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IMPLEMENTING ADVANCE AGREEMENTS INTO
MENTAL HEALTH TREATMENT AND CARE PLANNING: A
PILOT EVALUATION OF THE PROCESSES AND
OUTCOMES

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A thesis submitted for the degree of Doctor of Psychology (Clinical) of the
Australian National University
I hereby certify that the work embodied in this thesis is the result of original research and contains acknowledgement of all non-original work.
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ABSTRACT

Mental health Advance Agreements (AdAs) are a method of anticipatory planning. AdAs allow consumers to formally communicate their treatment and care preferences for an anticipated period of acute mental illness and impaired ability to partake in clinical decisions affecting their care. AdAs are individually tailored in collaboration with a mental health professional, and developed while a consumer is feeling mentally well, competent and motivated. AdAs are hailed as one strategy for promoting consumers’ autonomy and empowerment in the management of their mental illness. Furthermore, AdAs are considered to be a functional method for promoting meaningful consumers involvement and informed consent in treatment and care planning (TCP), goals that are consistent with the current Australian national and territory mental health plans.

The impetus for introducing AdAs into Mental Health, Australian Capital Territory (MHACT), arose out of local consumer and staff advocacy for a mechanism where consumers could advocate for themselves during periods of acute mental illness. Past literature has established strong ideological support for anticipatory planning documents tailored to a psychiatric population, whereas empirical evidence is relatively scarce but growing. This thesis reviewed the current literature to build the scene for the current project, and provide a structure for conceptualising the process of developing an AdA, associated benefits and surrounding issues.

The project is comprised of one major study, piloting AdAs within MHACT, and two smaller studies, to gather additional information on AdAs and consumer involvement in MHACT. The pilot project adopted an action research framework to develop, implement, and evaluate
AdAs within MHACT. The second study utilised focus groups comprising of consumers and carers to gather further opinions and suggestions regarding the implementation of AdAs within MHACT. The third study developed and implemented the Consumer Involvement Questionnaire for Clinical Managers to uncover and explore professionals' knowledge, opinions, beliefs, and current practice concerning meaningful consumer involvement in TCP. The qualitative methods adopted by the project resulted in a rich and comprehensive collection of information. Findings from the study support the notion that developing an AdA is a highly individualistic and potentially therapeutic process, where consumers progress through several stages towards completing an AdA in differing ways and rates. The study also provides support for the potential benefits associated with AdAs. Furthermore, the study identified a range of specific issues and concerns relating to the process of developing and utilising an AdA, along with broader systemic issues concerning the implementation of AdAs into the mental health system.

Overall, the current project established that relevant stakeholders generally consider AdAs to be a valuable strategy for anticipatory planning, and to achieve meaningful consumer involvement in TCP. Organisational commitment and sharing the responsibility for implementing AdAs are two broad recommendations from the study. Resource allocation, regular education and training, clear policies and guidelines, and the availability of additional staff/consumer support, are suggested as essential for AdAs to be effectively and successfully implemented. In sum, the project findings bestow further support to the current literature on anticipatory planning, and offer an initial indication of the promising prospects and future directions for AdAs tailored for MHACT.
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CHAPTER ONE

Consumer Involvement in Individual Treatment and Care Planning

1.1 Introduction

In conjunction with contemporary healthcare philosophy, community mental health services have embraced the current ethos of active consumer involvement to ensure human rights and improve service provision. When applied to a psychiatric population, however, actualizing consumer involvement in individual treatment and care planning can be problematic. The nature of mental illness frequently reduces an individual’s capacity to make decisions relating to his or her treatment and care, thus rendering one’s own involvement difficult or nonexistent. Anticipatory planning tools are one solution to overcome this barrier, increasing involvement in treatment and care planning and providing consumers with a “voice” during a period of acute mental illness (Srebnik & Brodoff, 2003). Mental health Advance Agreements (AdAs) are a method of anticipatory planning. AdAs are a formal documentation of a consumer’s individual treatment and care preferences for a future period of mental illness and impaired competency. Consumers volunteer or choose to have an AdA, which is developed during a period when consumers feel mentally healthy, competent and motivated. AdAs are individually tailored and developed in collaboration with a mental health professional (e.g. clinical/case manager) and other individuals closely involved in a consumer’s treatment and care program (e.g. family). When activated, the AdA provides a mechanism for a consumer’s wishes for treatment and care to be heard, considered, and guide clinical decision making.
The notion of “allowing” individuals with mental illness to influence their own treatment and management decisions for a future period of impaired competence originated from the medical field, where patients with terminal illness were given the option of stating their preferences. Thomas Szasz initially proposed the modeling of medical advance directives into psychiatry in 1980 as a psychiatric will (Szasz, 1982). In the United States, the concept of giving psychiatric patients the same rights as physically ill patients to anticipatory planning was triggered following the introduction of the Patient Self Determination act 1990, where all federally funded health care institutions were required to notify patients of their rights to make advance directives (Atkinson, Garner, Patrick, & Stuart, 2003a; Swanson et al., 2003; Swanson, Tepper, Backlar, & Swartz, 2000). Since then, twenty one states have enacted specific statutes to guide the use of Psychiatric Advance Directives (Swanson, Van McCrary, Swartz, Van Dorn, & Elbogen, 2006). Similarly, in the United Kingdom the profile of advance planning was raised following the reviews of mental health legislation in 2001 (Atkinson, Garner, & Gilmour, 2004). In Australia, the importance of consumer and carer participation was nationally recognised in the first National Mental Health Plan released in 1993, which marked a movement towards creating a united policy and implementation framework for responding to the needs of people with mental illness.

AdAs are advocated by consumers, mental health professionals, and academics, as an approach to enhance autonomy and empower consumers in the treatment and care of their own mental illness. Furthermore, AdAs are hailed as a strategy for facilitating a collaborative engagement between consumers and mental health treating teams, and for
minimising the likelihood, or impact, of involuntary and coercive interventions (Amering, Denk, Griengl, Sibitz, & Stastny, 1999; Henderson et al., 2004; Miller, 1998; Swanson et al., 2000; Thomas & Cahill, 2004). Anticipatory planning is considered suitable for a psychiatric population, particularly for individuals diagnosed with an episodic mental illness, where fluctuating levels of competence are expected (Gallagher, 1998). Through experience, individuals with episodic mental illness may also have accumulated a significant amount of idiosyncratic knowledge, which is considered highly valuable for a successful AdA.

