Cycle Four: educating peers and teaching to inject**

## **Planning**

The planning stage of cycle five involved the CAG discussing why they should learn about safer injecting, how this education would be presented, who should provide it, when it was going to take place and what they wanted to learn from it.

### **Why learn about safer injecting?**

In group three, Susan (staff) suggested that the group required safer injecting education so they could teach MSIC consumers less risky ways to inject (journal meeting three, 11/08/15). MSIC consumers often teach each other how to prepare and inject drugs, but not always with the best technique or evidence (journal meeting three, 11/08/15). The group liked this idea and debated how this education should be presented and who should provide it.

### **Providing the education**

It was suggested that the CAG should produce a safer injecting video that consumers could watch in stage three (minutes meeting five, 22/09/2015). The group also discussed participating in a safe injecting course, and considered whether it should be

provided by a peer organisation such as NUAA. I tried to contact NUAA on multiple occasions, but they were slow in responding to my emails and phone calls (journal meeting 12, 23/02/2016). Andrew (staff) who has extensive experience in conducting safe injecting workshops for drug user organisations offered to facilitate the course (minutes meeting 12, 23/02/2016), but unfortunately, left the CAG shortly afterwards because he got another job.

It was also suggested that MSIC should deliver the education, as they run safe injecting and tablet filtration workshops for MSIC employees and other organisations. These workshops are presented by MSIC's nursing unit manager and health education officer manager; I spoke with both, and they said that they were happy to teach the CAG. The group decided that the MSIC safer injecting course would be the most practical option and that they would like a certificate to show that they had completed the course.

### **Content of education**

The CAG decided that the injecting education would be held at the usual meeting time, allowing most consumer members to attend (journal meeting eight, 25/11/2015). The consumers decided they wanted to learn about safer injecting principles and techniques, and preparing pills, including the new formulation Oxycontin®, and fentanyl patches and methadone (minutes meeting 13, 01/03/2016) for injection. It was also decided that if the workshops enabled the CAG members to teach their peers safer injecting education, then they should be offered to consumers outside the group (journal meeting 12, 23/02/2016).

### **Action**

I brought the group's suggestions about the MSIC safer injecting and pill filtering workshops to the management team, which approved everything, except learning ways to inject the new formulation of Oxycontin®. The adverse effects of injecting this new drug were then and remain unknown, and no evidence-based techniques were known to minimise harms when it is injected (minutes meeting four, 01/09/2015).

The group engaged in two 90-minute workshops. The first was a safer injecting workshop that involved learning:

- drug trends among MSIC consumers;

- the reasons people inject drugs;
- the complications of injecting drugs and risky injecting practices;
- vein care; and
- safer injecting techniques via demonstration and practice on an arm manikin.

The second workshop involved learning:

- the risks of injecting pills;
- the principles of filtering drugs;
- the different types of filters that can be used to filter drugs; and
- the use of using commercial filters (e.g. wheel filters and Steri filters).

The consumers were encouraged to share their knowledge about safer injecting and filtering pills with other MSIC consumers.

## **Observations and reflections**

During the workshops I observed that consumer CAG members were already knowledgeable about safe injecting, but they still learned new information about safer injecting. In hindsight, the CAG should have considered the MSIC rules before allowing consumers to teach each other to inject, and in the future, it should consider co-facilitating safer injecting workshops with staff.

### **Consumers are knowledgeable**

The consumers were knowledgeable about current harm reduction interventions to reduce the risks of injecting drug use. They were aware of safe injecting and tablet filtration techniques that are considered best practice. Below are some examples of the consumers' knowledge.

*“You can get complications through not rotating injecting sites.”* (audio recording meeting 17, 17/05/2016)

*“Some clients have their tourniquet on for too long, and this makes it harder to get a vein.”* (audio recording meeting 17, 17/05/2016)

*“You should only swab in the one direction because you can spread bacteria around if you swab in different directions.”* (audio recording meeting 17, 17/05/2016)

*“You should filter tablets and other drugs because ‘chalk,’ ‘fillers,’ ‘coagulants’ and ‘bacteria’ can cause breathing problems.”* (audio recording meeting 18, 07/06/2016)

A game was played in the second workshop that demonstrated the consumers' knowledge about tablet filtration. The game involved placing items that are used to filter drugs (such as cotton balls, cigarette filters, tampons and commercial filters) in order of their ability to filtrate particles and pathogens from pharmaceutical tablets and other drugs. The consumers' placement of the filtering items was 100% correct (journal meeting 18, 7/06/2016).

The consumers also shared knowledge that was unorthodox and related to their lived experience of injecting drugs. Examples of this knowledge included that ice helps you cope when you are withdrawing from opioids because it increases your energy levels, and old curved TV screens can be used to sharpen blunt needles (journal meeting 17, 17/05/2016).

In the workshops, both facilitators were respectful of and acknowledged the consumers' knowledge about injecting drugs. The following is the facilitator's acknowledgment in the first workshop.

*“I have been doing this workshop for a long time since 2008, and today I feel slightly anxious because of you guys – this is all about you. You know this stuff. So, I am really keen to do this with you and get some feedback, so I can potentially change things for the next time we with do it with other people. Like the type of people, we do it with are people from other services, people who work for NSPs and lots of different types of people. So, this is certainly one of my special types of audiences so far, and I am very pleased to be here.”* (audio recording meeting 16, 26/04/2016)

### **Learning new information**

The workshops enabled the consumers to learn new information about safer injecting and pill filtering. Michael said, *“most of us think we know everything about using, but I learnt something new”* and Alice agreed, *“I learnt one or two new things”* (audio

recording meeting 17, 17/05/2016). Some of the new information learned in the second workshop was based on two peer-reviewed studies of injecting tablets (journal meeting 18, 7/06/2016). The first study reported that 373 deaths of PWID in Sydney over the period of 1997-2013 were mostly likely due to injecting tablets (Darke, Duflou & Torok 2015). The second study indicated that risks associated with injecting MS Contin® tablets, such as embolisms, pulmonary diseases, and necrosis could be significantly reduced by filtering tablets through a wheel filter (a commercial filter) with 3ml of cold water (McLean et al. 2009). This information was not new for Kevin, as he attended a pill filtration workshop based on the same research at the 2012 International Harm Reduction Conference.

The consumers said they were eager to learn more. Kevin asked *“can we do this course every couple of months or so?”* and Alice stated *“I will take any course that is going that is about drugs and that stuff”* (audio recording meeting 17, 17/05/2016). The consumers also said that they were keen to pass on what they learned to other consumers but acknowledged that this was going to be a challenge. This is because many MSIC consumers want to prepare their injections as quickly as possible, and McLean et al.'s (2009) method of filtration takes 10 minutes longer than the usual method that involves heating the tablet and less water. Many were suspicious that using more water would lessen the drug's potency.

Kevin pointed out that *“too many people are too impatient to do a cold wash, because of the extra time it takes”* (audio recording meeting 18, 07/06/2016). Paul advised that *“we have to work out a way to convince people to filter their drugs”* (audio recording meeting 18, 07/06/2016), but he also admitted that he does not always filter his drugs because it takes too long. Alice stressed that it was important to convince, not push, that using more water to prepare your pill *“is not going to take any of their drug”* (audio recording meeting 18, 07/06/2016). Alice gave an account of how she taught another consumer how to filter a pill one evening and how it was good that she knew the procedure because none of the staff on that shift knew (journal meeting 20, 28/06/2016).

### **MSIC rules**

With the CAG consumers teaching their peers to inject, the group should have considered the MSIC rule about moving between booths in stage two. At MSIC, consumers are not permitted to move to another booth once they are registered in

stage one. This rule was created to prevent drug dealing, because dealing on the premises breaches MSIC's licensing conditions. Because of this rule, members are unable to move between booths to help with injecting advice. However, some staff members were happy to bend this rule, because they value the concept of peer education.

The issue of CAG consumers moving booths to educate other consumers was brought to the MSIC management team. MSIC management decided that CAG consumers could only teach others if they were registered in the same booth as the consumer they were teaching. The management team also decided to work towards having a formally trained volunteer position at MSIC. These positions will enable CAG members to legitimately move between booths and teach their peers safer injecting techniques, because volunteers would be considered part of MSIC staff.

Some of the consumers in the group did not like MSIC management's decision about preventing them moving between booths, because they felt this decision thwarted their efforts to help their peers. On the other hand, consumer members liked management's plan to implement MSIC volunteer roles, but they became impatient when these roles did not materialise instantly.

Paul became particularly frustrated with the slow progress of volunteer position implementation. I tried to explain the complexities of implementing volunteer roles (such as insurance, and managing staff reactions), but unfortunately, Paul decided to resign from the group because he felt that MSIC management was not being supportive of the CAG. Through working as a nurse for 30 years, I know that progress with initiatives such as creating volunteer roles take time, but I can understand Paul's frustration because he does not have the same insights into how health care services operate.

The group should have also considered that not all MSIC staff would embrace the idea of CAG members teaching consumers safer injecting, an activity that was part of a staff role at MSIC. An announcement was made at the MSIC staff meeting that the CAG would be doing a safer injecting course so they would be better equipped to teach MSIC consumers, but many staff do not attend meetings or read minutes. A better way of promoting the development would have been a presentation involving the CAG at an MSIC training day. This would have enabled more staff to hear about the initiative and dialogue to occur about the CAG's plans.

## Conclusions

The creation of an MSIC police liaison office showed that it is possible for opposing groups such as PWID and the police to work in collaboration. The consumer members continued passionate discussions about the police paid off and enabled the creation of the police liaison position and constructive dialogue to occur between MSIC consumers and the police in and outside of meetings.

Through making a submission to the statutory review of MSIC, the group learned that their anxiety about time was unwarranted, because they submitted on time. In addition, members reached consensus about the questions for the survey that collected data for the review, even though some had differing views (e.g. about admitting young people and allowing clients to inject each other). Even though none of the consumers' recommendations to the statutory review was implemented, their involvement in the review showed them that they had a voice, and they are using it to transform MSIC service delivery.

The consumers were excited about the idea of the t-shirts as a way of promoting the group, but they took little part in its design. When the t-shirts were produced and handed out, enthusiasm dropped and the group became frustrated, because it was thought that the desired effect of wearing the t-shirts did not materialise fast enough. Nonetheless, the t-shirts gave the CAG members with a sense of pride and belonging, especially when they were worn in meetings with the police and while presenting at conferences.

The safer injecting workshops demonstrated that the consumers had considerable knowledge about safer injecting, but also provided them with new evidence-based information. The CAG had not considered that the existing MSIC prohibition on moving between booths meant that consumer members could only teach peers if they had registered in the same booth. To resolve this issue MSIC management are working towards having formally trained consumer volunteer positions.

## CHAPTER EIGHT: EVALUATION AND WITHDRAWAL STAGES

The previous chapter highlighted the CAG's achievements via four action research cycles. This chapter focuses on the project's evaluation, which comprised analysis of structured interviews and questions related to consumer participation in the 2016/17 MSIC client satisfaction survey. The chapter concludes with a discussion of my reflections and insights about my withdrawal from the PhD project. Figure 20 illustrates the 'evaluation and withdrawal' stage of the research process.

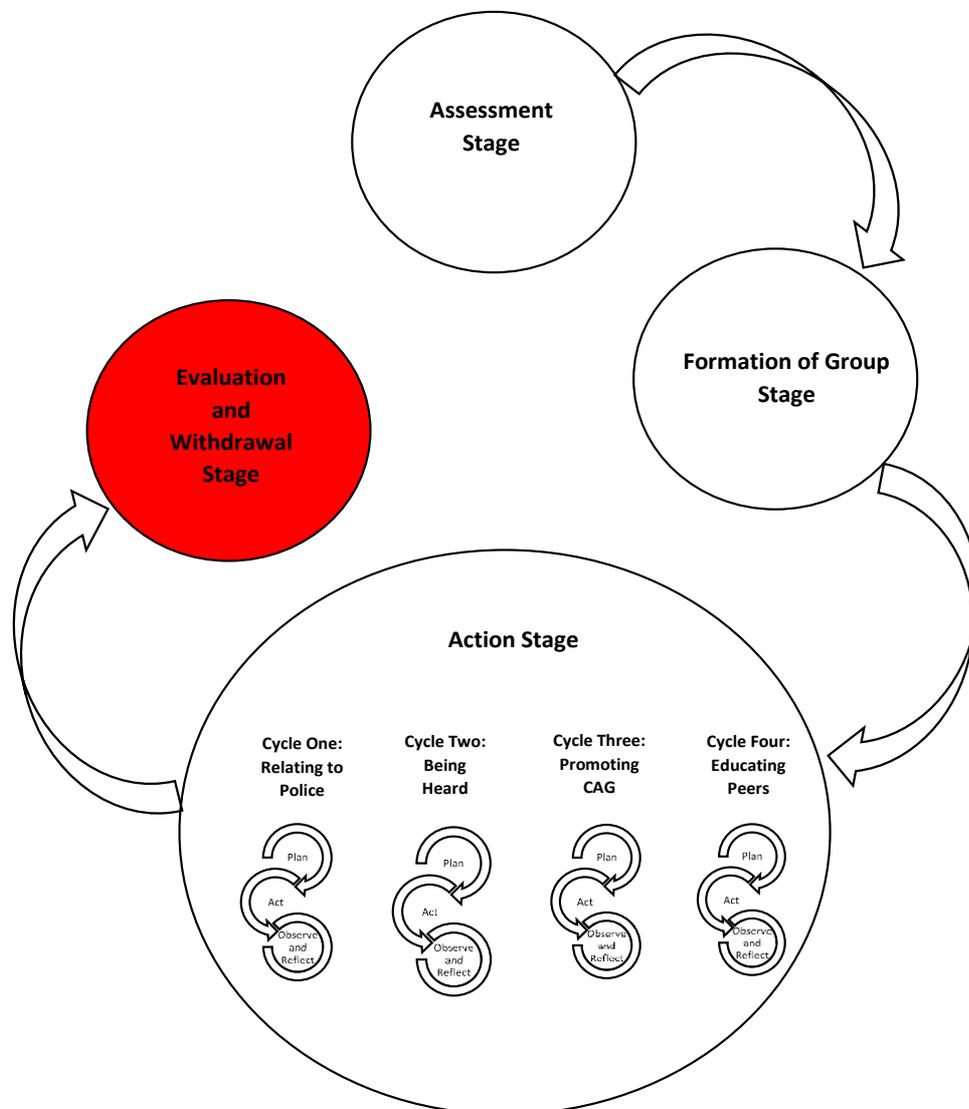


Figure 20. 'Evaluation and withdrawal' stage of research process

## Structured interviews

I interviewed nine CAG consumers (four woman and five men) and five CAG staff members (three woman and two men) and reflected on their experiences in the group and made suggestions on how it could improve. In addition, 10 MSIC staff (eight women and two men) who were not in the group were interviewed and discussed their knowledge of the group, their desire to join and made suggestions about improving the group. During analysis of the interview data, five themes emerged: views about achievements, group influence, provision of a consumer voice, group functioning and group improvement suggestions.

The interview schedule for the CAG members was as follows:

- How has the group helped MSIC's clients?
- What has the CAG achieved?
- How has the group helped you on a personal/professional level?
- What challenges have you experienced in the group?
- What are some barriers that have prevented the group achieving their goals?
- What suggestion do you have to improve the group?

The interview schedule was altered for staff members not in the group:

- How did you find out about the CAG?
- Are you aware what the CAG does and what they have achieved?
- Would you be interested in joining the CAG if a place becomes available and what are your reasons for joining or not joining?
- What suggestions do you have for improving the CAG?

## **Participant views about achievements**

The CAG achieved most of its goals: forming a group, the appointment of a police liaison officer for MSIC, engaging in safer injecting workshops, teaching peers to inject, and making a written submission to the MSIC statutory review.

### **Forming a group**

Five consumers and two CAG staff members thought that the formation of the CAG was the groups' biggest achievement. Their views were that the CAG represented the "*embryonic beginnings of a group*" (Sebastian, consumer), that had achieved its goals (Susan, CAG staff member), had direction (Barry, consumer), that had long-term keen members (Ellen, consumer), that had celebrated its first anniversary (Alice, CAG consumer) and that "*improves the service for everyone*" (Michael, CAG consumer). A CAG staff member with considerable experience of establishing consumer groups in drug and alcohol services felt that the CAG had developed efficiently and quickly (Andrew, CAG staff member). The CAG's rapid development was possible at least partly because MSIC management provided support and resources.

Interviewees also claimed that the consumer members had learned new skills, such as chairing meetings and writing minutes (Ellen, CAG consumer), presenting at conferences and advocating for other drug users (Andrew, CAG staff member), and "*processes to ensure that there is respectful conversation*" in meetings (Jane, non-CAG staff member).

### **Creation of the MSIC police liaison officer**

Seven consumers, five CAG staff members and six staff not in the group thought that the creation of the MSIC police liaison officer was the group's greatest achievement, because in the beginning few had hope that relationships with the police could be improved. MSIC staff described the establishment of the police liaison officer as "*massive*" (Monica, CAG staff member), "*the most exciting thing we have achieved*" (Arthur, CAG staff member), "*spectacular*" (Kylie, non-CAG staff member) and "*it's a big one, it's a tough one*" (Peter, non-CAG staff member). A consumer also commented how the role was a significant accomplishment, because it enabled a less convoluted way for MSIC consumers to make complaints about the police.

Three consumers and one CAG staff member said that the creation of this position had potential to improve relations between MSIC consumers and the local police. A

consumer said that the police had done little to improve relations with MSIC consumers over the past 15 years, but hoped the liaison officer would change this by educating other police, especially about their powers of discretion when searching MSIC consumers. Other consumers felt that the position was already having an impact, saying *“I hardly get searched at all anymore”* (Kevin, CAG consumer) and *“I used to get really harassed by the police here, and now it’s not so bad anymore”* (Paul, CAG consumer). A CAG staff member felt that the consumers’ respectful behaviour and communication in the meeting with the police liaison officer paved the way for relations to improve between the two groups.

In addition, participants highlighted one consumer’s additional efforts to improve relations with the police, as he promoted the CAG to the police on the street and educated MSIC consumers about the importance of engaging with the police in a respectful manner. He also represented MSIC consumers by attending a meeting with the police and MSIC’s executive management team.

*“Paul for example, has been a really good additive, you know. You know, like he’s done so much work with the police ... which is something I certainly wouldn’t want to do, so that’s good.”* (Ellen, CAG consumer)

*“Meeting with a local police member, and you know, for one member of the group being able to very eloquently and respectfully put their point of view across in a professional setting.”* (Jane, non-CAG staff member)

### **Safer injecting workshops and teaching peers to inject**

Five consumers, one CAG staff member and two staff members not in the group reported that the safer injecting workshop and consumers teaching their peers how to inject was one of the groups’ achievements. The consumers said that they had prior knowledge about safer injecting, but the workshops equipped them with new knowledge. The consumers reported that they learned new information about the risks associated with injecting and how filtering pill-based solutions before injecting them reduces occurrences of lung disease. They said they were keen to pass on this information to other MSIC consumers.

*“And I’ve told people, like things like, like taking care of swabbing and things like that, and yeah, stuff like that.”* (Robyn, CAG consumer)

*“I grabbed a couple of them [Steri filters], and I went straight back to my mate’s place and I said, “Hey, check these new filters out. You put them end of the syringe... .” (Michael, CAG consumer)*

*“... but since then I’ve been able to say to consumers, ‘This is how you do it...’ And felt more comfortable saying it to them because I’ve done the course and I’ve actually turned a couple of users onto [them]... One lady we were doing bingo and afterwards she said, ‘I want you to come and teach me how to filter because I’m having methadone...’ and all that. “ (Alice, CAG consumer)*

*“Like, this morning when I was sitting with a particular client showing him how to do a cold wash and explaining to him the benefits to doing a cold wash as opposed to a hot wash and because he’s got lung problems how it would dissipate his lung problems.” (Sebastian, CAG consumer)*

Monica, a CAG staff member, acknowledged the safer injecting workshops were *“really important”* for the consumers in the group. In addition, staff members outside of the group thought that the workshops were *“a great idea”* (Kylie, non-CAG staff member) and acknowledged that consumers are *“probably more likely to listen to another client than a staff member about safer injecting”* (Kim, non-CAG staff member).

### **MSIC statutory review**

Four consumers and one CAG staff member named the CAG’s submission to the MSIC statutory review as one of its achievements. Alice (consumer member) commented how she was *“over the moon”* about the CAG being involved in the statutory review, because changes in MSIC’s admission criteria and operating conditions affect the consumers greatly and it was important that their views on them were considered. She also commented that the consumers would be more likely to provide truthful responses to CAG consumers than MSIC staff when they administered the survey related to the review.

Interviewees revealed that the consumers were conflicted about some parts of the submission. A consumer said:

*“especially with the pregnancy one and the underage one, I was in two minds about that myself and there are pros and cons for both sides and all that kind of thing, but I do think that the age should be brought down to sixteen, but the*

*pregnancy one I'm in two minds about, it's a safe space to inject, but you're pregnant... I mean, they could go down a laneway, you know what I mean?"*  
(Alice, CAG consumer)

The consumer who administered the survey believed that it was not only about collecting responses but educating the consumers about the harm reduction benefits of allowing pregnant women and under-aged people to use the service. He said:

*"...once I explained what it was about... Because they look at that first question: Should pregnant women be allowed to access the service? And ninety-five per cent of people I spoke to said no. But once I explained the question to them, they changed their mind and said yes."* (Michael, CAG consumer)

## **Group influence**

The formation of the CAG influenced thinking, because it was the impetus for staff members to question MSIC's biomedical model and highlight how this model is incompatible with consumer empowerment. In addition, staff members questioned some of MSIC's existing procedures and protocols, because they believed these mechanisms decreased the consumers' engagement in participatory activities. Participants also reported that the CAG altered power differentials between consumers and staff, improved relationships between consumers and staff, improved relationships between the CAG consumers, influenced the consumers to make positive behavioural changes, and provided consumers with an alternative way to access information.

## **Questioning the biomedical model of care**

As in the interviews for the 'assessment' stage, three staff stated that MSIC's core business model – based on the biomedical model – was not compatible with consumer participation. A CAG staff member explained how MSIC was evolving and needed to adopt a core philosophy more aligned with consumer empowerment.

*"... yes people come here, people use drugs, some of them have low oxygen, we call it overdose, give them oxygen, but you know, to say that that's our core business? That was our core business fifteen years ago, today, everything else is more our core business, making people welcome, helping them to ask for help, to see the ways how to improve their lives, to do all these health promotions, art projects, you know, to help them feel something really good and*

*positive about themselves, about their lives, to understand what self-stigma is and to understand how to fight self-stigma, to understand that they are not scumbags of society, that is our role here.” (Susan, CAG staff member)*

### **Questioning existing procedure and protocols**

Some CAG staff members felt that MSIC’s admission and security procedures made it difficult for consumers to engage in CAG-related activities and that these procedures reinforced the notion that consumers are untrustworthy.

*“... you cannot let people in without injecting and then you have to invent certain rules or certain things to kind of, you know, skew that rule. Why is it so hard to let people come in and let people use computers and work on their tasks? You know, if MSIC is place where they around, they want to come in and do some work like Paul to do his artwork or whatever, posters that he’s doing for MSIC projects... Why we need to sit with that person? Why we need to have special permission? It is like, you know, we are really trying our best, we have all these values on the walls, but sometimes we are sending the wrong message, like we do not trust them, we have to monitor them, you know, all these security things, we have to open the door for them to go to the toilet.” (Susan, staff member)*

*“The internet, printers, staff members, management, the director, fucking everything. To me, what makes sense would be if they could come in any time they want, walk up through the mezzanine, to the staffroom, make themselves a cup of coffee in the staffroom, go and talk to the director.” (Andrew, CAG staff member)*

Despite the concerns reported above, the CAG began to use MSIC’s mezzanine level for meetings, a space previously considered off limits to consumers. The CAG using this space was considered problematic because it was allegedly “*going to cause ructions for some of the staff*”, due to altered power differentials between MSIC staff and consumers (Jane, non-CAG staff member).

### **Altering power differentials**

The CAG was portrayed as “*confronting to some staff*” because it involved “*ceding some of our own power*” (Jane, non-CAG staff member). Maybe this is why a consumer overheard some staff members saying, “*they didn’t see the point in the group and they*

*didn't see that anything would come from it and that it was just a whole waste of time*" (Alice, CAG consumer). Furthermore, clients providing *"advice to other clients is frowned on by some members of the staff"*. There were concerns about a CAG consumer exerting their power and preventing staff going home early by: *"deliberately staying for a rather long time in the evenings to make a point that actually we are still employed until ten pm"* (Kim, non-CAG staff member).

A CAG staff member stated his belief that the CAG had the potential to make staff more accountable. He said:

*"I think in a broader sense for staff members and management who aren't part of the group, to know that there is a group that has some theoretical or actual influence and say in what we do, there is a sense of being accountable. That, in my opinion, can and should be stronger, that sense of the CAG holding the other areas of the service accountable; so the clients hold us accountable for the decisions we make, and I think that's a good check and balance."* (Arthur, CAG staff member)

### **Improved relationships between consumers and staff members**

Both consumers and CAG staff members said that the CAG helped them to change their views of each other. Two of the consumers attributed the improvement in their relationships with staff members to the CAG. One consumer said that he formed a *"relationship and bond with certain staff members"* (Michael, consumer). Another described his view of staff before the CAG like *"just a person behind a bench that... you do your job and don't worry about what I'm doing or anything"*, but now this consumer describes staff as *"loving and embracing"* (Kevin, consumer).

A consumer said being a member of the CAG gave him some *"credibility"* that enabled him to *"close the gap somewhat between clients and staff"* (Sebastian, consumer). Some MSIC consumers felt that MSIC staff looked down on them because they come across as *"uppity' and look well dressed"*. He believed the consumers were *"misjudging"* these staff members because he felt they are *"not like that at all"*.

Most staff also felt that the CAG contributed to improved relationships between MSIC staff and consumers. Andrew (CAG staff member) said that through the CAG reducing power differentials at MSIC, consumers in the group had become more trusting of staff

and began asking them for more help (Susan, CAG staff member), and the CAG had enabled staff to see a softer side of the consumers.

*“And Kevin getting emotional when Barry came, that was a big eye-opener for me, I don’t think of Kevin as a dude that would ever cry in front of anyone else.”*  
(Kate, staff member)

Staff members who were not in the group confirmed that better therapeutic relationships were developing because attitudes towards the consumers were improving, even among staff who were considered distant.

*“I think there has been a general change here over the last year of attitude, and I think, slowly again, as staff kind of get used to new ideas, because change is hard for everyone, that the relationships are getting better between the clients and staff, and at the end of the day that’s about the best thing you could hope to achieve from a consumer group, I think. And I actually think this group has done it pretty damn quickly and that the staff here are more open to the idea of consumer participation.”* (Angela, non-CAG staff member)

*“There’s just [a] lot more humanistic relationships going on now between staff and clients, and staff who I think might have been a bit more standoffish a few years ago have, I’ve noticed, [been] developing their own relationships with certain people too.”* (Angela, non-CAG staff member)

*“It’s probably allowed staff as well to give the clients a little bit more respect and respect for their particular variety of knowledge.”* (Rachel, non-CAG staff member)

CAG staff members also felt that their improved relationships with consumers helped them on a professional level. A staff member reported that better relationship with the consumers had enabled him to improve his *“listening skills, be present, stay quiet and develop humility by acknowledging that I don’t know all the answers”* (Arthur, staff member). Other CAG staff members reported that the relationships they had developed with the CAG consumers helped them to *“increase my confidence”* and work with consumers in a *“pioneering and revolutionary way”* (Susan, CAG staff member) and work with consumers in a neutral space away from the clinical environment (Kate, CAG staff member).

Three of the staff members who were not in the group said that they were interested in joining the CAG to be more involved with the consumers (Melissa, non-CAG staff member), because consumer participation is *“an important way of improving the service”* (Angela, non-CAG staff member) and the meetings provide a *“different space to interact with consumers”* (Kylie, non-CAG staff member). The staff who were not interested in joining did not want to because, they said, *“I am an impatient person and consumer participation is a slow process”* (Rachel, non-CAG staff member), *“I don’t want to sit down there and talk to a bunch of ‘out of it’ people after work”* (Elizabeth, non-CAG staff member) and *“I would feel conflicted because of power dynamics and boundaries”*. Another staff member said he could not join because he was not rostered on Tuesdays, but if he was, he would like to join to:

*“see some kind of participation from the client group in what we do here, and you know, just hear what they have to say and try and make a change. I love that.”* (Rory non-CAG staff member)

### **Improved consumer relationships**

Certain consumers reported that the CAG influenced them to develop supportive friendships with each other. Michael stated the CAG helped him to strengthen the existing friendships he had in the group, make new friends and receive support when his 13-year-old daughter died. He also described the safer injecting workshops as a *“bonding experience for the group”*. Another consumer, Barry, said the CAG provided him with a *“support network of people”* which he could call on when needed.

Some of the socially isolated consumers reported that being a member of the CAG helped them to receive support and become more social. One of the quieter CAG consumers found it difficult to attend meetings, and said that the other consumers supported her by inquiring why she hadn’t attended and by encouraging her to attend the next meeting (Robyn, CAG consumer). Kevin said that the CAG had removed his *“sense of solitary confinement”* because it had helped him to build relationships with:

*clients in the group that I never even knew their names and now I’m inviting people over, you know, to home, you know, sit down, kick back. It’s just totally refreshed my whole opinion on life.*

## **Consumers' life improvements**

It was reported that the CAG may have promoted some of the consumers to change their behaviour, develop a more positive outlook on life, improve their health, become more motivated and interested in engaging with life beyond drugs, and having more confidence about be employed.

### ***Behaviour change***

The CAG did not set out to help consumer members to make behavioural changes, but the group did inadvertently help them to either reduce or completely cease using drugs or alcohol for the purpose of attending meetings. Alice said, *"just for us to not come fucked up in the beginning was a big step"*, and Kevin said he had stopped 'cocktailing' (taking multiple different drugs) because attending CAG meetings increased his self-respect. Paul said that he risked losing his place in the group because he attended several meetings drunk, and this motivated him to quit alcohol and receive treatment for hepatitis C. He said:

*"If it wasn't for the group and the fibroscan [scan for liver fibrosis] and all that, if it wasn't for that I'd still be drinking and I'd still have a fibroscan reading of probably twenty [indicates severe liver damage] by now".*

Barry said the CAG had helped him to develop qualities such as *"strength, courage and pride"*, to reunite with his family, and to detox from methadone, drugs and alcohol without the help of professionals. Another said that the CAG had given him hope of working in a drug and alcohol treatment service and made him see that he needed to reduce his drug use if he was going to achieve this (Michael).

### ***Positive outlook***

A staff member said that some of the consumers had used the CAG to *"springboard into different outlooks of life, or different outlooks of themselves"* (Arthur, CAG staff member). A CAG consumer was observed having *"a certain strength about him... in the way he carries himself"* (Rachel, non-CAG staff member) and a staff member noticed how the same consumer's self-esteem had improved significantly since he joined the CAG (Monica, CAG staff member).

### **Improved health**

There was a view that through *“understanding how to represent your community comes empowerment, and with empowerment comes amazing gains in terms of the consumers’ health outcomes”* (Andrew, CAG staff member). Monica (CAG staff member) commented on how healthy one of the consumers was looking since he had stopped drinking, and another reflected on how he was before he stopped:

*“we were collecting him from the street after days of drinking. He could not remember, you know, what was the day, how many days he was living in front of the MSIC; look at him now.”* (Susan, staff CAG member)

### **Increased motivation**

The group also influenced some consumers to become more motivated and more involved in their surroundings. A consumer said that the CAG gave her the:

*“incentive to, you know, get out of bed in the morning, put on my t-shirt, deal with depression, use less drugs on the day of the meeting and have a little bit more money.”* (Sally, CAG consumer)

Kevin (CAG consumer) mentioned how, prior to the group, he was never interested in MSIC’s notices or health promotion displays; since becoming part of the CAG he went out of his way to look at them.

### **Confidence about being employed**

Having a voice gave some of the consumers in the group a sense of belonging, purpose and empowerment (Arthur, CAG staff member), which led them to feel *“confident”* (Michael, CAG consumer), *“special, proud, not stupid and useful”* (Ellen, CAG consumer), have *“pride and courage”* (Barry, CAG consumer), and to see themselves as other than a *“dirty junkie, useless junkie”* (Jane, non- CAG staff member). This confidence and self-worth gave the consumers with hope that in the future they could volunteer or be employed in the drug and alcohol or community services industry. The following is a consumers’ account of how the group increased her confidence and planted a seed about working in the community service sector.

*“The fact that it was mentioned to me made me feel really special, you know, and it gave me something to think about; wow, I could be part of something. And from that moment, like, that grew and I’ve been so proud, I’ve told a lot of*

*people that, you know, I'm part of this project, you know? Because there hasn't been many things that I've been able to tell people I've been part of and that, you know, where I've got some sort of position of importance where people... You know, I can get something done, or where people listen to what I have to say and what the other members have to say, and then to be able to tell other addicts, 'Guess what? I work in MSIC where we all go to shoot up, so I can help us...' You know, it's a great feeling, and it's really... I want to do community, you know, community service work at some point in time." (Ellen, CAG consumer)*

Alice (consumer) reported that being a CAG member gave her focus and direction in her life; she was planning to volunteer for a drug user organisation and MSIC. She also stated her belief that her lived experience of drug use would enable her to help other drug users. Another consumer mentioned that he wanted to work in the drug and alcohol sector because he wanted to give back to the services that had helped him. He said:

*"for twenty-four years I've had access to these services, and I've used them, sometimes I've abused them, and this group is a doorway for me to be able to sort of, I guess right a few wrongs, but also give back to these services that helped me." (Michael, CAG consumer).*

One of the consumers had taken steps to activate his plan to work with homeless youth by enrolling in a Diploma of Community Service (Barry, CAG consumer), and several others were considering enrolling in courses.

### **Consumers providing harm reduction information**

The consumers and one staff member reported that the CAG created an alternative way for consumers to receive information about injecting techniques and the MSIC rules, which was useful because some MSIC consumers felt uncomfortable speaking with staff. Participants said some consumers preferred speaking to another consumer because:

*"it's probably something that's impregnated into our brains, you know, right down from going through school, schoolteachers and whatever, there's some sort of authority thing, and I think a lot of people still have a problem with." (Paul, CAG consumer)*

*“we’re ‘one of them’ and ‘we advocate for them’, in their words.” (Alice, CAG consumer)*

*“I think they feel they’re on equal ground, like they’re speaking to someone in the same boat as them.” (Michael, CAG consumer)*

*“they are quite happy that there’s people of our stature available to talk and communicate on a level that they feel comfortable.” (Kevin, CAG consumer)*

*“Where does somebody who injects drugs learn to inject drugs? From somebody else that injects drugs. So where should they get their education from to inject safely? From someone else who injects safely.” (Monica, CAG staff member)*

It was suggested that the CAG members were better placed than staff to inform the consumers of the rules, because they were more trusted and had more time available to provide advice.