Thus, anticipatory planning is regarded as a method to meaningfully involve consumers in their treatment and care plan (TCP) for mental illness. Following a brief description of terms employed throughout this thesis, this chapter will focus on the concept of consumer involvement in TCP by describing the rationale, providing a conceptual model, and reporting factors that inhibit or enhance consumer involvement. Finally, anticipatory planning, in particular AdAs, will be introduced as a supported method of operationalising consumer involvement, and accomplishing the related positive outcomes.

1.2 Definitions

In recent times the term consumer has been increasingly applied to individuals who are currently utilising, or have previously utilised, Mental Health services (Australian Health Ministers, 2003). Other interchangeable terms for mental health service users include patients, clients, and survivors (Pilgrim & Rogers cited in Peck, Gulliver, & Towel,
2002). Concerns have been raised about the appropriateness of the term consumer to describe individuals who utilize mental health services. This is primarily because the group is vastly heterogeneous, and more importantly, because the services typically offered are limited and the individual may have little or even no choice in the service they receive (Dickerson, 1998; Telford & Faulkner, 2004). While a more neutral term is service user, this thesis will adopt the term consumer for two reasons. Firstly, it is the label currently used by government and non-government bodies in Australia, along with advocates for individuals with mental illness within the current research setting. Secondly, consumer is the label that implies the most equal power relationship between service user and service provider.

Consumer involvement is an essential component of contemporary healthcare philosophy (Anthony & Crawford, 2000). Also labeled as negotiated care, collaborative care, patient participation, user involvement, and person-centered care, models of consumer involvement show that it manifests on a variety of levels within a service and to differing degrees (Bowl 1996; Hickey & Kipping 1998; Anthony & Crawford 2000; Milewa, 1997; Peck et al., 2002). The degree of involvement can be conceptualized as ranging along a continuum that differs with respect to how much power and influence consumers hold within the relationship between themselves, their clinical manager, and the system. The continuum ranges from a consumer being a passive participant (i.e. consumer having little or no power), to being a recipient of communication (i.e. being informed), to being a subject of consultation (i.e. sharing the power), to an active agent of control and making treatment decisions (i.e. transferring the power). Additionally, consumer involvement can
occur on many levels within a mental health system, from the individual level (e.g. assessment, diagnosis, treatment and care planning), to managing local services (e.g. education, advocacy, and hiring staff), to planning services (e.g. policy, advocacy). While the concept of consumer involvement seems reasonably clear, research has identified considerable confusion about the meaning and purpose of consumer involvement (Bowl, 1996). Differences exist within and between groups of professionals and consumers regarding perceptions of what involvement entails, along with beliefs around the purpose and impact of involvement.

The focus for this thesis is active and meaningful involvement of consumers in their individual TCP. In general, planning for treatment and care consists of identifying medical, psychological and social treatments that can be formulated into a plan with goals for recovery, symptom management and relapse prevention. Meaningful involvement in TCP entails consumers being active agents in each stage, such as being given and provided with information, being given the opportunity to express their views, having their views acknowledged, contributing to decision making, and agreeing with their TCP.

1.3 The Rationale for Consumer Involvement

Historically, the momentum towards increasing consumer involvement in mental health services was fuelled by consumer movements (Kaufmann, 1999). These movements sought greater self-determination, and challenged the domination of coercive treatments and the professional establishment (Dickerson, 1998; Peck & Barker, 1997). Three rationales have been identified for the continued emphasis on consumer involvement.
Reflecting the historical motive, the primary rationale for consumer involvement is human-rights oriented. Involvement is a measure of autonomy, based on the moral principle that every human has the right to self-government and to making decisions pertaining to their life (Ritchie, Sklar, & Steiner, 1998; Widdershoven & Berghmans, 2001). Improving service quality and provision is regarded as another rationale for involving consumers in individual TCPs. Prompting this rationale was the perceived unresponsiveness of services to the needs and wishes of consumers, and the release of documents debating the effectiveness of the mental health system in responding to and treating mental illness (examples of Australian reports include the “Burdekin Report” by HREOC, 1993 and “Not for Service” by MHCA, 2004). Through involving consumers, mental health professionals can explicitly acknowledge the expertise of people who experience mental illness, and utilise a consumer’s valuable knowledge to develop an effective TCP (Kent & Read, 1998). Thus, it has been strongly suggested that services that accommodate consumers’ preferences are more likely to be perceived as responsive and relevant, compared to externally imposed services (Crane-Ross, Roth, & Lauber, 2000). Lastly, many authors advocate that there is significant therapeutic value attached to being involved, particularly on the individual care planning level (Hickey & Kipping, 1998; Peck & Barker, 1997; Peck et al., 2002; Pilgrim & Waldron 1998).

At present, legislative and mental health documents from Australia, the UK, and US articulate commitments to involving consumers (O'Donnell et al., 1999; Soffe, Read, & Frude, 2004). While the Australian mental health system is committed to involving consumers, strategies for effective consumer involvement in TCP are at relatively early
stages of implementation. Theory, research and practice are all required to assemble realistic and practical strategies for involving consumers in TCP. The next section will describe the goals of treatment and care planning, leading into the proposal that consumer involvement can be conducive to the goals of TCP. Following this, a conceptual model will be presented to assist in the understanding of how consumer involvement can facilitate the goals of TCP.

1.4 Treatment and Care Planning

The primary objective of community mental health services is to assess and treat individuals experiencing mental dysfunction or illness, with the goal of reducing symptoms, disability, risk factors, and harmful social consequences (Treatment Protocol Protocol, 2000). Commonly experienced in community mental health settings is the revolving door syndrome, which refers to the frequent pattern of repeated hospitalisations, non-adherence to a TCP, and subsequent deterioration (Gallagher, 1998). Furthermore, the natural course of numerous mental illnesses is chronic, episodic, and insuppressible, plausibly leading to an acute period of mental illness requiring hospitalisation.

The path of recovery to mental health is complex and varied. Adherence to a successful TCP, and in particular medication compliance, is hailed as a necessary ingredient and can play a significant role in maintaining mental health. For instance, adhering to antipsychotic medication is one of the most effective means of preventing relapse for individuals with schizophrenia (Gray, Wykes, & Gournay, 2002; Perkins, 1999). Despite
this, approximately 40 per cent of individuals cease taking their medication within one year of commencing, and 75 per cent within two years (Perkins, 1999). Gray and colleagues (2002) conducted a review of the literature to identify aspects that impact on medication adherence. They concluded that awareness of illness, beliefs about treatment, and side effects of medication are important factors. Additionally, Gallagher (1998) noted that a significant number of consumers who may be regarded as “treatment resistant” express not so much their disagreement with treatment, but their opposition to a sense of depersonalisation and loss of control that often accompanies involuntary treatment. Overall, it is likely that both illness factors and personal experience have the potential to influence a consumer’s ability and willingness to adhere to a TCP. Given the important role of adhering to an effective TCP in preventing mental illness, strategies that address or ease the impact of non-adherence factors are clearly warranted.