*“So it gives people peers that they might trust more, if they’re not trusting of the staff ... it gives them someone else, an in-between that they can talk to.” (Kate, CAG staff member)*

*“And having to approach a staff member and say: ‘I don’t know how to do this, could you teach me?’ You know, they might feel like they’re going to be rejected or told no or... But with me they know that I’ll sit down and I’ll give them the time that they need and, you know, yeah... .” (Alice, CAG consumer)*

### **Provision of consumer voice**

The participants reported that the CAG gave MSIC consumers a voice that allowed them to formally contribute to service delivery and have a sense of service ownership, be regarded positively, be heard outside of MSIC, and have confidence to think about being employed in the future.

### ***Contributing to MSIC service delivery***

The CAG provided MSIC consumers with a voice that helped them to *“brainstorm, open up ideas to allow for a better service”* (Barry, CAG consumer). Consequently, a new formal process was created at MSIC that considered the consumers’ experience and *“broadens the scope of who is listened too”* (Arthur, CAG staff member). This new

process enabled the CAG consumers *“to really push their message”* (Andrew, CAG staff member) so their voice was heard by the MSIC management team (Michael, CAG consumer) and so that MSIC staff members were more conscious of the consumers’ voices (Susan, CAG staff member). Staff members who were not in the group valued MSIC consumers having a voice, because it helped them to be involved in the *“running of MSIC”* (Melissa), to suggest how *“we can do things better”* (Kim), *“to advocate for clients’ rights”* (Rory), *“to represent MSIC consumers”* (Rachel) and to become empowered through discussing issues that were important for them (Peter).

Two CAG staff members and two staff who were not in the group also reported that having a voice helped the consumers to develop an enhanced sense of ownership and responsibility for MSIC. A participant said:

*“we’ve known for a long time that the clients that come here have a sense of ownership over the place, but I think when, with the CAG existing and doing things like having the police there and doing the safer injecting workshop and inviting them to a training day, and then like letting them more into the inner circle of MSIC, gives them an even greater sense of ownership.”* (Monica, CAG staff member)

### ***Being regarded positively***

Because MSIC consumers are often stigmatised and socially marginalised, the CAG purposely developed a meeting environment in which the MSIC consumers’ experiences and voices were regarded positively.

*“It’s like, a place for them to drive their energies too, like an outlet for them to be able to use their experience as people who inject drugs, to be able to harness the positivity in that. To make... to turn it into a positive thing and for them to use the group as an outlet to be able to say: ‘Yes, I’ve got this experience, and I’ve got that to contribute to the group’.”* (Monica, CAG staff member)

*“It’s an opportunity to see and assess persons on a totally different level than just “a user”, their knowledge and their thought and opinion on where and what this place is doing and where it’s going.”* (Kevin, CAG consumer)

In addition, a consumer reported her peers were pleasantly surprised that she belonged to a committee in which her voice was respected. Her peers said: *“Wow, you*

*mean to say you're on some sort of committee? You know, like, where people want to listen to what you have to say?"* (Ellen, CAG consumer)

### ***Being heard outside of MSIC***

The MSIC consumer voice was also being heard outside of MSIC (Kate, CAG staff member), at conferences (Ellen, CAG consumer) and in the NSW parliament through the CAG's MSIC statutory review submission (Robyn, CAG consumer). A consumer reported that having a voice and speaking in public was *"enjoyable', but is also 'nerve-racking'"* (Paul, CAG consumer). This consumer said that he *"wants more practice with public speaking, so it will make him a better speaker"*.

Having a voice helped the CAG consumers' lives to improve, because it enabled them to develop a more positive outlook on life, improve their health and become more motivated and more interested in their surroundings.

## **Group functioning**

The factors that influenced the group's functioning were the interactions that occurred between the group members, time limitations, promotion of the group and its purpose, and the lifestyles of the consumer members.

### **Group dynamics**

Group dynamics are interactions that occur between group members that are influenced by members' behaviours, internal and expressed thoughts and feelings, nonverbal communication, relationships between group members and their past experiences. The dynamics that influenced the CAG's functioning included discourteous behaviour and group members' traumatic life events and mental health problems.

#### ***Discourteous behaviour***

CAG members became frustrated by the discourteous behaviour that occurred occasionally in meetings, and this made it difficult for quieter member to speak. Examples of this behaviour were members not listening, members interrupting others and members diverting from a meeting's agenda.

*"I think there's not a lot of listening going on sometimes. Even to oneself, I think that some people just talk, and that's sort of for no reason, or just to agree, or just*

*to vent. And I think that leads us off topic a lot of the time.”* (Arthur, CAG staff member)

*“So, you know, like, half an hour, forty minutes of the meeting has sort of been wasted because we’ve gone off track and started talking about something else.”* (Michael, CAG consumer)

*“They always speak first, and they’re always heard, other people might be feeling intimidated so the more that happens the less the other people who aren’t talking might be feeling less able to talk.”* (Monica, CAG staff member)

*“If I did try to talk someone would get answered before I would.”* (Robyn, CAG consumer)

Some MSIC staff group members believed that the discourteous behaviour in meetings resulted from the more vocal consumer members’ being more ‘talkative’ and having ‘dominating’ personalities. In addition, two MSIC non-CAG staff member heard that personality clashes occurred between some of the consumer members. It was also felt that discourteous behaviour occurred because of the consumer members’ lack of experience with participating in formalised meetings and their excitement about being involved in something new.

*“I think one of the tricky things with this group is that some of the members, or probably a number of the members find relating or cooperating in a group like that more difficult just because of lack of experience working in a group.”* (Peter, non-CAG staff member).

*“They, they’re excited by, you know, the challenges and the... probably for some of them doing something they’ve never done before, they get overly excited which makes them louder and harder to get them to hear those members of the group who are softly spoken or not moving at the same pace.”* (Sebastian, CAG consumer)

*“People never had the opportunity before to participate in something like this, to be in meeting and to be actually good listeners, to give each other space ... .”* (Susan, staff CAG member).

Kate (CAG staff member) felt that the staff in the group were more articulate and restrained than the consumers because of their prior experience and professional backgrounds. She also stressed that ill-mannered behaviour also occurs in meetings of health professionals.

A consumer member revealed she would “*just go quiet*” when louder members interrupted, but did not think they were disrespectful, “*as they don’t realise that I felt like that*” (Robyn, CAG consumer). A staff member in the group also pointed out that the more vocal consumers were not being malicious and felt that:

*“a negative or frustrating quality of any member, is totally outweighed by their enthusiasm and commitment and value, valuable insight, valuable experience, all positives outweigh the negative when we’re talking about individuals and also the group.”* (Arthur, CAG staff member)

Despite the concerns about occasional disrespectful behaviour, there was hope that with practice the consumers would eventually learn how to conduct themselves more professionally in meetings.

*“So, I think that is something that the guys will learn eventually.”* (Susan, CAG staff member)

*“One’s inability to sit with their thoughts and wait, and that’s a skill you can learn.”* (Arthur, CAG staff member)

*“The longer it works the more of a foundation there’ll be. Hopefully people just accumulate understanding and experience and knowledge.”* (Peter, non-CAG staff member)

*“The group is starting to learn about one another within the context of the group.”* (Sebastian, CAG consumer)

### ***Influence of past life events***

Four CAG members, including one staff member, felt that that the ramifications of consumer members’ traumatic life events and their mental health problems affected the way they interacted in meetings. For example, a consumer member who disliked the other consumers revealed that his animosity was not primarily related to his negative encounters with them, but because “*I can see the correlation between personality*

*types in this group and personality types that I've encountered in that dreadful childhood that I had to participate in*" (Sebastian, CAG consumer).

A consumer member also spoke during the evaluation interviews about how his 13-year-old daughter died from a heroin overdose and how his grief influenced his views about allowing underage people to access MSIC's services, despite the rest of the group voting differently.

*"I was so hurt, because of losing my daughter to heroin I knew it was the wrong answer, but because my daughter was so young, I guess I wasn't in the right mind to answer, but I snapped and said no."* (Michael, CAG consumer)

A staff member reported that being estranged from her son due to domestic violence motivated her to protect the quieter consumers in the group.

*"You know, some people are talking and others aren't, it's that protective thing – and I know, I have ruminated on this, that I'm a mother without her child and so my ability to mother has been robbed from me. Yeah. So I'm able to put that mothering instinct into working here and into the group."* (Monica, CAG staff member)

A consumer member disclosed that he nearly walked out of meetings a few times because of his mental health condition and difficulties with controlling anger.

*"I have bipolar and I've got some problems going on upstairs, so it depends on what mood I'm in. What upset me last week might not upset me another week, you know?"* (Paul, CAG consumer)

### **Time limitations**

The CAG members were concerned that meetings only occurred every three weeks for 90 minutes – *"there is a short amount of time with a long distance in between meetings to achieve its goals"* (Ellen, consumer). Anxiety about time led to concerns that too many ideas were discussed (Kevin, consumer) and that some were too ambitious and could not realistically be achieved by the group (Arthur, staff member). Therefore, the group needed to ground itself by *"prioritising realistic and achievable goals"* (Michael, CAG consumer).

There was frustration expressed about how some members wasted time by talking about personal problems and how this distracted the group from their goals (Ellen, CAG consumer). Frustration also produced worries that the group was not progressing because *“things aren't moving fast enough”* (Paul, CAG consumer) and *“we have good ideas, but they're not really getting achieved to their fullest extent”* (Ellen, CAG consumer).

CAG staff members disclosed that it was hard for them to commit to the CAG outside of meetings due to lack of time and resources.

*“Actually, I don't have the time or the resources to do that.”* (Arthur, CAG staff member)

*“From the staff contingent of it [the CAG], we've only got a certain amount of time in the day.”* (Monica, CAG staff member)

The follow-up interviews provided the CAG members with space to reflect on the group's achievements, and this changed some perspectives about the group's available time. Some felt that having three weeks between meetings was positive because it provided time to understand what happened in the last meeting (Kevin, CAG consumer) and think *“how can we improve on the things that we've spoken about?”* (Michael, CAG consumer). Members also discovered that three-weekly meetings did not prevent the CAG from achieving its goals (Paul, CAG consumer) and as time passed the group would be more likely to succeed, because they would have time to mature (Sebastian, CAG consumer).

### **Lifestyle of consumer members**

Participants reported that marginalised lifestyles (e.g. homelessness and unemployment), drug dependence and laws associated with illegal drug use challenged the functioning of the group.

#### ***Marginalised lifestyles***

Participants highlighted that the consumers' hard lives and lack of resources made it challenging for them to contribute to the CAG and to remember the day of the meeting.

*“You know, they’ve got to support their habit first, and or find housing and money and food and all these things, um, and deal with what’s out there, you know, it’s pretty volatile out there.”* (Monica, CAG staff member)

*“The lack of access to additional resources, especially amongst homeless members, or people without access to a printer or the internet or a computer, is going to be a physical, practical, resource constraint.”* (Jane, non-CAG staff member)

*“Yeah, we can’t even look after our children, our own hygiene at the worst of our goings-ons, so sometimes to actually even know that it’s Tuesday [day of the CAG meeting] is like quite amazing that some people sleep, you know, six days out of a week because they’re waiting on their pension cheque or something, you know.”* (Ellen, CAG consumer)

A non-CAG staff member had concerns that the group had a good chance of failing because of the consumers’ lifestyles.

*“I had a strong sense that the likelihood of its failing was not absolute, but it was more than fifty per cent. There was more of a chance of it failing than succeeding, in my personal viewpoint.”* (Jane, non-CAG staff member)

### ***Drug dependence***

Rachel (non-CAG staff member) felt that some of the consumer members were not fully committed to the group because of their dependence on drugs. Indeed, a consumer member spoke in the interview about how her strong compulsion to use drugs made it difficult for her to come to meetings sober.

*“Being a drug addict, even though, I mean, I don’t need... I don’t need... Because I’m on methadone, but... God, it’s like, when you’ve got it in your head, you won’t stop until you’ve got it, and I’ve never felt temptation or a feeling of will so strong for anything in all my life as I have the feeling... Like, a shot of something, drugs, it’s crazy, it’s... wow.”* (Sally, CAG consumer)

Sally also stated that she was not proud about coming to the safer injecting workshop intoxicated, because it impaired her ability to focus and learn.

*“Because if I’m going to be in the group then I need to know what was going on, and if I’m going to help other people, then I need to know what’s going on and me and being intoxicated in a group and not knowing what’s going on is not a very good, constructive member of the group, am I? No.”* (Sally, CAG consumer)

Interviewees felt that it was unrealistic to expect drug-dependent consumers to complete tasks outside meetings. A staff member reported that homework tasks set consumers up:

*“to fail because we always should have known that would be the bottom of their to do list for any given day, and that’s just the way, ah fuck, that’s the way my life is, you know. So yeah, just maybe we need to rethink setting tasks for people, what that actually means for them.”* (Angela, non-CAG staff member)

A member described being addicted to drugs as a full-time job and explained that’s why consumers members rarely engaged in homework tasks (Paul, CAG consumer). He also explained that recovering from an addiction was just as time-consuming and how it prevented him from working on the rights and responsibility cartoon booklet, a task allocated to him.

*“My last six months has been on, basically just on personal health, you know? Jeez, I lost and gained fifteen kilos in the last couple of months, and just that alone has been a fulltime job, trying to do weight.”* (Paul, CAG consumer)

One of the consumers did not see her and the other consumers’ drug dependence as a major challenge for of the group, as she described herself and most of the others as *“functioning addicts”* (Alice, CAG consumer).

### **Legal issues**

One staff member and three consumers in the group felt that the laws and penalties associated with illegal drug use were a major challenge for the group. A staff member noted that drug dependence was often criminalised in society instead of being treated as a health issue, and felt that MSIC consumers were at greater risk of being arrested than members of the general population because:

*“celebrities or politicians using drugs and that’s okay and then you have our poor guys living in the street and just because they are exposed, they don’t*

*have home to hide and use [drugs] within their homes, police is just, you know, catching them, hunting them, filling for numbers.”* (Susan, CAG staff member)

Two members missed CAG meetings because they were incarcerated for drug-related offences. One member reported that she was worried she would be expelled from the group because she was in jail, and this made her feel upset and depressed, and being in jail prevented her from *“doing the things that I was meant to be doing, like the bag thing, I couldn’t finish that, you know”* (Alice, CAG consumer). The other consumer also missed groups on release from prison, because her bail conditions stipulated that she had to reside outside of Sydney and missing groups made her feel ‘upset’ (Ellen, CAG consumer).

Barry (consumer) reported that his main challenge was the thought of having to meet with the police face to face. This was because he had numerous negative encounters with the police through being a long-term homeless drug user.

### **Promotion of group and its purpose**

One of the CAG’s biggest challenges was to promote its purpose to the other MSIC consumers. Sebastian (CAG consumer) felt that the CAG was not *“visible”* and that the t-shirts were not helpful in promoting the group. Paul (CAG consumer) reported that he did not wear his t-shirt much and was confused about when he was supposed to wear it. He thought that the t-shirt was to be worn on special events, not when he was using the service to inject. He also mentioned that he was no longer using MSIC regularly, because he was being prescribed methadone. Kate (CAG staff member) said that she had only one conversation with a consumer wearing the t-shirt, and Monica (CAG staff member) could not recall discussions in meetings about the t-shirts after they were distributed.

Consumers and staff in the group believed that the consumers outside of the CAG became jealous and paranoid because they were unaware of the CAG’s purpose and they thought consumers in the group were perceived as ‘special’. Three consumer members reported that some consumers outside of the group were unhappy because the CAG consumers were ‘paid \$40, ate pizza and received a t-shirt’.

All of the staff outside the group said that they had found out about the CAG through conversations with me, emails or presentations at the staff training day. One staff member was concerned because she felt that the CAG was only benefiting a small

number of MSIC consumers. Another (Rachel) was worried about whether some CAG consumers could promote the group effectively, because she witnessed one speak in a *“derogatory and insulting way”* to another consumer. She also felt that some members did not have the right *“attitude”* to promote the group, because they were *“pretending to do stuff”* and *“not pulling their weight”*.

## **Group improvement suggestions**

Interviewees suggested the CAG could improve by expanding participatory opportunities for consumers, improving mechanisms to promote the group, and providing training for the consumer members. They also suggested ways of improving group dynamics. Some polarised views were expressed about the group’s rules.

### **Expanding consumer participatory opportunities**

Participants suggested that consumer participation at MSIC should expand by having a consumer coordinate the CAG, creating volunteer positions, and establishing better connections with organisations outside of MSIC.

#### ***Consumer coordinating the CAG***

One consumer and two staff members in the group proposed that as the group became more established, I should pass my position as the CAG facilitator to a MSIC consumer. Their argument was that *“there comes a point in time where you need to step out”* because the consumers *“are representatives of the rest of the clientele and they need to step up and they need to take your place”* (Andrew, CAG staff member). It was also suggested that the consumer facilitator should attend MSIC management meetings to represent the CAG, but initially they needed:

*“one of the staff members who is sitting on the CAG to come along with that person as a support to be able to express what the CAG says in the case that the representative gets scared, because it’s really high-level stuff.”* (Andrew, CAG staff member)

#### ***Volunteer positions***

Three of the consumers suggested that consumer participation at MSIC should be expanded through consumer volunteer positions. It was suggested that a volunteering roster should be created to allow consumer CAG members to help staff in stages one and two (Paul, CAG consumer). It was also suggested that consumers volunteer their

time on the streets of Kings Cross by helping the homeless and responding to overdoses because emergency services are usually slow to respond (Barry, CAG consumer).

### ***Better connections with other organisations***

Jane (non-CAG staff member) suggested that the CAG should have more *“interaction and sense of shared connectedness”* with peer organisations such as NUAA, AIVL and Hepatitis NSW, and with the peer workers at Insite (the supervised injecting centre in Vancouver, Canada).

### **Better promotion of the group**

Interviewees suggested that the CAG requires better mechanisms to promote itself *“so that people know what we’re there for all the consumers, and we’re a conduit between them and the staff”* (Sebastian, CAG consumer). In addition, promotion of the group would allow it to be less of *“a secret society for the privileged few”* (Kate, CAG staff member).

Interviewees suggested the CAG members should:

- wear their t-shirts more consistently (Paul, CAG consumer);
- create flyers that explain the purpose of the CAG (Kevin, CAG consumer);
- display photos of the CAG members, so MSIC consumers know who is representing them (Sebastian, CAG consumer),
- be more proactive by actively communicating the benefits of the CAG to consumers not in the group (Angela, non-CAG staff member) and stress that the group represents their voice and *“feeds their ideas to management”* (Andrew, CAG staff member);
- make CAG minutes available to MSIC staff (Kylie, non-CAG staff member) and;

- have a CAG launch week in stage three consisting of posters, food, music and group members available to answer questions about the CAG (Kate, CAG staff member).

To decrease the mystery and sense of exclusiveness about the CAG, interview participants also suggested that consumers who were not in the group should be invited to meetings. Kevin (CAG consumer) said that he would *“love to see the group to take on more members”*, and Robyn (CAG consumer) felt that the CAG needed a bigger meeting space, so more people could attend meetings. It was also suggested that consumers who are not in the group should be invited to meetings, so they could see how things work (Monica, CAG staff member) and that membership be for a limited term so more MSIC consumers have the opportunity to represent their peers (Jane, non-CAG staff member).

### **Training for consumers**

Participants suggested that the CAG consumers engage in training on how meetings are conducted and advocating for PWID and the issues that affect them. Training about meetings would equip the CAG consumers with knowledge and skills that would enable them to partake effectively in formalised meetings (Angela, non-CAG staff member). Peter (non-CAG staff member) argued that advocacy training would provide members with a *“common sense of purpose that we’re here to represent our folk”* and create a sense of social justice. Susan (CAG staff member) added that advocacy training has the potential to improve group dynamics, because members would become more focused on MSIC consumers as a group instead of their own personal issues. It was also suggested that CAG members attend harm minimisation and law reform conferences to become more politically aware of issues that impact on PWID (Alice, CAG consumer). It was recommended that this training should be provided by a peer group such as NUAA, because the trainer would have a lived experience of injecting drugs (Andrew, CAG staff member).

### **Suggestions to improve group dynamics**

Interviewees told me that members needed to stop talking over each other, staff need to model the chairing role, the quieter consumers need to speak up more, and that there were highly polarised views about the group’s rules. Two consumers also suggested that they needed to be more vocal in groups so that their voice was heard and they could take more ownership of their feelings. A staff member contended that

staff in the group need to chair more so they can role model the role and how to behave appropriately in meetings (Monica, CAG staff member).

It was suggested that the talking stick should be brought back, because consumers were still interrupting others while they were talking (Michael, consumer); and Kate (CAG staff member) suggested members should:

*“put their hands up, and possibly go around the circle, I think would be really good. Because that’s another frustration, when it’s just the same people talking, and they have great points, but the quieter ones don’t always feel confident to put their hands up).”*

Views about the group’s rules were polarised. A member thought that being expelled from the CAG only after coming to meetings intoxicated three times was too lenient, and argued that members should get only one let-off because *“it hurts me when people turn up intoxicated and don’t contribute but still get paid and get to eat pizza”* (Michael, CAG consumer). On the other hand, another member believed that the group needed to be flexible with the rules, because if they were too strict with *“the three chances rule, you know, Robyn and Sally would be gone”* (Susan, CAG staff member).

## **2016/17 MSIC client satisfaction survey**

One hundred MSIC consumers (29 woman, 70 men and one transgender consumer) responded to the survey. They commented about their opportunities to provide feedback, MSIC’s suggestion forms, MSIC’s complaints procedure, their awareness of the CAG and their interest in joining. The proportions of valid responses to questions in the survey ranged from 91% to 99%.

### **Opportunities for feedback**

Of the 99 survey respondents who gave a valid answer to the question about how often they are consulted about how MSIC could improve, 32% reported that they were never asked, while 17% considered that they were rarely asked. In contrast, 32% reported being sometimes asked, and 16% perceived that they were often asked. Some respondents shared suggestions for service improvement.

*“Let in pregnant and intoxicated people – we shouldn’t refuse people.”*

*“If the Centre didn’t have to deal with so much bureaucracy, they could spend more time doing their real job.”*

On the other hand, some respondents stated that they had no suggestions to improve MSIC because they are happy with it the way it is.

*“If it ain’t broke, why fix it.”*

*“All good in the hood.”*

A substantial number of respondents wrote about how staff often engage them in conversation to obtain their ideas on how the service can improve. Below are two of the responses.

*“Staff are good at engaging you in a conversation to get your ideas.”*

*“The staff ask me questions on the service can improve all the time.”*

Respondents also wrote that there should be more opportunities to express their opinions via surveys and the suggestion box, but some requested that surveys should be shorter in length.

*“Maybe a shorter survey haha. 14 pages Really?”*

## **MSIC consumer suggestion forms**

A total of 98 respondents provided a valid response regarding MSIC suggestion forms: 39% stated that they had completed a suggestion form, 56% stated they had not completed a MSIC suggestion form, and 5% were unsure. Forty-two respondents provided a valid answer regarding receiving a response to their suggestion: 24 (56%) stated that they did not receive a response, and 14 (33%) stated they received a response to their suggestion. Twenty-four respondents (56%) felt their suggestions had been taken seriously. Twenty-four respondents provided written responses; just under half wrote they were uncertain if their suggestion was taken seriously or if it was received, or that they were dissatisfied with the response to their suggestion.

*“I hope my suggestion was taken seriously.”*

*“It would be good if I got a response.”*

*“I suggested that we should be able to watch TV in Stage 3 and was told it was only for training, I am homeless and don’t have a TV. I was not happy with this response.”*

Positive comments include:

*“Totally Stoked!”*

*“Everything is suited to a user’s need.”*

There was also some feedback suggesting that the suggestion box was poorly located, and that its sign needs to be larger so it can be seen.

## **Consumer complaints**

Of the 98 respondents who provided a valid answer when asked if they had ever made a complaint about MSIC service, 86% had not and 14% had. Seventeen respondents provided a valid response regarding receiving feedback, of whom 47% had received a response and 53% did not. The 14 respondents who reported making a complaint were asked if they felt their complaint was taken seriously: 53% reported that it was taken seriously, 35% did not, and 12% didn’t know or were unsure.

Ten respondents provided written responses; they mostly felt that their complaint was not taken seriously or that making a complaint did not bring about change.

*“Would like someone to speak to that is able to make things change. Because just putting a paper in a box feels like it isn’t getting anywhere. Would like to have a chat with someone in charge and feel suggestion is really taken into account.”*

On the other hand, a few respondents were happy with the way their complaint was handled.

*“They took my complaint seriously.”*

## **Awareness of the CAG**

Forty-four per cent of respondents said they were aware of MSIC’s CAG; 55% were not aware and 1% said they were unsure. Thirty-seven provided written feedback and 18 wrote that the purpose of the group was to make service improvements through MSIC

consumers' voices and ideas. However, only 13 of these responses came from those who were not in the group; five respondents noted they were CAG members. Six other respondents wrote that they knew about the group because they knew a member. The following written responses highlight awareness of the CAG's purpose and achievements.

*"It is a group that puts the client's view across and they have connections with the police."*

*"They sit down and ask consumers how the place can improve. They have done a safer injecting course. If I have any questions about the place I can ask."*

Fourteen respondents reported knowing that the CAG existed, but were unsure of its purpose.

*"I know about them, but not sure what they do."*

## **Interest in joining the CAG**

Of 91 respondents who answered validly, 66% stated they would be interested in joining the CAG. Seventy-five per cent provided written responses about why they would or would not like to join. Most wrote that they would be interested in joining because it could help them, others or MSIC, and that their lived experience would enhance their ability to help other MSIC consumers. Many of the respondents wrote how their lived experience of injecting drugs and use of harm reduction and drug treatment services would make them effective CAG members.

*"I have the ability to listen, understand and communicate with PWID. I also have an insight into their backgrounds, because of my troubled upbringing and can feel what they have been through. The clients enjoy talking to me."*

Respondents wrote that being a CAG member could provide them with a purpose, help them do something other than inject drugs, learn something new and communicate better. On the other hand, respondents also noted that being in the group could help them advocate for others, decrease stigma, save lives and *'make the community safer for everyone including my family and friends'*. Many also wrote that their ideas, views and feedback could help make MSIC a better place.

Others, however, wrote that they were not interested or able to be a CAG member, because they lived too far away, were going into drug treatment, had multiple health problems, would get bored and *'because I get frustrated. I was asked by NUAA to be an advocate for homeless youth, but I think I would lose it because I would get too angry'*.

## **Withdrawal from the project**

I decided to resign from my full-time position as MSIC's mental health coordinator so I could devote more time to my thesis. After I resigned, I joined MSIC's casual pool and worked two days a week in service provision as a registered nurse.

The group felt that a staff member should facilitate the group when I resign. Therefore, a proposal for a one-day-a-week CAG coordinator position was written and submitted to MSIC management for consideration. The proposal was rejected because MSIC management decided that the position should be given to the new mental health coordinator (my replacement). At first, I had reservations about this decision, because I thought a CAG staff member who knew the workings of the group and showed dedication to the consumer members should fill the position. Nevertheless, I quickly changed my mind because I realised one day a week would not be enough time to adequately support the CAG consumers.

The above realisation materialised after I resigned and tried to make several appointments with a CAG consumer to work on an oral presentation that we were jointly delivering at a conference. The consumer never arrived at any of the five appointments I arranged, and this caused frustration for both of us – for me because the meetings were in my own time, and for the consumer because I arranged for another consumer to speak in their place. Therefore, I acknowledged the new mental health coordinator was the best person to lead the CAG because she worked full-time and had the flexibility in her role to see consumers spontaneously, without appointments. I remembered that when I was working in the role I was able to support the CAG consumers easily, without appointments, when they required support or needed help with CAG-related tasks. I also realised that my initial expectation that the CAG consumers commit to tasks or appointments outside of meetings was fruitless, because they were substance dependent, and relieving withdrawal and emotional pain was often their first priority; this realisation and acting on it helped the project succeed.

I was fearful that the CAG might stop functioning without me, which would have been a waste due to the large amount of time and effort that I and others had contributed. Fortunately, the CAG did not end with my resignation. Rather, it was strengthened by the establishment of terms of reference and norms that were facilitated by the new coordinator, who was able to support the group as needed five days a week.

## Conclusions

This evaluation provides evidence that when marginalised people such as MSIC consumers are supported by staff they can successfully develop a group that positively influences service delivery and planning. Being members of the CAG helped the consumers to be heard, create more enriching and meaningful friendships, reduce or cease drug and alcohol use, address health problems, and gain hope of future employment. This evaluation also highlights that consumers' active involvement in service delivery and planning has the potential to lessen power differentials between consumers and staff. In addition, consumers being educated about safer injecting creates an alternative pathway of providing information to consumers who are reluctant to engage with staff about this matter.

The evaluation highlighted that MSIC's biomedical model of care and security procedures constrained the CAG. MSIC's current biomedical model of service delivery and security procedures encourages the power divide between consumers and staff and reinforces the notion that PWID are untrustworthy. Consumers' substance dependence, marginalised lifestyles, traumatic histories, mental health problems and contact with law enforcement were other factors that constrained consumers' participation. However, these factors did not totally preclude consumers' involvement, because staff support enabled their participation.

This evaluation suggests that consumer participation at MSIC can be improved by having more people with a lived experience of injecting drug use contributing to service delivery. Interviewees suggested having a person with a lived experience of injecting drugs facilitate the CAG and the creation of MSIC consumer volunteer positions. The suggestion that MSIC build better connections with drug user organisations also has merit, as this will help consumers learn more skills in service delivery and advocacy for PWID.

The results of the MSIC client satisfaction survey provides evidence that most MSIC consumers are interested in being involved in contributing to service delivery. The consumers' reasons for joining the CAG were mostly altruistic: they wanted to help others, their community and make MSIC a better place.

# CHAPTER NINE: DISCUSSION

## Introduction

I investigated how the process of forming a consumer group influenced active consumer participation in service planning and delivery at MSIC. My research answered the following questions:

- At what level of consumer participation were MSIC service providers and consumers engaged, before, during and at the end of the project and what was their understanding of consumer participation over this time?
- What processes were involved in the development of objectives and action plans to implement consumer participation at MSIC?
- How did consumer participation affect consumer–staff relationships?
- What factors facilitated and constrained consumer participation at MSIC?

The results of this study indicate that highly marginalised people such as MSIC consumers can actively participate in service delivery and planning to realise the health and social benefits of consumer participation, as reported elsewhere (Patterson, Weaver, Agath, Rutter, et al. 2009; Tober et al. 2013; Van Hout & McElrath 2012). Throughout the project, the majority of participatory activities were at the lower levels of the consumer participation ladder. Nevertheless, this study demonstrated that participatory activities, even at lower levels, can help to positively shape service delivery and consumer outcomes. The formation of the MSIC CAG enabled consumers and staff to work in a partnership that reduced power differentials and enabled them to appreciate each other's humanity. Empowering consumers through active participation thus facilitated a transformation in their relationships with service providers.

Consumer participation at MSIC was enhanced by the creation of a CAG. The group developed objectives and action plans in an egalitarian manner and helped consumers to represent their peers and actively contribute to MSIC service delivery. These processes empowered consumers by providing a space for their voices to be heard and CAG staff members to role model the skills and behaviour required for formalised

meetings to run effectively. This assisted individual consumers to realise their strengths and the group to achieve its goals.

As with any change process, several forces either facilitated the success of the enhanced consumer participation at MSIC or constrained the process. Figure 21 is a force field analysis that depicts the facilitating and constraining forces for change that were evident during this project. The force field analysis is a change management tool developed by Kurt Lewin, one of the modern pioneers of social and organisational psychology; it aids in understanding change processes and highlights the driving forces that assist or hinder change (Institute for Manufacturing 2016). As depicted in Figure 21, there were more and stronger forces that facilitated the process of enhanced consumer participation than those constraining it.

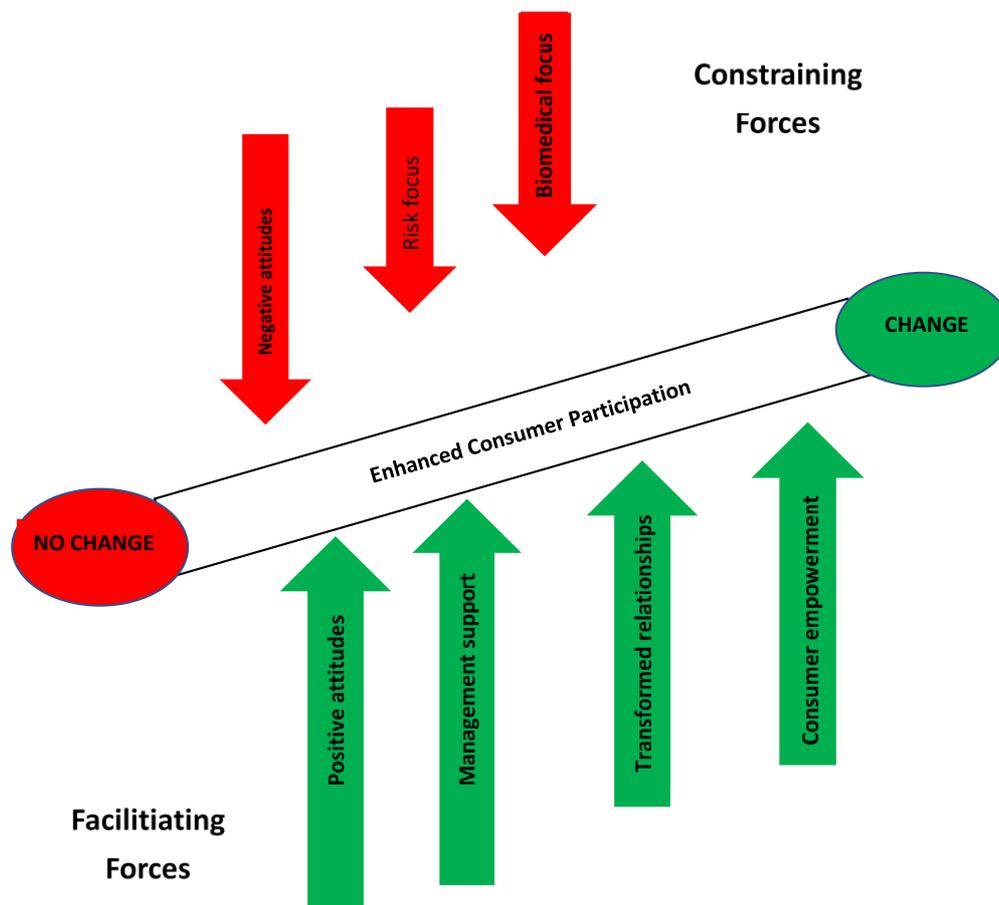


Figure 21. Forces affecting consumer participation

## **Facilitating forces**

The forces that facilitated change at MSIC were the positive attitudes of MSIC staff towards consumer participation, management support, transformed relationships and consumer empowerment. These forces were strong enough to drive the change in consumer participation. They are discussed in turn below.