Meaningful involvement of consumers in individual care planning is being increasingly recognised as an effective approach for increasing adherence to a TCP. One criterion for enhancing adherence is to develop a version of a TCP that the consumer will agree with, and commit to, where “it would seem logical that gaining agreement is linked to inclusion in the process of care planning” (Anthony & Crawford, 2000, p. 430). Corrigan (2002) also emphasised the importance of a mutually respectful and optimistic collaboration between consumer and service provider. Consumers “empowered in these collaborative relationships will benefit more from treatment and be more successful in controlling their symptoms” (Corrigan, 2002, p. 218). Thus, consumer adherence to TCP is likely to be enhanced through meaningful involvement and collaboration.
Consumer involvement, in the context of individual care planning, is proposed to enhance the potential of a successful TCP. To assist in explaining how involvement and collaboration have the potential to influence adherence to a TCP, a model describing styles of developing a TCP will be presented. Understanding some of the mechanisms underpinning consumer involvement could guide the development of effective strategies that are compatible with the objectives of a TCP. Anticipatory planning will later be described as one initiative to increase meaningful consumer involvement in TCP.

1.5 A Conceptual Model for Developing a Treatment and Care Plan

The existence of a successful TCP may be enough to assist recovery and maintain an individual’s mental health. Without, however, a consumer’s adherence, the TCP is worthless. The model presented in this section is based on the premise that how a TCP is developed with a consumer, can significantly impact one’s adherence to the plan. Conceptually, the style or method a professional adopts when developing a TCP with a consumer is notably similar and intertwined with the continuum of consumer involvement described previously. The style can range from a strictly paternalistic style, where the consumer has minimal power and involvement; to a meaningful collaboration, where the consumer is actively involved and retains power and influence with the TCP. Realistically, there are circumstances when the style at either extreme of the spectrum may be considered appropriate. In a mental health setting, the style adopted is presumably based on clinical judgment, and operationalised on an individual and situational basis.
In clinical practice, it is widely assumed that the more a consumer is meaningfully involved in their TCP, the more they will subjectively perceive the experience as voluntary, autonomous, empowering, and humanizing. These are some of the underlying mechanisms proposed to drive the success of consumer involvement. Consequently, such perceptions are likely to impact on a consumer’s outlook toward his or her plan, resulting in a plan that he or she is more likely to understand, agree, and accept. Combining those perceptions and attitudes, it is expected that consumers would feel more motivated, confident, and in control of adhering to their TCP, which as outlined previously is an essential component for reducing the rate of relapse and sustaining mental health. An explanation for how a paternalistic style is more likely to result in harmful outcomes compared to a collaborative approach will be proposed. Three psychological mechanisms will be outlined to illustrate how consumer involvement is likely to result in a TCP that a consumer will agree with and commit to.

1.5.1 The Provision of treatment and care

A paternalistic style of treatment is frequently associated with a more historical means of providing care to individuals with mental illness (Rich, 1998). At present, according to the principle of least restrictive care, methods requiring a paternalistic stance are intended to be employed only as a final resort (Australian Capital Territory, 1994). Fragments of paternalism in everyday practice however, continue to persist. Paternalism is a practice of treating or governing people by providing for their needs without providing them with rights or responsibilities (The American Heritage, 2000). Compared
to meaningful involvement, paternalism as a framework for communicating with a consumer is more likely to be coercive, or be perceived by a consumer as coercive.

Coercion is a practice that involves the use of authority to restrain another’s autonomy (O’Brien & Golding, 2003). Furthermore, implied in the concept of coercion is that the action imposed upon an individual is against his or her wishes (Carroll, 1991). Debates regarding the rationale, benefits and harmful impacts of coercion are beyond the scope of this thesis and have been discussed elsewhere (e.g. Borum et al., 1999; Elbogen, Swanson, & Marvin, 2003; La Fond & Srebnik, 2002; Mulvey, Geller, & Roth, 1987; O’Brien & Golding, 2003; Strachan & Spaulding, 2003). In general, the application of coercive practices within a mental health setting are justified based on the presumption that at times, individuals’ suffering from mental illness have limited ability to chose or act in their own best interest (O’Brien & Golding, 2003). Involuntary interventions are coercive by nature and can result in a positive therapeutic outcome, such as the reduction of mental illness. Coercive interventions, however, deprive individuals of their autonomy and decision making power, and have been associated with feelings of disempowerment, apathy, submissiveness, dehumanisation, and dependency (Fitzsimons & Fuller, 2002; Gallagher, 1998). In more severe cases, it has been suggested that coercion has the potential to result in post-traumatic symptomatology, an undermining of trust with service providers, disengagement with health care, and non-adherence with treatment programs (Amering et al., 1999; O’Brien & Golding, 2003).
Given that not all consumers experience harmful effects from coercion, it is probable that perceptions of coercion are just as influential as acts of coercion. Gardner and colleagues (1993, cited in La Fond & Srebnik, 2002) demonstrated that consumers’ perception of coercion is influenced by the degree of control they hold, the degree of influence others hold, the choices available, and the amount of freedom they have in the hospital admission process. Therefore, perceptions of coercion could be reduced through respecting consumers’ rights to have opinions, and allowing consumers to have more choice and control over treatment decisions. So, “rather than viewing the consumer as a passive receptacle for treatment, clinicians must partner with them to design treatment programs that meet the person’s goals” (Corrigan, 2002, p. 222). This framework has several possible optimistic outcomes such as heightening self-esteem, developing decision-making skills, and facilitating consumer autonomy (O’Brien & Golding, 2003). Overall, while at times paternalism and coercive practices are justified and implemented on behalf of consumers’ best interests, principles of harm-minimisation and least restrictive means should take precedence. Developing and implementing strategies congruent with that philosophy should be a high priority for mental health services.