### **Positive attitudes**

The positive attitudes of staff and consumers concerning the involvement of MSIC consumers in service delivery was a key factor that contributed to the success of the CAG. At the outset and throughout the study, the majority of MSIC consumers and staff held positive attitudes about consumer participation. They expressed views that improved consumer participation and would enrich MSIC consumers' lives; they believed that consumers would learn new skills, gain education and employment opportunities, feel less judged and improve their self-esteem. In addition, staff and consumers perceived that their participation would create a service that was more relevant to consumer needs. Optimistic attitudes such as these have been shown to foster consumers' involvement in service delivery (Greer et al. 2016; King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Patterson, Weaver & Crawford 2010; Rance & Treloar 2015; Tober et al. 2013; Van Hout & McElrath 2012).

The positive attitudes of MSIC staff towards consumer participation align with reports that describe staff who work in harm reduction services as less paternalistic or authoritarian than those who work in mainstream drug treatment health settings (Leppo & Perala 2009). The MSIC philosophy is based on reducing the harm associated with injecting drug use through the provision of compassionate and practical health care (Uniting 2018). At MSIC, health care providers are encouraged to connect with and welcome consumers in a non-judgemental, person-centred way through holistic support, dignity and respect. Thus, the positive attitudes of staff were a facilitating force of considerable strength.

This finding contrasts with evidence from other research that describes providers who believe that consumers lack the capacity, interest and skill to actively participate, especially in relation to higher levels of service involvement (Bryant et al. 2008a;

Patterson, Weaver, Agath, Albert, et al. 2009; Schulte et al. 2007; Van Hout & McElrath 2012). Other research reports providers in drug treatment services stating that the chaotic lifestyles of consumers reduce their capacity to participate in service delivery and planning, rendering consumer participation a challenging endeavour that they were unlikely to pursue (Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver & Crawford 2010; Treloar et al. 2011; Van Hout & McElrath 2012). These attitudes prevail in drug treatment services, despite providers also reporting (contradictorily) that they are supportive of the notion of consumer participation (Greer et al. 2016; King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Patterson, Weaver & Crawford 2010; Rance & Treloar 2015; Tober et al. 2013; Van Hout & McElrath 2012). Therefore, while provider support for consumer participation is necessary, alone it is insufficient to alter the pessimistic attitudes of all providers.

The MSIC consumers in this study were not as confident as staff about their ability to effectively participate in the CAG, as they felt that their drug dependence and chaotic lifestyles would decrease their ability to influence service delivery. They expressed the view that effective participation would require taking control of their drug use, or at least stabilisation on methadone. This is consistent with evidence from other research that consumers often report lacking confidence in their involvement in drug treatment service delivery because they perceive that they do not have the required skills, stability, interest, confidence and are not entitled to participate (King 2011; Treloar et al. 2011).

The success of the CAG was not only fuelled by the optimism that service providers and consumers expressed concerning consumer participation but supported by the response of the management at MSIC. This support was a vital organisational factor that influenced the success of the project and is reflective of the philosophy enshrined in the MSIC service. Nonetheless, other organisational factors – such as security procedures and biomedically focused care – constrained the project at times, and these factors are discussed later.

## **Management support**

Organisational factors have been shown to be essential to the success of consumers contributing to service delivery. These factors include adequate dedication of time (Patterson, Weaver, Agath, Rutter, et al. 2009), the provision of travel expenses and

peer support (Greer et al. 2016), and training regarding service structure, processes and formal meeting procedures such as agendas, chairing meetings and minute taking (Patterson, Weaver, Agath, Albert, et al. 2009). In addition, evidence indicates that groups such as the CAG work well when they have well-defined communication pathways with management, because this enables expectations to be clearly articulated and consumers to receive feedback about their requests and ideas (Patterson, Weaver & Crawford 2010).

In this study, service support for and commitment to consumer participation was demonstrated by improvements in the way management responded to consumers' complaints and suggestions. These changes were initiated in response to the findings of the consumer satisfaction survey that indicated that many consumers did not receive a response to their complaints. As a result, staff created a poster that was displayed on a notice board in stage three outlining management's responses to consumer complaints and suggestions. This exemplified the support from management that was evident throughout the study.

In addition, MSIC management support facilitated the success of the CAG by approving most of the group's objectives and providing the funds to pay consumers \$40 to attend each meeting, for refreshments, the production of the t-shirts, and fees for CAG consumers and staff to attend a conference. The commitment of financial resources is noteworthy, because this provides tangible proof of the extent of management support, especially because fiscal constraints are often considerable in health care service delivery. Managers at MSIC also committed to continue funding the group once the formal aspect of my research concluded. Like staff attitudes, management support for the project was a facilitating force of considerable strength.

Compared to reports in the literature, the level of organisational support for consumer participation demonstrated in this study was unusually high. Previous studies report that participatory endeavours were hindered by a lack of capacity and commitment from drug treatment organisations to support consumer engagement. This evidence indicates that many drug treatment services and harm reduction services do not consider consumer participation as core business (Greer et al. 2016; Treloar et al. 2011) and many services lack drive when it comes to consumer participation (King 2011). Other organisational priorities and time constraints often impede participatory projects (Patterson, Weaver, Agath, Rutter, et al. 2009), so insufficient financial and

human resources are allocated to them (King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Schulte et al. 2007; Treloar et al. 2011; Van Hout & McElrath 2012). In addition, projects are often disrupted by staff turnover and deficient handovers (Greer et al. 2016; Treloar et al. 2011).

## **Transformed relationships**

MSIC management's high level of support for this project facilitated the transformation of staff–consumer relationships during this project. Evidence indicates that consumer involvement in drug treatment service delivery enhances staff–consumer relationships through the alteration of power differentials (King 2011; Patterson, Weaver, Agath, Albert, et al. 2009; Rance & Treloar 2015). The CAG improved the relationship between MSIC consumers and staff by creating a supportive and egalitarian meeting environment. Because the CAG was governed by PAR principles, CAG staff members and I relinquished our professional power so that consumers could control the conditions and the direction of the group. As a result, the CAG members determined the group's philosophy, aims and objectives. The members also decided on group formalities such as terms of reference, group norms, chairing, meeting reminders, minute taking, the meeting location, voting procedures, homework, and communication with management. Meetings lessened the unequal power dynamic between staff and consumers that usually occurs in clinical environments, thus allowing the two groups to bond in a neutral and relaxed space.

This project helped the CAG consumers and staff to change their views of each other. A consumer said he was able to see staff beyond a person sitting at a bench, a staff member said she was able to see the consumers' softer sides, and staff reported that the consumers became more trusting of them. Another CAG consumer said that the group enabled him to close the gap between MSIC consumers and staff, because he was able to convince consumers that not all staff were 'uppity'. The consumers who presented at the staff training day also helped MSIC staff to hear their perspectives on service delivery. Staff in the group reported that the CAG helped them to improve their relationships with consumers, because membership improved their listening skills, made them humbler, and increased their confidence to work with consumers. Studies in drug treatment settings have reported that consumer participation initiatives have decreased the distance between consumers and staff, reduced the stigmatisation of consumers, helped consumers and staff to discover each other's humanistic qualities,

and assisted consumers and staff to find common ground (Patterson, Weaver, Agath, Albert, et al. 2009; Rance & Treloar 2015; Tober et al. 2013).

Consumer presentations of CAG endeavours and achievements at MSIC staff training days also affected the attitudes of providers who felt threatened by consumer participation. The CAG consumers felt it was important to educate staff about their lived experience, humanity and innate strengths. Consumer led information and education has been shown to help providers improve their relationship with consumers, decrease their stigmatising views of them and improve health professional confidence of their caring role (Roussy et al. 2015).

## **Consumer empowerment**

This project empowered MSIC consumers, because it provided them with a voice to effectively articulate service delivery issues that they regarded as important and work towards addressing them. This, in turn, created more equal and humanistic relationships between consumers, MSIC staff, and the local police. The type of empowerment the CAG consumers acquired can be described as psychological empowerment. Psychological empowerment differs from an individual's sense of confidence, because it relates to active engagement in one's community and an understanding of the socio-political environment (Zimmerman 1995). Greater participation in community and organisational activities fosters psychological empowerment (Zimmerman & Rappaport 1988), and participatory strategies that help empower disadvantaged people have been associated with improved health outcomes and decreased health disparities (Wallerstein 2006).

Johnson's model of health care empowerment (Figure 1) is useful for explaining how the CAG consumers became empowered. Through the CAG, the consumers developed a collective voice that challenged society's stigmatising views of PWID and helped them to realise their inner strengths. This voice enabled the consumers to have access to and develop personal resources such as improved communication and problem-solving skills, social support and increased control over substance and alcohol use. Consequently, the consumers acquire hope for a better life, which allowed them to become more engaged, committed, informed and empowered MSIC consumers. Overall, having a voice helped the consumers to become more aware of and actively involved in issues that are important to their community.

## **Constraining forces**

Despite the CAG receiving tangible support from MSIC management and staff that allowed them to improve relations with the police, there were organisational features that constrained consumers' involvement in service delivery: negative staff attitudes, a focus on risk, and biomedically focused care. While evident, these forces were not strong enough to impede enhanced consumer participation.

### **Negative attitudes**

Some MSIC staff found this project confronting because it had the potential to make them more accountable or would undermine their power. There were also concerns about consumers providing advice to each other, as this was seen as a key role of professional staff. Staff were concerned that consumer participation may involve consumers rating their performance; some saw this as inappropriate, and others feared poor appraisals. Evidence indicates that drug treatment providers feel threatened by consumer involvement in service delivery, because they lack trust in consumers, and they fear that their professional authority might be weakened (Leppo & Perala 2009; Patterson, Weaver, Agath, Albert, et al. 2009; Rance & Treloar 2015; Treloar et al. 2011). In addition, some staff purposely avoided interpersonal contact with consumers, behaviour that is not conducive to consumer participation and empowerment.

### **Risk focus**

Drug and alcohol services "are framed by an environment that is strongly risk averse" (The Royal Australian and New Zealand College of Psychiatrists 2012: p. 18). As a result, many clinics resemble jails because they are fitted out with bulletproof glass and buzzing doors (Crawford 2013). Evidence indicates that this environment undermines trust between consumers and providers, because it portrays consumers as 'criminals', 'addicts' and 'junkies' (Crawford 2013; Harris & McElrath 2012; Radcliffe & Stevens 2008). In addition, the biomedical model and 12-step programs that underpin much of drug treatment exacerbates this negative view, because it classifies drug dependent people as 'diseased' (International Network of People Who Use Drugs 2014; Nathan, Conrad & Skinstad 2016; Verde Valley ArizoNA 2014).

A focus on risk is reflected in MSIC's security procedures: consumers are monitored by a guard and are restricted from using staff areas because it is thought they will steal

valuables. These procedures reinforce the view that consumers are untrustworthy, and mean that they cannot access office equipment or interact with staff and management to discuss issues that relate to service delivery. Views such as this constrain consumer participation.

## **Biomedical focus**

Staff described the care at MSIC as very medically focused. Consumers' health issues were not often described beyond physical parameters, such as measuring low oxygen saturation levels after an overdose. In the biomedical model, drug dependence is conceptualised as a 'disease' (Nathan, Conrad & Skinstad 2016) and care is focused on consumers' physical signs and symptoms. According to this model, health care providers are considered experts with solutions in the form of treatment; this encourages interpersonal distance between the patient and providers (Sillars 2015). This model constrains collaborative relationships between drug treatment consumers and providers because it encourages 'the them and us divide' and the notion that staff know best (Leppo & Perala 2009; Patterson, Weaver, Agath, Rutter, et al. 2009; Rance & Treloar 2015).

The biomedical model contravenes the aim of consumer participation, which involves critique and transformation of the dominant systems of service delivery to provide care that is more reflective of consumers' perspectives. Therefore, when consumers are no longer 'patients' that receive care, the relationship between health care providers and consumers is challenged and the voice of the consumer can be heard in determining their own care.

The success of enhancing consumer participation in this study was a result of the strength of the facilitating forces; they outweighed that of the constraining forces. Another facilitating force was that, through the process of the study, consumers discovered that they could have a voice in service delivery. Doing so raised their critical consciousness and built social capital, two theoretical constructs that are relevant to the findings of this study.

## **Having a voice**

Enabling consumers to express themselves allows them to emphasise their political concerns (Rance & Treloar 2015) and invigorates their desire for social justice

(Patterson, Weaver, Agath, Albert, et al. 2009). The ability of consumers to voice their needs highlights their awareness of important issues (Patterson, Weaver & Crawford 2010; Rance & Treloar 2015), such as making drug treatment more accessible (Patterson, Weaver, Agath, Albert, et al. 2009).

Before the formation of the CAG, some individual staff members and mechanisms assisted consumers to voice their concerns about MSIC's service delivery and planning. MSIC's complaint and suggestion procedures were a good foundation for enhancing consumer participation, because they helped consumers write their suggestions and complaints and pass them on to management.

However, my initial consumer satisfaction survey revealed that complaints were made less often than suggestions. This lower rate could be because consumers are often reluctant to make complaints against staff because they worry that staff will assert their power (Patterson, Weaver, Agath, Albert, et al. 2009). Evidence indicates that there are barriers that prevent services that provide care to PWID from providing feedback about service delivery. This is because they often do not know how to make a complaint (Bryant et al. 2008a) and can be unaware of the location of the suggestion box (Brener et al. 2009; Bryant et al. 2008a).

The formation of the CAG further increased consumers' influence on MSIC service delivery, because it created a forum for consumer issues to be discussed and addressed. The main issue the group discussed was their relationships with local law enforcement, because police searches were reportedly occurring in close proximity to MSIC during the research period. The changed relationship with law enforcement as a result of the CAG serves as a good example of how consumers exercised their voice.

## **Changing relationships with law enforcement**

Of all the CAG's goals, improving relationships with the police was the most frequently discussed in meetings, and illustrates the importance of raising the consumers' voice. The high frequency of discussion about law enforcements' actions towards PWID is not surprising, as high rates of arrest generates fear leading to poor relationship between PWID and law enforcement (Aitken et al. 2002; Cooper et al. 2005; Maher & Dixon 1999).

According to Burris et al. (2004), drug laws are enforced through the practices, knowledge, attitudes and beliefs of frontline officers. A recent study reported that officers who believed that drug dependence should be treated as a public health issue were less likely to arrest PWID and more likely to refer them to services (Cepeda et al. 2017). This can be demonstrated in the experience of Vancouver's SIF: 17% of 1090 consumers who were referred to it between December 2003 and November 2005 were referred by a police officer (DeBeck et al. 2008). Another study found that police who are educated about harm reduction are more likely to have positive relationships with harm reduction services (Strike & Watson 2017).

As part of their job orientation, local police officers visited MSIC and were educated about harm reduction and their ability to exercise discretion about whether to search consumers for illicit drugs. The police also have guidelines that promote police discretion near harm reduction services (NSW Police Force 2013). Despite these measures, consumers were regularly searched close to MSIC during the research period, which was a major concern of the CAG consumers. The group acknowledged that their efforts were only the first step to improving relations with the police and reducing the occurrence of searches near MSIC. Consumers have only engaged a small proportion of the local police officers, and it will be challenging to influence the attitudes of the majority of police when their role is to enforce the law in an environment where the discourse emphasises a war on drugs that has encouraged punitive responses towards PWID (Hari 2016). However, consumer members of the CAG empowered themselves to communicate in a less combative manner, and this will help to gradually improve the negative perceptions police have of MSIC users.

The process of empowerment raised the consumers' critical consciousness (Freire 1993). Through the realisation that they could evaluate the situation with law enforcement in a new light, the consumers were able to develop workable solutions to what they perceived as an intractable problem. In doing so, they addressed problems of oppression and marginalisation.

## **Critical consciousness**

Freire (1993) developed the theoretical construct of critical consciousness by examining traditional education delivered via a 'banking' system, in which teachers deposited knowledge into students without discussion and debate, thus suppressing

their voice. Freire (1993) asserted that if oppressed people are to be empowered, they need to engage in a different style of learning, which involves dialogue that allows their ideas and concerns to be heard by their oppressors. This dialogue can only be achieved when drug treatment consumers and staff are both humanised via the process of critical consciousness.