1.5.2 Empowerment, Autonomy and Motivation

Complimenting a harm minimisation standard, added predominant incentives for enhancing consumer involvement in TCP are to enhance consumer empowerment, autonomy, and motivation. The exact nature of the relationship between each psychological construct and involvement remains unclear. It is suggested, however, that these constructs are essential characteristics and products of consumer involvement.
Underpinning consumer involvement is empowerment, defined as “a process through which clients obtain resources at multiple levels to enable them to gain greater control over their environment” (O'Donnell et al., 1999, p. 685). The concept of empowerment, along with the processes and outcomes of empowerment, has been described in more detail elsewhere (Clark & Krupa, 2002; Dickerson, 1998; Fitzsimons & Fuller, 2002; Nelson, Lord, Ochocka, 2001; Zimmerman, 1995). To improve the applicability of the concept, Dickerson (1998) operationalised empowerment as the consumer demonstrating firstly, competence e.g. accepting psychiatric illness; secondly, self determination e.g. actively making choices about involvement in own treatment; and thirdly, social engagement e.g. identifying with, and supporting other consumers.

In general, Corrigan (2002) noted that when consumers’ personal power is enhanced, their general health goals are greatly improved. In a mental health setting, empowerment has been shown to be associated with quality of life and community participation (Rogers, Chamerlin, Ellison & Crean, 1997), along with a reduction in rates of re-hospitalisation (Nelson, Ochocka, Griffin & Lord, 1998). Fitzsimons & Fuller (2002) outline several characteristics of a setting or organisation that facilitate consumer empowerment. These characteristics are the provision of competency building activities, a flexible, collaborative approach, individualised and strengths focused approach and the provision of supports (Fitzsimons & Fuller, 2002). This framework supports other strategies suggested to promote empowerment, such as allowing consumers to make
choices about the services they receive, and encouraging decision making and self-responsibility (Corrigan, 2002; Dickerson, 1998; Nelson et al., 2001).

Intimately linked with empowerment is the notion of autonomy. The essence of autonomy rests in the principle that every individual holds the right to control and make decisions pertaining to their life (Ritchie et al, 1998). Every individual has certain constraints on the degree of autonomy they genuinely hold. Given the nature of mental illness, consumers frequently encounter unique constraints on their autonomy impacted by families or caregivers’ desire to protect, society’s duty to allocate health resources, and the professionals’ duty to act in consumers’ best interest and do no harm (Ritchie et al, 1998). It is not within the scope of this thesis to describe the mechanisms of autonomy in depth. In general, the psychological benefits of autonomy are related to theories of self-determination (e.g. Williams, Rodin, Ryan, Grolnick, Deci, 1998) and choice theory (e.g. Winick, 1992). Overall, consumer involvement is one means of enhancing a consumer’s autonomy, which is frequently restricted by paternalistic or coercive practices, and resulting in a voluntary TCP that a consumer is motivated to adhere with.

A consumer’s level of motivation is commonly considered to be another factor associated with his or her level of involvement and adherence to a TCP. There are many and diverse theories that have been developed in an attempt to explain motivation and the role of motivation in psychological wellbeing (e.g. Cordova & Lepper, 1996; Deci, Koester, & Ryan, 1999; National Advisory Mental Health Council, NAMHC, 1995; Ryan & Deci, 2000). For the purposes of this body of work however, the term motivation refers simply
to the participants lay understanding of the concept. In general, it is proposed that consumers would be more motivated to contribute to a TCP if they perceive themselves to be meaningfully involved. It has been suggested that consumers who are given choices will feel less coerced into accepting treatment, enter a treatment program that reflects their preferences, and be more invested in the treatment compared with consumers who are not provided with choices (La Fond & Srebnik, 2002).

It is widely acknowledged that if one chooses to do something then they are more likely to comply with that decision than if they have been told to do something (Miller, 1998). Not only are individuals more likely to follow through with their decisions but they are likely to perform more effectively and with greater motivation. This phenomenon has been explained using the goal setting effect, which has been associated with a variety of therapeutic benefits (Locke & Latham, 2002). This principle states that the setting of an explicit goal is a significant factor in accomplishing that goal. For instance, when a consumer voluntarily agrees to a treatment, the initial step of setting a goal has been made. Once committed to a goal or decision, the individual is more likely to pursue that goal or decision. Pursuing a goal can be self-reinforcing, which in turn acts as a mechanism to facilitate goal achievement (Winick, 1996). Thus, it is apparent that when designing strategies to involve consumers, it is important to understand the factors that motivate consumers to want to participate in a TCP, and the factors that motivate them to adhere to a TCP.
To sum up, the conceptual model presented above described how different styles of approaching treatment and care (paternalistic-collaborative) could impact on a consumer's adherence to a TCP. This provided a framework for understanding the relevance of increasing the practice of active consumer involvement in treatment and care planning. To further substantiate the notion of meaningful consumer involvement, the following section will highlight the supported and hypothesised benefits related to involving consumers in their TCPs.

1.6 Outcomes of Consumer Involvement

Developing a TCP in collaboration with consumers clearly indicates numerous benefits for the consumer at the intrapersonal level, such as an increased sense of empowerment, autonomy, and motivation. In addition, there are many hypothesised and empirically supported benefits at the interpersonal (consumer-professional) level; and mental health system level. For consumers, a recent study demonstrated that of those who felt involved in their TCP, 82% reported that the plan had made a positive impact on their lives (Peck et al., 2002). Nelson and Borkovec (1989 cited in Kent & Read, 1998) also found a positive relationship between the level of client participation in treatment, and therapeutic outcome.

At the interpersonal level, meaningful involvement has been argued to establish and maintain relationships with key workers in mental health services, such as case managers (Kelson, 1997 cited in Crawford & Rutter, 2004), where both parties are more cooperative and understanding of each others viewpoint (Summers, 2003). On a systemic
level, a study by O'Donnell and colleagues (1999) found that consumers with a diagnosis of schizophrenia and bipolar disorder, who received client-focused case management, reported greater satisfaction with service delivery compared to consumers who received standard case management involvement. Additionally, consumer involvement has been argued to improve services and the use of available resources through consumers providing information, practical contributions, or political pressure (Crawford et al., 2003; Kent & Read, 1998; Soffe et al., 2004; Summers, 2003). Overall, consumer involvement has been proposed to challenge institutionalized thinking and discrimination, in order to increase the systems responsiveness to a consumer's individual wishes and needs.

Despite the growing trend towards consumer involvement and the supporting literature, many studies have found a dissonance between supportive opinions and actual practice (Anthony & Crawford 2000; Soffe et al. 2004; Summers, 2003). For example, Anthony and Crawford (2000) interviewed nine qualified mental health nurses to gain an understanding of their perceptions around service user involvement. Findings suggested that there was cultural change towards more consumer involvement in care planning, but that in actual practice this was inconsistent and variable. Attempts to explain the existence of dissonance have sought to identify factors that enhance, or constrain, the use and impact of consumer involvement. The following section will draw on several models that attempt to understand factors identified by previous authors.
1.7 Factors that Influence Consumer Involvement

There are numerous models in current literature and research that describe and explain factors that impact the utilisation and implementation of consumer involvement in treatment and care planning (e.g. Anthony & Crawford, 2000; Hickey & Kipping, 1998; Pilgrim & Waldron, 1998; Wadsworth, 1998). Underlying many of the factors reported to impact on consumer involvement is the transition, and ongoing influence, of conceptualising treatment for mental illness within a medical model, to the adoption of a biopsychosocial framework. By placing emphasis on the medical aspects of treatment and care, however, the medical model continues to be significantly influential and less conducive to consumer involvement. It has been argued that the medical model encourages the consumer to adopt a passive role, where even if the provider genuinely attempts to facilitate consumer participation “the implicit message contained in a medical diagnosis and the dispensation of medication…may inadvertently work against the client’s assuming control and taking responsibility” (Kent & Read, 1998, p. 298). The cultural framework adopted by a mental health system inevitably influences the system on many levels including policy, legislation, clinical practice and professional culture. In addition, the debilitating effect of mental illness and side effects of medical treatment, could further impact a consumer’s ability to be involved in a TCP.

The most apparent factor that will facilitate the shift towards consumer involvement is organisational commitment. Organisational commitment is reflected through policy, procedures and clear strategies; and is a prerequisite for the allocation of resources and funding to support the realisation and potential of consumer involvement initiatives
(Crawford et al., 2003; Hickey & Kipping, 1998; Peck & Barker, 1997; Pilgrim & Waldron, 1998). Current mental health legislation is one organisational aspect claimed to be counter to consumer involvement. Given the perceived conflict between consumerist philosophy and statutory duties or responsibilities, current legislation has been argued to place significant constraints on the realisation of a consumer involvement framework (Anthony & Crawford, 2000; Crawford et al., 2003). While initially this dilemma appears insurmountable, the current legislation and consumerist philosophy are not mutually exclusive and, given the complex and individual experience of mental illness, are both regarded as necessary to achieve and sustain mental health. The mental health system is obligated to protect individuals experiencing mental illness, and is responsible for acknowledging and reducing the serious and debilitating impact mental illness can have on an individual. Thus, legislation and guidelines are necessary to provide voluntary and involuntary treatment. Furthermore, in conjunction with this legislation, the system is required to recognise the significance and value of involving consumers at all levels of the service.

At the community service level, several factors have been reported to hinder consumer involvement in TCP including busy healthcare environments (Anthony & Crawford, 2000); a lack of education or information (O'Connell & Stein, 2005); the time consuming nature of involving consumers (O'Donnell et al., 1999); a low level of managerial & staff support (Crawford et al., 2003); and tokenistic involvement (Kent & Read, 1998; Peck et al., 2002).
Professional culture including opinions, attitudes and traditional role expectations are also considered important factors when understanding the uptake of consumer involvement in TCP. Mixed opinions amongst service providers and other decision makers, around the value of consumer participation, are identified as a frequent barrier to effective participation (Mental Health Council of Australia, MHCA, 2004). Two studies, utilising a questionnaire developed by Kent and Read (1998), indicated that in general, professionals held positive attitudes towards the concept of consumer involvement; however most respondents predicted that services would improve only a little if consumers were involved in planning and delivery (Kent & Read, 1998; Soffe et al, 2004). Additionally, Peck and colleagues (2002) found that individual mental health professional’s determined the amount a consumer was involved in individual care planning.

A range of studies have suggested that professionals’ opinions around the characteristics of individuals with mental illness, the treatment model employed, the perceived need for involvement, and anticipated benefits associated with consumer involvement, all impact on if and how they involve consumers in TCP. For example, professionals who believe that consumers have the required skills, expertise, or ability to adequately judge the treatments they are given, are more likely to include consumers, compared to professionals who do not believe consumers hold these qualities (Crawford et al., 2003; Kent & Read 1998). Conversely, mental health professionals are less likely to adopt involvement strategies if they believe that mental illness can only be diagnosed and treated by professionals (Hickey & Kipping, 1998); if they believe that professionals are
able to adequately judge a consumers best interest (Bowl, 1996); if they feel cynical about the benefits associated with involvement (Bowl, 1996); or if they believe that consumers should be grateful for services they receive (Kent & Read, 1998).

Staff resistance towards consumer involvement could also be attributed to insufficient training (Crawford et al., 2003) or sensing one’s own professional autonomy is being threatened or opinion undermined (Hickey & Kipping, 1998; Katan & Prager, 1986 cited in Soffe et al., 2004). Other findings suggest differences of opinion between professionals with differing theoretical orientations or backgrounds. One study reported that psychiatrists are less optimistic, more defensive, less similar to consumer in their values, believe involvement could potentially cause more stress on consumers, and are less willing to involve consumers compared to mental health professionals not from a biological orientation (Summers, 2003). Obviously, successful consumer involvement in TCP requires staff dedication and cooperation. Subsequently, it is imperative to identify concerns, opinions and beliefs held by professionals that hinder consumer involvement and address those concerns in a sensitive and respectful manner.

The relationship between a consumer and their key worker has been suggested to influence consumer involvement (Crawford et al., 2003). An investigation by Peck and colleagues (2002) indicated that the relationship between consumers and their key worker appeared crucial in determining the extent that consumers were involved in the design and review of their care plans. Often, a power difference between a consumer and key worker exists in favor of the worker. This imbalance is reinforced by the reality that
during a period of acute illness, the consumer is likely to exhibit a high level of dependency on staff and the system (Bowl, 1996). Furthermore, Kent and Read (1998) noted that there may even be reluctance on a consumer’s behalf to assume responsibility within the relationship, primarily as a result of the dynamics inherent in a medically oriented interaction. Also, some consumers may not seek partnership, desire more power within the relationship, or wish to participate (Peck & Barker, 1997; Hickey & Kipping, 1998). As noted previously, the dynamic between consumer and professional should be flexible and determined on an individual and situational basis.

Factors inherent in the nature and complexity of mental illness and medical treatment can also significantly impact the extent of consumer involvement (MHCA, 2004). For example, symptoms of mental illness, effects of medication, individual coping abilities, and stages of illness acceptance could all impact on a consumer’s capacity to be meaningfully involved (Bowl, 1996; Hickey & Kipping, 1998). Previous negative experiences or fear of being involved present further barriers (ACT Government, 2006; Bowl, 1996; Pilgrim & Waldron, 1998). Thus, mental illness factors, subjective experiences, and particular individual characteristics are all suggested to influence the uptake and effectiveness of consumer involvement.