According to Freire (1993), dehumanisation “is a distortion of being more fully human” (p. 28), and for the oppressed to become emancipated they not only have to restore their own humanity but that of their oppressors. This is because oppressors disguise their attempts to help the oppressed through false generosity, so that the status quo and their power can be maintained. Consequently, oppressors are also afflicted by the act of dehumanisation, therefore only the oppressed have the power to restore their humanity. To overcome dehumanisation, Freire (1993) suggested that the oppressed and oppressor engage in the process of critical consciousness, which exposes the world’s social and political contradictions, allowing both to develop an in-depth understanding of the consequences of these contradictions. In my study the power differential between providers and consumers was altered via dialogue and the process of critical consciousness in the CAG meetings, thus relationships were transformed, and consumer empowerment was advanced. In addition, some consumers improved their relationships with staff and became able to reduce their drug use. Others were able to reconnect with family, address health problems, and express their desire to enrol in a drug and alcohol course or work in the drug treatment industry. Therefore, the enhancement of social capital was manifest in the findings of this study.

## **Building social capital**

The CAG consumers’ social capital was enhanced because the study helped to improve the relationships between consumers and staff. Social capital pertains to an individual’s relationships that are connected by networks, norms and trust that allow people to embark on shared objectives and perform together more effectively (Kreuter & Lezin 2002). The concept of social capital is increasingly associated with positive health outcomes (Bolin et al. 2003; Kawachi, Subramanian & Kim 2008; Niemien et al. 2013; Rocco & Suhreke 2012). Social capital also has been linked to harm reduction and drug treatment outcomes such as reduced risk of relapse (Panebianco et al. 2016) and overdose (Zoorob & Salemi 2017), and recovery from substance and alcohol dependence (Granfield & Cloud 2001; Weston, Honor & Best 2018). For consumers in

drug treatment, social capital has been shown to be enhanced through non-judgemental relationships with staff; this union cultivates “possibilities for the production of self, belonging and citizenship” (Rance & Fraser 2011, p. 121).

Two types of social capital were evident in the findings of my study: bonding (shared connections between consumers) and linking (consumers creating relationships with staff).

### **Bonding social capital**

The CAG consumers’ bonding social capital was enhanced through having a safe place to socialise and the prosocial norms that promoted group functioning. The group norms gradually guided the consumers to respect, encourage, comfort and listen to each other. These behaviours supported consumers to strengthen existing friendships, develop new ones and teach their peers techniques that they learned in the safer injecting workshops. The consumer who achieved abstinence reported that he did so as a result of bonding with the CAG members and reconnecting with his family.

A recent qualitative study revealed that PWID are rarely seen as people who want to help or bond with others, but as antisocial individuals who only care about their next injection (Nieweglowski et al. 2017). The results of my study paint a different picture. The majority of survey respondents indicated that they wanted to join the CAG because it would provide them with an opportunity to help MSIC, their peers and their community. Other studies have provided similar evidence of the desire of PWID to help their peers. For example, a study involving homeless PWID in San Francisco revealed that they cared for each other through “the moral economy of heroin sharing” so community members didn’t experience uncomfortable withdrawals (Bourgois & Schonberg 2009 p. 82). Likewise, people who are prescribed methadone often stockpile their takeaway doses to prevent their friends from withdrawing (Harris & Rhodes 2013).

Evidence indicates that positive social capital, such as trusting, supportive, caring and compassionate relationships among PWID, has the potential to decrease needle sharing (Kumar, McNeely & Latkin 2016) and transmit reliable harm reduction information (Kirst 2009). In addition, prisoners’ awareness, uptake and adherence of hepatitis C treatment has been found to be influenced by peer reassurance and personal accounts of treatment (Lafferty, Treloar, Guthrie, et al. 2017).

## Linking social capital

To maximise linking social capital, a strengths-based model was employed. Illicit drug consumers are often told that they are dangerous to society (Lloyd 2010) and that they have deficits in drug treatment services (Shaima & Narayanan 2018); therefore, pointing out their weaknesses would have been counterproductive to their learning. A strengths-based model goes beyond what is wrong with an individual (Rapp & Goscha 2011) and systematically assesses their skills, attributes and assets (National Registry of Evidence-Based Programs and Practices 2009) .

The consumer's linking social capital was enhanced because the CAG provided them with opportunities to develop new skills and egalitarian relationships with the CAG staff members. Enhanced linking social capital was achieved through the staff and me sharing our professional skills and power by teaching the consumers how to communicate effectively in formalised meetings, chair meetings and write minutes. While the CAG consumers did not undertake any formal training, it has been reported that drug treatment consumers involved in service delivery can benefit from reflective education on organisational structures and processes, and formalised meeting procedures; as these skills can enable consumers to obtain paid employment (Patterson, Weaver, Agath, Rutter, et al. 2009; Patterson, Weaver & Crawford 2010).

Another example of linking social capital was the creation of the police liaison officer. MSIC's medical director and the local area commander exercised their power to make the position possible. The CAG's meeting with the liaison officer and his colleague enabled the MSIC consumers and the police to interact and better understand each other. The meeting allowed the officers to witness the consumers' humanity and their appropriate communication skills. Through listening, the consumers reflected on their past encounters with law enforcement and realised that their aggressive approach was counterproductive. This realisation enabled the consumers to start conversing with the police on the street in a calmer manner. This study is unique in reporting PWID engaging in dialogue with the police to address the issue of police conducting drug searches in close proximity to MSIC. Other studies have focused on increasing officers' knowledge of harm reduction and behaviour towards PWID (Cepeda et al. 2017) and officers' relationships with harm reduction services and harm reduction education (Strike & Watson 2017).

## **Promoting lifestyle change**

The CAG consumer members' increased access to social capital reduced their drug and alcohol use and assisted one member to address a chronic health problem. CAG membership also helped consumers to envision future study and employment opportunities.

The consumers' reduction in drug and alcohol use and uptake of hepatitis C treatment was related to the enhanced social capital they developed as a result of CAG membership. The meetings provided the consumers with a supportive and encouraging meeting environment that allowed them to bond with other members. These positive social interactions increased the consumers' self-esteem and helped them envision new possibilities. The consumers said that the CAG enabled them to see that there is more to life than injecting drugs and that it is possible for them to pursue education and employment. A CAG consumer was invited to undertake voluntary work with a drug user organisation as a result of presenting with me at a conference and through networking with the other delegates.

Other studies report considerable support for consumers working in drug treatment services because their lived experience provides them with specialist knowledge, insight and empathy for drug users (King 2011). In addition, such consumers can demonstrate to others that recovery is possible (Tober et al. 2013). If the concept of consumer participation and the employment of people with a lived experience is to be fully realised, harm reduction organisations such as MSIC need to promote a culture that values the principles of co-production.

## **Moving from consumer participation to co-production**

Co-production moves beyond traditional models of consumer participation by appreciating that consumers have unique knowledge, assets and expertise that are critical to quality service delivery (Needham & Carr 2009; Roper, Grey & Cadogan 2018). As a result, co-production disrupts the usual passive patient–expert professional relationship, because it is centred on two experts and “shared or supported decision-making” (Roper, Grey & Cadogan 2018 p. 2). The process of co-production involves consumer working with professionals or taking the lead to plan, design, deliver, and audit public services (Needham & Carr 2009; Roper, Grey & Cadogan 2018). Ideally, consumers should be involved before an agenda is set, so they are engaged in the

initial identification of issues and are included in setting priorities to tackle the issue (Roper, Grey & Cadogan 2018).

In mental health services, there is evidence that co-production roles are associated with increased levels of well-being (Sharma, Conduit & Rao Hill 2017). Mental health consumers who were involved in the co-production of their treatment and care, co-creation of service delivery and the improvement of mental health for the broader community reported an increase in hedonic (sense of happiness) and eudaimonic (sense of achievement and purpose) well-being (Sharma, Conduit & Rao Hill 2017).

My project achieved the co-production of services on several occasions. On one occasion a CAG consumer participated in a decision-making meeting with MSIC executive management and senior police to implement the recommendations from the CAG's meeting. Another example was a CAG consumer and I jointly preparing a paper and presenting it at a conference, and a third was the CAG's submission to the MSIC statutory review. These examples show that it is possible for co-production to occur at MSIC, and has the potential to further improve MSIC service delivery and consumers' well-being. However, co-production needs to be introduced gradually into MSIC and other harm reduction organisations, because many of these services still operate via a biomedical model that does not encourage collaborative relationships with consumers.

Co-production can only work when services that provide care for PWID create organisational cultures that values more equal relationships between consumers and professionals. This process could begin with professional education concerning the importance of power sharing with consumers and valuing their knowledge and expertise (Needham & Carr 2009; Roper, Grey & Cadogan 2018). In addition, consumers and professionals need to become more empowered (Roper, Grey & Cadogan 2018) through engaging in critical dialogue about the constraints that prevent them working in partnership.

## **Strengths and limitations of the study**

Validity is a term that is commonly used to describe the quality of positivist research, while trustworthiness describes the quality of naturalistic research (Herr & Anderson 2015). However, these terms do not adequately describe the additional outcomes of action research (Herr & Anderson 2015). Action research goes beyond the generation

of new knowledge and aims to produce action-orientated outcomes, equality between researchers and participants, and the empowerment of participants.

Terms such as goodness, trustworthiness, credibility and workability are commonly used to describe the quality of action research. However, Herr and Anderson (2015) recommended that doctoral students undertaking action research use the term validity, because they are often required to justify their proposals to committees comprised mainly of positivist researchers.

According to Herr & Anderson (2015), the traditions of action research (e.g. PAR, community-based action research, action science) are mostly focused on creating new knowledge, achieving action-oriented outcomes, educating researchers and participants, producing results that are relevant to the local setting, and ensuring that the investigation is guided by a sound and appropriate methodology. To assess an action research study's quality, Herr & Anderson (2015) developed the following criteria: outcome, process, democratic, catalytic and dialogic validity. Table 16 depicts the relationship between action research's goals and these validity criteria.

Herr and Anderson's criteria are useful to assess the quality of my study, because it was designed to predominantly assess insider-initiated action research projects. I will also discuss this study's external validity by explaining how the study's outcomes are transferrable to other drug and alcohol and harm reduction settings.

**Table 16. Goals of Action Research and its relationship with validity criteria (adapted from Anderson & Herr 2015)**

Goals of Action Research	Quality/Validity Criteria
1. The achievement of action-oriented outcomes	Outcome validity
2. The generation of new knowledge	Process validity and dialogic validity
3. A sound and appropriate methodology	Process validity
4. Results that are relevant to the local setting	Democratic validity
5. The education of both researcher and participants	Catalytic validity

## **Outcome validity**

Outcome validity is the degree to which actions transpire and the problems being investigated are resolved (Herr & Anderson 2015). My study arose out of the MSIC clinical service manager's desire to enhance consumers' involvement in service delivery and planning, because participation was limited to suggestions and complaint mechanisms. Overall, the CAG provided MSIC consumers with a stronger voice that allowed them to more effectively convey their ideas and complaints about MSIC and produce outcomes. The CAG also enabled consumers to decrease their drug use, address health issues, learn new skills, develop more meaningful relationships with each other and staff, and develop hope of being employed in the drug and alcohol/harm reduction industry. Ultimately, this study achieved outcome validity because the CAG has been in operation for close to four years and has become a permanent and valued part of MSIC service delivery.

Outcome validity is also dependent on the action researcher's proficiency in conducting research procedures and helping participants to achieve action outcomes (Herr & Anderson 2015). For example, I realised how subcommittees and discussion of issues outside CAG meetings could impede the group's democratic processes and cohesion, because they did not allow all participants to contribute to group discussions and decisions.

Being a mental health nurse also enabled me to help the participants achieve action outcomes. My nursing practice has taught me that illicit drug consumers are more likely to gain control over their drug use when you concentrate on their strengths instead of their deficits. If I had focused on the consumers' substance use and lifestyles, the group might not have been successful. Focusing on the consumers' deficits would have silenced and shamed the consumers, whereas their voices were a vital part of the CAG's success.

## **Process validity**

Process validity refers to the degree to which problems are outlined and solved in a way that encourages ongoing learning of the individual and organisation (Herr & Anderson 2011). The CAG used robust action research cycles to investigate consumer related issues and achieve their goals. This process enabled the consumers to learn

new skills, and for MSIC as an organisation to appreciate that consumers' voices can positively shape service delivery.

Process validity also addresses the ongoing action research debates over what determines quality of evidence and quality of relationships with participants (Herr & Anderson 2015). Using a wide range of data is one way that quality of evidence can be improved in action research, because it involves a variety of methods so that findings are not limited to one type of data source (Herr & Anderson 2015). This study had a rich array of data sources, including interviews, a brainstorming exercise, a reflective journal, minutes, audio recordings of meetings and surveys, to help answer its questions.

According to Gilbert (2008), PAR researcher/participant relationships focus on doing *with* and *for* rather than *on* others, and concentrate on who controls the expertise and knowledge in the relationship (Livingston & Perkins 2018). The CAG staff and I created an atmosphere in which we could work as equal partners with the consumers, so we could help them to become empowered and influence MSIC service delivery. This was achieved by valuing and trusting the consumers' expertise and opinions and allowing them to take ownership of the group's terms of reference, rules and goals.

## **Democratic validity**

Democratic validity refers to the degree in which research is done in partnership with all stakeholders who are interested in the issue being studied; if it is a local project, it should produce solutions that are applicable to the service (Herr & Anderson 2015). This study included the views of MSIC consumers and staff who were interested in enhancing consumer participation by inviting them to participate in a wide range of activities. However, it was difficult to capture the views of all MSIC consumers, as over 16,000 were registered at the midpoint of the study, and the evaluation of my study highlighted that few consumers outside of the group were aware of its purpose. The study also produced outcomes that could help MSIC to evolve, because it helped consumers to become more empowered, learn new skills, and improve relationships between consumers and staff.

Another feature of action research that relates to democratic validity is that participants should be involved in all stages of a project, from the formulation of the question to the writing up of the results (Livingston & Perkins 2018). However, implementing this

condition is not always feasible (Koch & Kralik 2006), because doctoral work is heavily time-limited (Herr & Anderson 2015). In addition, total participant involvement would not been realistic in this study, because the consumers' drug dependence would have made it difficult for them to commit to activities such as data analysis outside of meetings. In addition, data analysis is a skill that requires training (Livingston & Perkins 2018), and finding the time to train the consumers and getting them to attend training would have been logistically difficult. In addition, we only had 90 minutes every three weeks to conduct meetings, and therefore it would have been impossible for the consumers to be involved in all facets of the study.

Even though the consumers were not involved in the analysis or write-up of this study's results some of the CAG consumers helped me to present their achievements at an academic conference and MSIC staff training days. This was important, because marginalised people who use drug and alcohol services are often excluded from research, because they are deemed too chaotic and risky (Livingston & Perkins 2018). However, all of the consumer participants were highly marginalised people, and this did not preclude them from actively contributing to this research.

### **Catalytic validity**

Catalytic validity is "the degree to which the research process reorients, focuses and energizes participants towards knowing reality in order to transform it" (Lather, 1986, p. 272). This study did reorientate and energise the CAG consumers through the realisation that they did have a voice that can effectively communicate with more powerful groups like the police and influence new positions such as the MSIC police liaison officer position. The group also came to support the decriminalisation of drug use, because during the study several consumers were incarcerated, and this helped the CAG consumers realise that they were all victims of the punitive laws that have materialised through the 'war on drugs'.

### **Dialogic validity**

Dialogic validity "is similar to democratic validity but differs in that the focus is less on-board inclusion than on the validation – both during and after the study – that methods, evidence, and findings resonate with a community of practice" (Herr & Anderson 2015 p. 70). As evidence of dialogic validity, I engaged in critical dialogue during supervisory sessions with both my supervisors (experienced action researchers), published this

thesis' systematic review in a drug and alcohol journal, and presented the outcome of this study at various conferences.

## **External validity**

Quantitative researchers define generalisability from a statistical viewpoint and therefore can generalise from a sample to a population (Herr & Anderson 2015). The concept of generalisability is also known as external validity (Herr & Anderson 2015). Qualitative and action researchers conceptualise generalisability differently, through the concept of transferability, which involves knowledge being transferred from one setting to another (Herr & Anderson 2015). This project provides evidence that when a pragmatic, humanistic, and collaborative approach is adopted it is possible for the most marginalised consumers to positively and actively contribute to drug and alcohol and harm reduction service delivery and planning. Hence, the evidence and learnings in this study can be transferred to other drug and alcohol and harm reduction services.

## **Recommendations for services**

If drug and alcohol and harm reduction services are to enjoy the full benefits of consumer participation, they need to gradually move towards co-production, adopt a strengths-based and supportive approach and reconsider the hierarchical nature of the ladder of consumer participation.

### **Towards co-production**

- To build upon the success of the CAG, MSIC and other services need to create organisational cultures that embrace co-production.
- Services need to commit adequate human and financial resources for co-production to succeed.
- The process leading towards co-production needs to be implemented gradually and with caution, as drug treatment organisations have a poor history of transitioning consumer participation policy into action, and staff often exhibit poor attitudes about consumer's capabilities (Goodhew, Stein-Parbury & Dawson 2019).
- For co-production to evolve successfully, services need to progressively create an ethos that values the expertise and lived experience of their consumers. This could be achieved by educating existing staff about strength-based

interventions and employing new staff who are able to look beyond consumers' deficits and recognise their capabilities. To select such employees, interview panels could include a consumer representative to help decide if the applicant has the qualities to work in partnership with service users.