In summary, the literature suggests that there are four extensive clusters of factors that impact the implementation of consumer involvement in TCP. Organisational factors, community service factors, professional culture factors, and mental illness factors all contribute and potentially influence consumer involvement. Previous literature provides
suggestions to improve the likelihood and success of consumer involvement. For instance, the National Consumer and Carer Forum of Australia (NCCFA, 2004) suggested that for consumer involvement to be truly effective, “all participants involved in the mental health sector must display a high level of commitment and belief in the value of consumer and carer participation” (p. 9). Peck and colleagues (2002) recommend that promoting positive staff attitudes and behaviors will assist in achieving a consistent involvement of consumers in care plans. More specifically, Anthony and Crawford (2000) identified several themes that could promote consumer involvement, including the provision of information, the need to examine practical dimensions, user-friendly documentation, high staff morale and motivation, service user feedback, and valuing the clients’ perspective and involvement.

The above framework was employed by the current study to conceptualise and organize the information collected, and particularly for identifying factors impacting on the implementation of Advance Agreements. Suggestions provided by previous studies were also highly influential during the development of advance agreements as a consumer involvement initiative.

1.8 Advance Agreements

Advanced agreements (AdAs), and other anticipatory planning tools, are considered a supported strategy for implementing the objectives of consumer involvement in mental health care. This section will introduce anticipatory planning tools as one method for enhancing consumer involvement in TCP, along with outlining current support for the
service-wide implementation of AdAs to form a component of routine clinical management.

1.8.1 Anticipatory planning tools

There are numerous names for anticipatory planning documents, frequently used interchangeably and with modest consistent meaning. Mental health anticipatory planning tools include advance refusals, advance statements, instructional or psychiatric advance directive (PAD), proxy or agent driven directive, Ulysses contract, and advance agreements (AdAs). Consistent across all variations is the underlying idea that the consumer communicates his or her preferences, instructions, viewpoints, and desires for future treatment and care in anticipation of a reduced capacity to participate in informed decision-making.

Atkinson, Garner, Stuart, and Patrick (2003b) collected qualitative data to deduce five models of advance directives that differed on levels of initiation (staff or consumer), cooperation and agreement, legal status, competency assessments, and the interventions covered by the document. Utilising these dimensions, types of anticipatory planning can begin to be distinguished. Advance refusals allow a consumer to opt out of treatment (Atkinson et al., 2003b). An advance statement refers to the consumer alone stating their choice for treatment if they suffer loss of mental capacity (Atkinson et al., 2003b; Beever, 2002). The term instructional or advance directive, known as a “living will” in the medical realm, is developed by the individual without assistance, is considered as legally enforceable in many countries, and provides instructions to medical providers for opting
in or opting out of specific treatments (Atkinson et al., 2003a; Gallagher, 1998; Srebnick & La Fond, 1999). A Ulysses contract is considered more legally binding, as the consumer states they do not want to be able to revoke their contract once they relapse into their mental illness or when they display impaired competence (Gallagher, 1998). Proxy advance directives entail nominating a representative or power of attorney who can exercise substituted judgment (Amering et al., 1999) or use the “best interest” standard to make decisions on a consumer’s behalf (Srebnick & La Fond, 1999). One main advantage of allocating a proxy is to allow for the consumer’s current circumstances to be considered and to guide clinical decisions (Srebnick & La Fond, 1999). A problematic feature, however, of proxy advance directives is that many individuals suffering from severe mental illness either do not have a social support to nominate or anyone they could trust (Backlar & McFarland, 1996). Finally, AdAs refers to an agreed plan, where a consumer’s preferences for future treatment and care are developed in collaboration with relevant stakeholders. AdAs best fit model II, as described by Atkinson et al. (2003b; 2004), where developing an AdA is a cooperative process viewed as complimenting the normal process of clinical decision making. The notion of preferences, compared to instructions, is emphasised, where preferences are dispositions to act and not necessarily a definitive or binding statement of actions that will happen in the future.

This project evaluated an implementation of advance agreements (AdAs) to emphasise the value of collaboration when documenting preferences for future treatment and care. Listing preferences, as opposed to one specific instruction, is more suitable for a psychiatric population where future episodes of mental illness cannot be predicted with
complete accuracy. Although the consumer is expected to have the most input and control over their AdA, it is a clinician's duty of care to ensure the preferences have been made through an informed and logical decision process, during a period of adequate competence (Savulescu & Dickenson, 1998). The content of an AdA is individualistic. The Information documented in an AdA can include a relapse prevention plan, informed consent to opt in or out of treatment/s, personal values and acceptable tradeoffs in treatment, preferences for treatment facility, treating professional/s, emergency care, and involvement of significant others. The AdA is, therefore, a document that the consumer creates in collaboration with a mental health professional, which states specific preferences and reasons, along with providing a list of alternative options should the consumer be unable to receive their first preference.

1.8.2 National and Local Support for Consumer Involvement and AdAs

As suggested previously, effective and successful initiatives for consumer involvement in TCP require organisational commitment and support. A historical account on the commitment to consumer involvement within Australia is documented elsewhere (MHCA, 2004). More recently, the National Practice Standards for the Mental Health Workforce (2002) stated a requirement for consumer and carer participation. Standard 2 is particularly relevant to the current project, stating that

Mental health professionals encourage and support the participation of consumers and carers in determining (or influencing) their individual treatment and care.

They also actively promote, encourage and support the participation of
consumers, family members and/or carers in the planning, implementation and evaluation of mental health service delivery (cited in MHCA, 2004, p. 13)

The current National Mental Health Plan 2003-2008 adopts a population health framework that emphasises a holistic approach to improving mental health. The new plan outlines four priority areas with key directions, many of which are in align with the aims of an AdA program. For instance, key direction 4.2 “to increase the capacity of consumers to take charge of their own care” (Australian Health Ministers, 2003, p. 17) is clearly synonymous with the overall goals of AdAs.