- Organisations need to provide staff regular education about the principles of co-production and generate dialogue about the issues that could arise with consumers and staff working in partnership. This could be achieved through consumers attending staff meetings and education sessions and conducting in-service education sessions about their expertise and lived experience.
- As staff become more accustomed to co-production, consumers could help to appraise staff performance in their yearly work performance review. In addition, voluntary and paid consumers positions could be created; one of these positions should be a co-production coordinator who can oversee the organisation's participatory activities and support consumers that participate in them.
- If harm reduction organisations are going to embrace the principles of co-production, they need to soften their security procedures and allow consumers who are contributing to service delivery to have more access to the necessary resources. In addition, less stigmatising security procedures will help lessen the divide that often exists between consumers and staff.

## **Strengths-based and supportive approach**

- If co-production is to succeed in drug and alcohol and harm reduction services, providers need to focus on consumers' strengths and humanistic qualities. Focusing on deficits such as chaotic drug use only stigmatises and shames consumers, and this is the antithesis of consumer empowerment, which is an essential ingredient of co-production.
- Providers need to support consumers to learn how services operate. This can be achieved by providers sharing their knowledge with consumers about how the service runs and teaching them skills that will enable them to contribute to service delivery and planning. In addition, various peer and drug user organisations are well equipped to provide education about how consumers can contribute to health service delivery and planning.
- Providers need to be aware that many consumers of drug and alcohol and harm reduction services were abused as children and as a result experience high

rates of mental ill-health and trauma-related disorders. Coordinators of co-production projects need to be skilled in managing interpersonal conflict and providing emotional support, because people with psychological conditions often find interacting with others and group situations challenging.

## Reconceptualising the consumer participation ladder

- The fact that the CAG mainly achieved its aims through lower-level activities on the consumer participation ladder (Bryant et al. 2008a, 2008b) indicates that the hierarchical nature of the ladder needs to be reconsidered. The ladder places too much emphasis on consumers participating in activities that involve power (Tritter & McCallum 2006), and because of chronic substance dependence, many MSIC consumers are unable to commit to participating in higher-level decision-making activities.
- Evidence from this study demonstrates that harm reduction service delivery or consumers are never straightforward or linear. Therefore, a flexible framework of consumer participation that equally values participatory activities is required. This framework could visualise:

*participatory activities in a more dynamic fashion, with participatory activities, displayed in an integrated manner rather than ranked within a hierarchy. This will allow for reference to “bundles” of activities from all levels of the ladder to better illustrate the complexity and need for tailoring according to the context. (Goodhew, Stein-Padbury & Dawson 2019)*

## Further research

- It would be interesting to see if this study’s results could be replicated in another SIF, such as the one that opened in Melbourne last year. Compared to MSIC, the Melbourne SIF is an unestablished service, so it would be interesting to see how the formation of a CAG would impact on this new SIF.
- Further research should include examination of how organisational culture affects consumer participation, as the results of this study indicate its relevance to enhancing such participation.

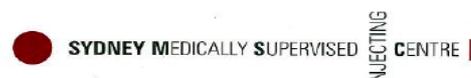
- Future researchers in this field could investigate the formation of a CAG in a drug and alcohol treatment service. Compared to MSIC, drug and alcohol treatment services are very strongly underpinned by a biomedical model, have more intense security procedures and higher thresholds for sanctions and discharge from the service when consumers do not adhere to rules. Therefore, compared to MSIC, staff in drug and alcohol services are more likely to have negative attitudes about consumers' abilities to contribute to service delivery, and it would be interesting to see if and how these attitudes constrain the formation of the group.
- Finally, further research could include repeated surveys of staff and consumer attitudes about consumer participation in drug and alcohol and harm reduction services. The results will help services to develop and evaluate effective education programs that help explore and address negative attitudes about consumer participation and co-production.

## Conclusion

This project provides evidence that consumer participation can be enacted in harm reduction and drug and alcohol services with consumers who are highly socially marginalised and actively using drugs. This study used PAR to meet its aims, and its emancipatory nature helped to create a CAG which provided MSIC consumers with a voice, an opportunity to influence service delivery and make MSIC's services more reflective of their needs. However, this success would not have been possible if the CAG staff members' attitudes did not align with PAR's key components of support, empowerment and equality.

The success of this project was driven by supportive staff who valued consumers' expertise, accepted their drug use and lifestyles, and were willing to cede some of their professional power. Through these positive attitudes and actions, the CAG consumers felt valued and found a voice, which helped them to become empowered and access social capital. Bonding and linking social capital allowed the CAG consumers to successfully communicate their ideas about MSIC's service delivery to management, express their grievances about the local police and act on them through direct dialogue, form better relationships with each other and staff, learn new skills, reduce their substance use, make positive lifestyle choices and have hope for the future.

## Appendix A: Information for participants



### INFORMATION SHEET

#### Enhancing consumer participation in a medically supervised injecting centre through participatory action research (UTS APPROVAL NUMBER: 201400835)

##### WHO IS DOING THE RESEARCH?

My name is Mark Goodhew and I am a PhD student at UTS and employee of the Sydney MSIC. (My supervisors are Professor Jane Stein-Parbury and Dr Mellanie Rollans)

##### WHAT IS THIS RESEARCH ABOUT?

This research will investigate consumer participation at the Sydney Medically Supervised Injecting Centre (MSIC) through participatory action research (PAR). Consumer participation in health care relates to consumers being involved in decisions about service delivery, planning and the design of health care facilities.

The aims of this research is to find out what MSIC consumers and staff think about consumer participation, and to form an action group who will develop a plan to increase consumer participation. This plan will be put into place and then evaluated to see if increased consumer participation adds value to the MSIC service. Both consumers and staff will be members of this group.

##### IF I SAY YES, WHAT WILL IT INVOLVE?

Participation involves being **interviewed** and/or becoming a member of the **action group**.

If **interviewed**, you will be asked about your views regarding consumer participation at MSIC. The interview will be recorded and transcribed (a word for word record). You will be given a copy of the transcript to make sure it is accurate. You will be given an option to repeat the interview after the action group evaluates its progress.

If you are a consumer you will receive a \$20 gift voucher for each interview.

If you are a staff member you will be interviewed during work time.

If you become a member of the **action group** you will attend meetings over period of 12 to 18 months that will run for 90 minutes. In the group there will be eight MSIC consumers and four MSIC staff and Mark Goodhew, who will facilitate the group. The period of 12 to 18 months is an estimate because the length of the study depends on the time it takes for group achieve its goals.

Light refreshments, tea and coffee will be provided 30 minutes before the group.

Consumers will be paid \$40 per meeting attended to acknowledge their contribution to MSIC service delivery planning

Staff members will attend the meetings during work hours.

Please note: You will not be interviewed or able to attend a group meeting if you are highly intoxicated.

##### ARE THERE ANY RISKS/INCONVENIENCE?

Yes, there is some risk/inconvenience.

In the **interview** you may become upset if you recall negative and/or include unpleasant memories about MSIC. You can stop the interview at any time you feel uncomfortable.

Within the **action group** you may feel embarrassment or anxious, as speaking in front of a group may be stressful. There may be disagreements amongst group members, which may cause conflict.

To ensure that individuals feel safe to openly talk, ground rules will be agreed upon during the first group meeting. These rules will promote respect for others' opinions, maintain confidentiality and ensure the individuals feel safe. As the group's facilitator Mark Goodhew will be responsible for monitoring the rules and group dynamics to ensure that all members are being included.

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission. , This includes information about illegal activity, but MSIC staff are required by law to report offences that may be tried by jury and/or carry a sentence of five or more years in prison or that cause immediate danger. In addition, MSIC staff are also mandatory reporters and legally are required to report child protection issues. Only the researchers (Mark and his academic supervisors) will have access to your details and results will be stored securely.

If you provide us (Mark Goodhew and his academic supervisors) your permission by signing the attached consent document, we plan to publish or discuss the results in a thesis, scientific journals, conference presentations to health professionals and consumers. In any publication, information will be provided in such a way that you cannot be identified.

Overall, it is not anticipated that high levels of stress will occur through participating in this study, but if you do become highly distressed through your participation you will be offered counselling. Consumer participants will be referred to a MSIC counsellor or to a Unifam counsellor if they prefer to see someone outside of MSIC. Staff participants are able to access counselling via the Uniting Care employee assistance program. It is envisioned that participating in the study will provide benefits by increasing consumer participation at MSIC that will outweigh any risks/inconveniences.

#### WHY HAVE I BEEN ASKED?

Because you are a consumer or employee of MSIC and able to provide information needed to enhance and improve consumer participation at MSIC. If you have been asked to join the group you are seen as someone who is interested in consumer participation and is able to commit to attending group meetings over a 12 – 18 month period.

#### DO I HAVE TO SAY YES?

You don't have to say yes, as participation in this study is voluntary.

#### WHAT WILL HAPPEN IF I SAY NO?

Nothing. Mark will thank you for your time so far and won't contact you about this research again. In addition, saying no will not affect your current or future relationship with MSIC, either as consumer or employee.

#### IF I SAY YES, CAN I CHANGE MY MIND LATER?

You can change your mind at any time and you don't have to say why. Mark will thank you for your time so far and won't contact you about this research again.

#### WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think Mark or his supervisors can help you with, please feel free to contact one of us. Mark can be contacted by phone on 02 9360 1191 or via email at [mgoodhew@unitingcarenewswact.org.au](mailto:mgoodhew@unitingcarenewswact.org.au) and Jane Stein-Parbury (primary supervisor) can be contacted by phone on [REDACTED] or via email at [jane.stein-parbury@uts.edu.au](mailto:jane.stein-parbury@uts.edu.au).

If you would like to talk to someone who is not connected with the research, you may contact the Research Ethics Officer on 02 9514 9772, and quote this number (*UTS HREC Approval Number: 2014000835*).

## Appendix B: Consents



### CONSUMER CONSENT FORM FOR STRUCTURED INTERVIEW

I \_\_\_\_\_ agree to participate in the research project titled: **'Enhancing consumer participation in a medically supervised injecting centre through participatory action research'** (UTS HREC approval reference number: 2014000835) being conducted by Mark Goodhew (Sydney MSIC, 66 Darlinghurst Road, Potts Point NSW 2011, Tel: 02 93601191) of the University of Technology, Sydney for his degree: Doctor of Philosophy. Funding for this research has been provided by the Sydney Medically Supervised Injecting Centre (MSIC).

I understand that the purpose of this study is to find out what MSIC consumers and staff think about consumer participation, and to form an action group who will develop a plan to increase consumer participation at MSIC.

I understand that I have been asked to participate in this research because I am a MSIC consumer and able to provide information needed to enhance and improve consumer participation at MSIC. I am aware that my participation will involve an hour interview about my views and experiences of consumer participation at MSIC, and this interview will be recorded. I am also aware that I will receive a \$20 gift voucher for my time and will not be interviewed if I am highly intoxicated.

I am aware that the interview may cause stress and I can stop the interview at any time I feel uncomfortable and if I become highly distressed I will be referred to a counsellor.

I am aware that I can contact Mark Goodhew or his supervisor Professor Jane Stein-Parbury if I have any concerns about the research. I also understand that I am free to withdraw my participation from this research project at any time I wish, without consequences, and without giving a reason and my current or future care and treatment at MSIC will not be affected.

I agree that Mark Goodhew has answered all my questions fully and clearly.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

\_\_\_\_\_  
Signature (participant)

\_\_\_\_/\_\_\_\_/\_\_\_\_

\_\_\_\_\_  
Signature (researcher or delegate)

\_\_\_\_/\_\_\_\_/\_\_\_\_

#### NOTE:

This study has been approved by the University of Technology, Sydney Human Research Ethics Committee. If you have any complaints or reservations about any aspect of your participation in this research which you cannot resolve with the researcher, you may contact the Ethics Committee through the Research Ethics Officer (ph: +61 2 9514 9772 [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au)) and quote the UTS HREC reference number. Any complaint you make will be treated in confidence and investigated fully and you will be informed of the outcome.

### STAFF CONSENT FOR STRUCTURED INTERVIEW

I \_\_\_\_\_ agree to participate in the research project: **Enhancing consumer participation in a medically supervised injecting centre through participatory action research** (UTS HREC approval reference number: 2014000835) being conducted by Mark Goodhew (Sydney MSIC, 66 Darlinghurst Road, Potts Point NSW 2011, Tel: 02 93601191) of the University of Technology, Sydney for his degree: Doctor of Philosophy. Funding for this research has been provided by the Sydney Medically Supervised Injecting Centre (MSIC). I understand that the purpose of this study is to find out what MSIC consumers and staff think about consumer participation, and to form an action group who will develop a plan to increase consumer participation at MSIC.

I understand that I have been asked to participate in this research because I am a MSIC clinical employee and able to provide information needed to enhance and improve consumer participation at MSIC. I am aware that my participation will involve an hour interview about my views and experiences of consumer participation at MSIC, and this interview will be recorded and take place during work hours.

I am aware that the interview may cause psychological distress and I can stop the interview at anytime I feel uncomfortable and if I become highly distressed I can access free counselling through the Uniting Care employee assistance program.

I am aware that I can contact Mark Goodhew or his supervisor Professor Jane Stein-Parbury if I have any concerns about the research. I also understand that I am free to withdraw my participation from this research project at any time I wish, without consequences, and without giving a reason and withdrawal will not jeopardise my current or future employment at MSIC. I agree that Mark Goodhew has answered all my questions fully and clearly. I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
Signature (participant)

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
Signature (researcher or delegate)

**NOTE:**

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## CONSUMER CONSENT FOR CONSUMER ACTION GROUP

I \_\_\_\_\_ agree to participate in the research project titled: **'Enhancing consumer participation in a medically supervised injecting centre through participatory action research'** (UTS HREC approval reference number: 2014000835) being conducted by Mark Goodhew (Sydney MSIC, 66 Darlinghurst Road, Potts Point NSW 2011, Tel: 02 93601191) of the University of Technology, Sydney for his degree: Doctor of Philosophy. Funding for this research has been provided by the Sydney Medically Supervised Injecting Centre (MSIC).

I understand that the purpose of this study is to find out what MSIC consumers and staff think about consumer participation, and to form an action group who will develop a plan to increase consumer participation at MSIC.

I understand that I have been asked to participate in this research because I am a MSIC consumer who is interested in consumer participation and able to commit to approximately 12 -18 consumer action group meetings over a period of 12 – 18 months. I know that the group will consist of MSIC consumers and clinical staff and the group will plan and decide on activities that will enhance consumer participation at MSIC and evaluate the results of actions undertaken by the group. I also know that I will receive \$40 cash for each meeting that I attend and I will not be able to participate in the group if I am highly intoxicated. I also agree to adhere to the group's ground rules.

I am aware that I may experience stress and conflict may arise if there are disagreements amongst group members. I know if I do become highly distressed by participating in the group I will be referred for counselling.

I am aware that I can contact Mark Goodhew or his supervisor Professor Jane Stein-Parbury if I have any concerns about the research. I also understand that I am free to withdraw my participation from this research project at any time I wish, without consequences, and without giving a reason and my current or future care and treatment at MSIC will not be affected.

I agree that Mark Goodhew has answered all my questions fully and clearly.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

\_\_\_\_\_  
Signature (participant)

\_\_\_\_/\_\_\_\_/\_\_\_\_

\_\_\_\_\_  
Signature (researcher or delegate)

\_\_\_\_/\_\_\_\_/\_\_\_\_

### NOTE:

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### STAFF CONSENT FORM FOR CONSUMER ACTION GROUP

I \_\_\_\_\_ agree to participate in the research project: **'Enhancing consumer participation in a medically supervised injecting centre through participatory action research'** (UTS HREC approval reference number: 2014000835) being conducted by Mark Goodhew (Sydney MSIC, 66 Darlinghurst Road, Potts Point NSW 2011, Tel: 02 93601191) of the University of Technology, Sydney for his degree: Doctor of Philosophy. Funding for this research has been provided by the Sydney Medically Supervised Injecting Centre (MSIC). I understand that the purpose of this study is to find out what MSIC consumers and staff think about consumer participation, and to form an action group who will develop a plan to increase consumer participation at MSIC.

I understand that I have been asked to participate in this research because I am a permanently employed MSIC clinician who is interested in consumer participation and able to commit to approximately 12 -18 consumer action group meetings over a period of 12 – 18 months. I know that the group will consist of MSIC consumers and clinical staff and the group will plan and decide on activities that will enhance consumer participation at MSIC and evaluate the results of actions undertaken by the group. I also know that I will be able to attend the group during work hours.

I am aware that I may experience embarrassment and anxiety and conflict may arise if there are disagreements amongst group members. I know if I do become highly distressed by participating in the group I will be able to access free counselling via the Uniting Care employee assistance program.

I am aware that I can contact Mark Goodhew or his supervisor Professor Jane Stein-Parbury if I have any concerns about the research. I also understand that I am free to withdraw my participation from this research project at any time I wish, without consequences, and without giving a reason and withdrawal will not jeopardise my current or future employment at MSIC.

I agree that Mark Goodhew has answered all my questions fully and clearly.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

\_\_\_\_\_  
Signature (participant)

\_\_\_\_/\_\_\_\_/\_\_\_\_

\_\_\_\_\_  
Signature (researcher or delegate)

\_\_\_\_/\_\_\_\_/\_\_\_\_

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This study has been approved by the University of Technology, Sydney Human Research Ethics Committee. If you have any complaints or reservations about any aspect of your participation in this research which you cannot resolve with the researcher, you may contact the Ethics Committee through the Research Ethics Officer (ph: +61 2 9514 9772 [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au)) and quote the UTS HREC reference number. Any complaint you make will be treated in confidence and investigated fully and you will be informed of the outcome.