More locally, the ACT Mental Health Strategy and Action Plan 2003-2008 supports the AdA project under Action 27 that aims to establish a Clinical Review Committee with representation from Mental Health ACT, consumers and carers to accomplish a variety of tasks, one being to “Establish advance agreements as a routine component of care planning” (2004, p. 74). Additionally, the ACT Mental Health strategy and action plan outlined two gaps within the current system that may impact on the success and need of implementing AdAs. Firstly, it was reported that the emphasis on managing the moderate to severe psychiatric population had seen reduced provision of services to those who had become relatively stable and discharged from care, and that this is the population who are likely to be most suitable for developing AdAs. Secondly, a gap was identified in relation to meaningful engagement with carers, where the option of advance agreements was recognised as a possible tool for involving families or carers.
1.9 Summary

AdAs are considered a nationally and locally supported technique for increasing consumer involvement in TCP. Current governmental documents clearly acknowledge the expertise of consumers, and state a commitment to involving consumers across all levels of the mental health system. Consumer involvement has been advocated as a method of ensuring the protection of human rights, improving mental health service provision, and endowing therapeutic value. Despite the growing trend towards consumer involvement, and recognition of associated benefits, many factors have been identified that impact the progression and success of involvement in TCP. These factors are important to consider when developing the infrastructure of research programs, and to guide the framework for evaluation and recommendations.

An action research methodology was adopted to develop AdA documents, investigate the individual process of developing an AdA, and generate knowledge for effective and meaningful implementation of AdAs in Mental Health Australian Capital Territory (MHACT). The overall objectives of AdAs are to firstly, provide consumers with a tool to formally document their preferences for treatment and care intended to be referred to, considered and implemented during periods of mental illness; and secondly, to provide a vehicle for consumers to be meaningfully involved in their treatment and care plans. Both processes, developing and utilising an AdA, have associated benefits that will be outlined in Chapter Two.
CHAPTER 2

Implementing Advance Agreements into Clinical Practice

2.1 Introduction

This chapter will present a model for Advance Agreements (AdAs) that depicts the stages of developing an AdA, the processes involved, the underlying mechanisms, and associated outcomes. Insight and competence, which are two necessary conditions for developing an AdA, are also reviewed. Furthermore, the chapter will outline specific issues and considerations proposed to impact the implementation of an AdA initiative in a community mental health setting. Given the relatively scarce knowledge on AdAs, the proposal of an original model for AdAs, and the complex issues involved, an action research methodology was employed to implement an AdAs within MHACT. The action research framework will be illustrated as a method for investigating the aspects involved in implementing AdAs within MHACT as part of treatment and care planning, along with evaluating the individual application of AdAs.

2.2 An Operational and Conceptual Model for Advance Agreements

Illustrating the stages, processes and outcomes associated with AdAs is central to implementing and evaluating an AdA initiative. Previously, most literature on mental health advance planning have focused on the outcomes of anticipatory planning documents, and listed hypothesised benefits generated for the consumer, significant others, mental health professionals and the mental health system. Some critics have suggested that if a mental health advance plan, such as an AdA, is consistent with the
consumer's best interests, then the plan will serve chiefly to support the decisions that health care professionals would have made anyway (Dressor, 1994 cited in Miller, 1998). This criticism requires an assumption that the mental health professional's judgment of "best interest" for the consumer is congruent with the consumer's interpretation of best interest. Regardless, this thesis is proposing that the process of developing an AdA can be just as, if not more, beneficial than the actual utilisation of the completed document. The notion that there is value in the process of developing an AdA is supported by Amering, Stastny, & Hopper (2005), who recognised that executing an advance directive is "a sustained act of self-examination and situation appraisal" (p. 248). Furthermore, Swanson and colleagues (2000) proposed a model consistent with the idea of breaking down the process and associated outcomes, which was influential in the development of the model proposed in this thesis.

Developing an AdA is a highly individual process considering that professional practice styles vary, along with consumers experiencing differing psychiatric issues and personal needs (Peters & Chiverton, 2003). The operational and conceptual model, depicted in Figure 1, aims to illustrate the general process and mechanisms involved in developing an AdA. Following the establishment of a systemic commitment to providing AdAs as a service, the AdA process begins with offering a consumer the opportunity and choice to engage in the service. This is achieved through regular advertising campaigns and education of AdAs by the mental health system and associated staff. Clinicians, consumers, carers or family members can indicate that they would like to engage in developing an AdA and initiate the process. The second stage of developing an AdA
involves the consumer contemplating their mental illness, including past treatment successes and failures. The third stage entails discussing choices, problem solving and making decisions for preferences, and then incorporating the preferences into a relapse prevention framework. During the fourth stage, the considered preferences are agreed upon by the consumer and relevant treating team members, formally documented, stored on a shared mental health database, and distributed to significant others. And finally, the AdA is activated and implemented during a mental health crisis, when the consumer is experiencing a decreased ability to participate in decisions relating to treatment and care. The AdA is a “living document”, flexible and available for review on a periodic basis and following a relapse.

The entire process of developing an AdA is intended to be collaborative. Furthermore, psychoeducation is provided when necessary, forming an essential component of informed decision-making. The following section will describe each stage and process in more detail, and propose connections or explanations for outcomes associated with AdAs.
Figure 1. The five stages of developing and activating an Advance Agreement
2.2.1 Stage one & two: Providing the opportunity and Contemplation

Prior to developing an AdA, a consumer must first be presented with the opportunity to do so. For some consumers, being offered this concrete opportunity may be an introduction to the concept that they can actively participate in their individual treatment plans (Sherman, 1998). The availability of AdAs as part of a TCP allows community mental health providers to demonstrate that they value consumers’ perspectives and respect their choices, and promote consumer autonomy and responsibility (Atkinson et al., 2004; Savulescu & Dickenson, 1998). The option of developing an AdA provides an opportunity to enhance consumers’ sense of being meaningfully involved and in control of future decisions regarding their treatment and care (La Fond & Srebnik, 2002). Overall, through AdAs, mental health providers can send the message that treatment is individualised, and that consumers can be involved in and influence their TCP.

There are many reasons that consumers’ may not wish to engage or participate in developing an AdA. In a study on joint crisis planning, only 36% of the consumers’ eligible to participate accepted the offer (Henderson et al., 2004). Consumers who declined either did not anticipate becoming unwell, already had a plan in place, believed that the plan would be beneficial, or believed that no-one would acknowledge or use the plan (Henderson et al., 2004). Thomas and Cahill (2004) suggested additional reasons for a consumer’s reluctance to develop AdA. They suggested that consumers may already feel demoralized, disempowered and oppressed by negative experiences within the mental health system, and they may not wish to acknowledge the possibility of readmission. Other studies seem to generate similar reasons. In a survey of opinions on
Psychiatric Advance Directives (PADs), consumers identified that the barriers to
developing a PAD included a lack of understanding, inability to express preferences, the
unavailability of assistance, the belief that the PAD will not be accessible, and the belief
that completing a PAD is time consuming and difficult (Swanson et al., 2003).
Additionally, Amering et al. (2005) found that the main reasons consumers reported for
avoiding PADs were fears that reviewing past experiences would be traumatic and could
lead to a relapse, and pragmatic issues, such as too much paperwork or the possibility that
the plan could be overwritten in practice. Amering et al. (2005) also identified aspects
that would enhance the likelihood of engaging consumers, including discussions with
professionals, being invited to develop a plan while in hospital and when mental illness
is a priority, and encouragement from significant others.