## Appendix C: Consumer Participation Information Sheet



### Consumer Participation Information Sheet

Thank you for agreeing to share your views about MSIC’s consumer participation. This information sheet will help you answer the interview questions, as it explains what consumer participation is and how MSIC service users can be involved in consumer participation activities. Please take some time to read this sheet and feel free to ask questions.

#### Who is a consumer?

A consumer is anyone that uses a service. Therefore, those who use MSIC’s services are MSIC consumers.

#### What is consumer participation?

Consumer participation occurs when consumers are actively and ‘meaningfully involved in decision-making about health policy and planning, care and treatment, and the wellbeing of themselves and their community’ (ACT Government Health 2011 p 7).

#### What are the activities that MSIC consumers potentially can be involved in?

Consumer participation occurs on several levels, which range from satisfaction surveys at lower levels to involvement in service planning at higher levels. The ladder of consumer participation illustrates the varying levels that MSIC consumers can potentially be involved in.

#### Ladder of Consumer Participation

Level	Type of Participation	Example of activity
HIGH	Consumers share in decision-making activities.  Consumer participation is built into service’s values and policies.	<ul style="list-style-type: none"> <li>• Consumers are involved in service planning.</li> <li>• Consumers attend staff meetings.</li> <li>• Consumers participate in staff selection and performance appraisal.</li> <li>• Consumer participation is incorporated into vision or mission statement.</li> </ul>
MID	Activities that promote and support consumer involvement but ones in which consumers have non-decision making roles.	<ul style="list-style-type: none"> <li>• Consumers are supported to conduct their own group activities.</li> <li>• Consumers are involved in staff training.</li> </ul>
LOW	Activities concerned with providing information to or receiving information from consumers.	<ul style="list-style-type: none"> <li>• Service displays user group publications.</li> <li>• Consumer councils provide advice as to how services and programs should run.</li> <li>• Forums are held so that consumers can express their views on service delivery.</li> <li>• Surveys are conducted that ask consumers for their opinions about how services can improve.</li> <li>• Complaints process is in place where consumers can register their complaints about service delivery</li> </ul>

## Appendix D: CAG Structure and Rules

### MSIC's Consumer Action Group's Aims, Structure and Rules

#### Aims

- The aim of the MSIC consumer action group is to represent and empower MSIC consumers through including their perspectives within MSIC service delivery and planning, so the service is more reflective of their needs.

#### Structure

- The group will be documented through participatory action research and all group members will be considered equal investigators in the research project.
- The group will be structured through several cycles of planning, action, observing and reflection about MSIC service delivery.
- All group members will have input into decisions about the research project including, rules, data analysis and may have the opportunity to be co-authors on publications.
- Everyone gets a turn to chair the group and minute taking will be shared among those who are comfortable with writing notes.
- The group will have a quorum of three consumers for votes to pass.

#### Rules

- Consumers will not be able to attend the group if their intoxication is impairing their concentration and is disrupting the group.
- Only one group member is to speak at a time.
- Group members are to be considerate by attempting not to interrupt each other.
- If interruptions are frequent the group will use a talking stick to prevent interruptions.
- The chair will monitor the group rules and Mark will monitor and mediate group dynamics.
- Group members are to be mindful that personal details discussed in the group are confidential and are not to be discussed outside the group.
- Consumer group members who are going to be late to meetings are to ring MSIC and inform that they will be late.
- If consumers are consistently late without an understandable reason, the group will decide if their \$40 payment is to be withheld.
- If group members miss more than three groups in a row and they do not have a good reason (e.g. illness, personal problems or incarceration) they will have to resign from the group and make the way for a new member.

- Consumers who leave half way through the group will only receive half pay.
- There will be a five minute break during the group if time permits.
- The rules and group structure may change overtime depending on the group and study developments.

## Appendix E: CAG Chairing Guidelines

### Consumer Action Group Chairing Guidelines

The following are guidelines about chairing the consumer group to help the meetings to stay on track.

- Everybody is to be supportive and respectful of the chair and mindful that chairing a meeting can be stressful.
- If members are frequently interrupting each other and are not sticking to the agenda the talking stick is to be used.
- A staff member will be assigned to support a consumer who is chairing the group and intervene if they appear stressed or the meeting is not on track.

The meeting is to run in the following order:

- Appoint someone to take minutes
- Confirm previous minutes
- Agenda items
- New business

If group members are talking about matters that are not relevant to the agenda, but are important the chair is to politely intervene and appoint these matters to new business or the next meeting.

The group will aim to have a five – 10 minute break, but only if we have completed the agenda items.

## Appendix F: MSIC Statutory Review Submission



9<sup>th</sup> May 2016

Ms Cathryn Cox  
A/Deputy Secretary, Strategy and Resources  
NSW Ministry of Health  
73 Miller Street  
North Sydney  
NSW 2060

email via Daniel MAEDDU  
[DMADE@doh.health.nsw.gov.au](mailto:DMADE@doh.health.nsw.gov.au)

Dear Ms Cox,

Consumer participation involvement in health care service delivery has been occurring for the past three decades and is considered gold standard in contemporary health care. The MSIC Consumer Action Group (CAG) was formed in June 2015 and consists of eight consumers and five staff who meet every three weeks to discuss and plan activities that will enhance consumers' involvement in MSIC service delivery.

So far the CAG have achieved the following:

- designed a T-shirt to promote the group;
- successfully lobbied for a police liaison officer so consumers can improve their relationship with the police and there is an avenue of redress when MSIC consumers have complaints;
- arranged a safer injecting course so they can teach their peers the safest ways to inject;
- and a consumer and a staff member presented the achievements of the group at an academic conference.

Overall the group has given a voice to MSIC consumers who are some of society's most highly marginalized and stigmatized people.

The CAG believe that the consumers' views should be included in the Statutory Review of MSIC's operating conditions because they are the people who use the service.

The following outlines the CAG's opinions about the review.

**Please note**, these views are forwarded on behalf of the CAG but do not necessarily represent, or align, with the views of all MSIC consumers and/or MSIC Management and staff. -

The CAG is supportive of allowing pregnant women and people under the age of 18 years accessing MSIC services. This is because both these groups inject in places without supervision or support which greatly increases their chance of death or injuries related to overdose. If these people are able to access MSIC services they will be able to inject under the supervision of professional staff, receive nonjudgmental care and be referred to services to address their drug dependence and related social issues. In addition, it is essential for pregnant women to be referred to drug treatments such as opioid substitution therapies, as withdrawals in the first and second trimesters can be fatal for the fetus.



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The CAG also supports allowing highly intoxicated consumers to access MSIC's services for the same reason as pregnant women and people under the age of 18. The CAG believes that the majority of highly intoxicated MSIC clients rarely hurt other clients or staff, but those who that are displaying high levels of aggression should not be admitted, as they are more likely to harm others.

The CAG would also like to see MSIC extend its operating hours and have a NSP in stage one. The CAG believes that MSIC should open at 08:00 am in the morning instead of 9:30 am. This is because many need to relieve withdrawal symptoms, as they have slept and not used overnight. The CAG also feels that MSIC consumers should be able to access injecting equipment in stage one as the other needle and syringe programs in the area may be closed. Also some people do not feel comfortable injecting in MSIC so it is important that we provide clean equipment to reduce the transmission of blood borne viruses.

Finally, the CAG would also like to see MSIC allow consumers to engage in non-injecting activities , without having injected. This is because activities such as the art project and writing group increase consumers' self- esteem, help consumers learn new skills and allow them to do other things besides taking drugs.

The CAG acknowledge that they do not represent all of MSIC consumers' views. Therefore, the CAG has written a questionnaire for others who are not in the group to express their opinions about the review. Please find a summary of the results of the questionnaires attached to this letter.

Thank you for taking the CAG and MSIC consumers' views into consideration.

Yours Sincerely

Production Note:  
Signature removed  
prior to publication.

Mark Goodhew

Mental Health Coordinator (forwarded on behalf of the MSIC Consumer Action Group)

# Results of Uniting MSIC Consumer Survey – Statutory Review 2016

*Note: views of MSIC consumers presented here do not necessarily represent views of all MSIC clients and/or MSIC Management and staff.*

Seventy five MSIC consumers completed a survey about how MSIC should operate into the future. Members of the MSIC Consumer Action Group encouraged consumers to complete the survey and assisted those who needed help with answering the questions.

## **Question 1: Do you think that pregnant women should be able to access MSIC services.**

*The majority of consumer respondents agreed pregnant women should be able to access MSIC.*

- 75% supportive
- 19% not supportive
- 7% unsure

### **Written responses**

The majority of responses were not supportive of pregnant women injecting, but acknowledged it happens and pregnant women should have the right to inject in a safe and non-judgmental environment. Respondents also reported that if pregnant women are allowed to access MSIC services they can engage with professionals to provide support and referrals to other services. Responses include:

- *Pregnant women should be treated just as equal as non-pregnant women. We all should deserve the same help and be treated equal for any kind of help (██████).*
- *MSIC is a better idea than using on the street (██████).*
- *Safety for both the woman and her unborn baby they should be allowed to use under the supervision of medically trained professionals (Anonymous).*
- *It will help if they have any problems with the baby and using and the staff can refer them to services (██████).*
- *Should be harm minimisation and not moral high ground (Anonymous).*
- *Not good, but if support is available, yes sweet let them in every day for monitoring. Get your own ultrasound! (Anonymous).*
- *I really don't believe a pregnant women should use drugs because of the innocent baby, but if they are going to use, it is best to do it safely here (Anonymous).*
- *It's not the baby's choice, but it's a safe place to inject (Anonymous).*

Responses that are not supportive of pregnant women at MSIC include:

- *It may hurt the unborn child and they will be addicted (██████).*
- *It not fair on the workers if anything happened to her baby (██████).*
- *They should not be using and the government should not support (██████)*

## Question 2: Do you think that people under 18 years should be able to access MSIC services?

*The majority of consumer respondents agreed under 18 year olds should be able to access MSIC.*

- 73% supportive
- 23% not supportive
- 4% unsure

### Written responses

Responses suggested that underage clients should be separated from older clients so they do not negatively influence them. Responses include:

- *Those who are under 18 are more vulnerable and mentally unaware of dangers. If they can access the service they can be taught safe using, injecting and disposing (Anonymous).*
- *Young people need a service that will help them with their problems (██████).*
- *Better than dying on the street and they need a bit of help (██████).*
- *It's obvious that most people no matter what age they are should not be using drugs. If they are 16 or 25 it does not change the fact they are using drugs and by using MSIC they are under supervision and can be educated and referred to drug treatment (██████).*
- *Some younger children are using drugs and MSIC could be a place to learn to inject more safely. They also need support and are a greater risk of OD (Anonymous).*
- *But they should be kept in a separate section so they don't mix with the "old and ugly" (██████).*

Responses that do not support under age clients accessing MSIC include:

- *Because they shouldn't be exposed to the full extent and lifestyle of this place (██████).*
- *Brains have not finished forming (██████).*
- *16 -18 year olds should have another place (██████).*
- *Anyone under the age should not be allowed in as it just encourages them more (██████).*

## Question 3: Do you think that highly intoxicated clients should be admitted to MSIC?

*The majority of consumer respondents agreed highly intoxicated clients should have access to the service.*

- 68% supportive
- 28% not supportive
- 4% unsure

### Written responses

The majority of responses supported highly intoxicated clients accessing MSIC as they a higher risk of overdose and are likely to inject in unsafe places if they are denied access. Some respondents expressed hesitation about admitting intoxicated clients that are also aggressive. Responses include:

- *It is safer for them to be near trained medical staff in case of overdoses (██████).*
- *If they are drunk they can come here and will be safe (██████).*
- *You have nurses to help (██████).*
- *Because serious risk of overdose (Anonymous).*
- *On one hand it's better to let them in, but it depends on the amount of drink they have had and their alcohol reading (██████).*
- *They are going to do it anyway, so it is safer for them to use here (Anonymous).*

- *At least you can keep an eye on them. Better they are a pain in MSIC than dead in the doorway (B565).*
- *Yes, but under strict supervision (██████).*
- *As long as not agro (██████).*

Responses that do not support highly intoxicated clients accessing MSIC include:

- *Highly unnecessary risk absorbing resources (██████).*
- *No not at all (Anonymous).*
- *Sober up first (██████).*
- *Would be silly and more work for you fellas (Anonymous).*
- *If they are drunk, leave them out (██████).*

#### **Question 4: Do you think that MSIC should change their opening hours?**

*The majority of consumer respondents agreed MSIC should change their opening hours.*

- 64% supportive
- 31% not supportive
- 5% unsure

#### **Written responses**

Eleven respondents requested that MSIC be open 24 hours a day and requested that MSIC should open earlier in the day, especially for clients who are working. Responses also requested that MSIC close later on the weekend.

Responses included:

- *If people work, it's not open early enough. Maybe open at 8 or 8:30am? (Anonymous)*
- *Open early to meet client's work times. This could help a lot (██████).*
- *To support the employed or those lives that requires an early start (██████).*
- *Yes, most people get their drugs as soon as they wake up. So I think the hours should be 07:30 am til 7pm (Anonymous).*
- *Yes a lot of us get here earlier than 09:30 am (██████).*
- *0930 -2130 7 days a week (██████).*
- *Sundays at least till the same time as every other day (Anonymous).*
- *Further opening hours on weekends – even it was til 8pm instead 5:30pm. Better if they could open later (██████).*
- *Weekends close at 10pm (██████).*
- *In the morning from 9 am and close at 10 pm on weekends (██████).*

## Question 5: Do you think you should be able to access injecting equipment in Stage 1?

*The majority of consumer respondents agreed MSIC should have Stage 1 NSP.*

- 74% supportive
- 23% not supportive
- 3% unsure

### Written responses

The respondents state that consumers should be able to access injecting equipment in Stage one, because needle and syringe programmes (NSP) in the Kings Cross area are sometimes closed, clients who are sanctioned from using the service would be able to access clean equipment to use elsewhere and clients sometimes lie that they are injecting, so they can access clean equipment. Responses include:

- *Yes as other places might be closed or vending machines broken (██████).*
- *Yes, because you don't always want to have a shot here and you might go home and KRC are closed. (Anonymous).*
- *Depending on the circumstances for example if they are intoxicated and cannot come in yes (██████).*
- *Because if people who are barred from the service should be able to access clean equipment (██████).*
- *I know consumers who have lied to get in the door to get their equipment, which is silly (██████).*

Unsupportive respondents state they are happy with MSIC's current NSP arrangements in Stage three, because a NSP in Stage one would decrease discretion, increase traffic and slow down the registration process. Some suggest having prepacked equipment, a fit machine outside and accessing equipment in another area would remedy these problems. Responses include:

- *What we do now is perfect don't change something that is not needed (██████).*
- *Stage three is sufficient (Anonymous).*
- *If equipment was available in Stage one I am worried about walking in and out of the front door. Isn't that defeating the purpose of using the centre? (Anonymous).*
- *It will be busy and we don't want the attention (██████).*
- *Too much traffic people would be in a lot (██████).*
- *Too many people in stage one waiting to use (██████).*
- *Without causing delay to other clients waiting to go into Stage two (██████).*
- *Why not prepacked equipment. It won't absorb time from the consumers getting inside to use (██████).*
- *There should be a fit machine outside (██████).*
- *Dispense from a separate area, so those booking in are not delayed (██████).*

## Question 6: Do you think that clients should be allowed to engage in MSIC activities, such as the art project and writing group without injecting?

*The majority of consumer respondents agreed MSIC clients should access without injecting for some activities.*

- 91% supportive
- 8% not supportive
- 1% unsure

### Written responses

The respondents state that activities such as the art project foster social interaction and creativity, but this activity should only be for registered clients. Responses include:

- Yes! The activities are great for social wellbeing. I suppose even more so on days clients cannot afford to/don't want to use but would like the social interaction (Anonymous).
- It helps people be creative and also art makes people happy (██████).
- As long as it's for existing clients (██████).
- Should be only for the clients that use this facility (██████).

### Other

Below are some interesting responses that do not relate to the main questions:

- *Should be able to get drugs and equipment together (██████).*
- *Sometimes I feel very unsafe on the street and I need some place I can go so I don't hurt myself or others. Sometimes I need someone to just watch me so I stay safe, because I have woken up in lane ways naked and don't know how I got there (██████).*
- *MSIC in itself is a fantastic service with all it has to offer. None of this would be available if it were not for the wonderful men and women behind the desk and behind the scenes to make it all possible, because not just anybody can work at MSIC. Many times I have needed a helping hand organising the arrival at detox and rehab, which a supportive MSIC worker is only happy to give me confidence, support and direction. I am a member of the consumer group, which has given me purpose, meaning and a sense of being a part of something constructive and a part of the community (Anonymous).*
- *I think it's great that consumers are being asked for their comments about this place, as it is for us and it feels great to play a part (██████).*
- *Clients should not fear police searches when coming into MSIC (██████).*
- *MSIC has stopped so many people from dying and you don't see needles all over the streets like before. Also you don't have people shooting up in peoples' driveways (Anonymous).*
- *Research is needed into a more suitable premise - one that does not flood. MSIC should relocate to a less visible location with consideration to the changing social demographics in this neighbourhood. Discretion is essential. The new place needs hiding away, so I can remain anonymous (██████).*

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