Once a consumer has arrived at the decision to develop an AdA, the second stage entails
contemplating and actively reflecting on his or her mental illness, early warning signs,
past effective treatments, and treatments that have not worked, in order to arrive at
treatment decisions in relation an anticipated period of acute mental illness (Swanson et
al., 2000). Previous literature has noted the potentiality of contemplation and discussions
around mental illness to lead to harmful consequences for the consumer (Amering et al.,
2005). Given the sensitive nature of the topic, developing an AdA with a trained
professional is one means of reducing the possibility of negative effects. More
optimistically, contemplating and actively thinking about one’s illness could stimulate
ownership and responsibility for one’s actions, and provide an incentive to employ
preventative measures and continue with a treatment plan (Miller, 1998).
2.2.2 Stage three: Deciding on and listing preferences

The third stage engages the consumer in problem solving and decision-making. A structured problem solving approach is one recommended strategy and requires a consumer to define the problem, generate alternative options, consider and evaluate advantages and disadvantages, and choose a favored option in collaboration with a mental health professional (Treatment Protocol Protocol, 2000). Thus, the structured problem solving approach gives consumers a strategy to make decisions and increase their understanding of options regarding mental illness treatment and care. As suggested previously, consumers who are given choices will feel less coerced into accepting treatment, enter a treatment program that reflects their preferences, provide informed consent, and be more invested in the treatment (La Fond & Srebnik, 2002). Thus, this phase provides an opportunity to develop and increase a consumer’s decision-making abilities, which has been proposed to promote a sense of autonomy, and lead to an increase in self-esteem and sense of control over one’s health (Swanson et al, 2000). Such skills easily transfer to other areas of life, which could potentially reduce the “sick role” that many individuals with mental illness carry (Miller, 1998).
2.2.3 Stage four & five: Seeking Agreement, formal documentation and activation

Seeking agreement and formal documentation of one’s preferences is a means for effectuating individual empowerment and self-responsibility. Documenting preferences is a form of informed consent and can act to reduce stress and anxiety frequently associated with anticipating a relapse of mental illness (Miller, 1998). More generally, for those in one study who did complete an Advance Directive, completion was a source of satisfaction and pride (Amering et al., 2005). Advance agreements are “living” documents, and maintaining up to date preferences ensures accurate information that validly reflects a consumer’s current wishes. Regardless of the reason or motivation fuelling the initial energy to create an AdA, it is possible that as the novelty of an AdA dissipates, so to will the motivation levels. Scheduling revisions could assist in maintaining a consumer’s motivational levels for adherence to the AdA. Therefore, the AdA is an ongoing process designed to keep a consumer motivated through regularly updating their preferences as they experience life.

An AdA is activated when a consumer is judged, by professionals or by the consumer themselves, to be experiencing a period of mental illness and a subsequent reduction of ability to partake in decisions relating to their own mental health. It has been suggested that consumers who believe their wishes will be followed through, may be more likely to seek and engage treatment (Calsyn, Winter, & Morse, 2000 cited in O’Connell & Stein, 2005). Srebnik & Brodoff (2003) suggested that determining when to activate an AdA involves both clinical and legal decision making as “when in crisis, many consumers present for care who are not legally incompetent, but nonetheless display indecision or
ambivalence or are otherwise unable or unwilling to make reasoned decisions” (p. 264).
Once activated, utilising an AdA requires treating professionals to endeavor to honor the AdA by considering, in each consumer’s case, the applicability of the AdA under the current circumstance, and the consumer’s best interests.

The emphasis on empirical research to date has mostly focused on investigating the benefits of possessing an AdA (stages four and five) rather than exploring the earlier stages of developing an AdA. AdAs are frequently cited as tools to reduce the frequency and length of involuntary hospital admissions (e.g. Swanson et al., 2000; Srebnik & La Fond, 1999). Papageorgiou, King, Janmohamed, Davidson, and Dawson (2002) investigated this hypothesis by conducting a randomised control trial of psychiatric advance directives (PADs). Inpatients that were close to being discharged from compulsory treatment were recruited and randomised into usual care, or usual care plus a PAD. The PAD consisted of seven statements revolving around relapse prevention planning and preferences for hospital e.g. ‘if I have to be admitted into hospital again I would like…’ The trial found no significant differences between the control and PAD group in subsequent compulsory readmissions, voluntary readmissions or days spent in hospital. Additionally only 13.5% of the consumers in the PAD group reported they found the directive useful. Regardless, consumers identified several positive outcomes, reporting that the PAD was useful for significant others, and that the PAD enabled them to evaluate their illness, along with remind them of actions they could take to improve their life.
Papageorgiou and colleagues (2002) presented several noteworthy reasons to explain why the PAD and control group did not differ. Firstly, consumers entered the study near the date of discharge from compulsory admission. This is a time when consumers are likely to be in partial remission, and therefore display a reduced competency at recruitment, impacting on their ability to develop a meaningful PAD. Secondly, participant's views may have already been incorporated into care plans or the PAD may have been viewed by staff as an administrative burden. Thirdly, the information documented in the PADs may not have been practical, and requests may have been ignored due to limited resources. And finally, a lack of sustained awareness of the PAD throughout the 12 months of follow-up may have contributed to the PADs perceived long-term usefulness. This study provided little information on the basis for the actual PAD tool, or on the methodology and process of developing the PAD, both of which are considered essential to evaluating benefits associated with such methods (Thomas, 2003).

By contrast, Henderson and colleagues (2004) conducted a single blind randomized control trial of 160 consumers with a diagnosis of psychotic illness or non-psychotic bipolar disorder. The intervention group consisted of participants who developed a joint crisis plan that contained advance statements of preferences for care in the event of future relapses (Henderson et al., 2004). The crisis plan documentation was developed in a pilot study, which also showed promising results for consumer satisfaction and sense of control regarding treatment (Sutherby & Szmuckler, 1998). The trial found that participants in the intervention group experienced significantly fewer compulsory
admissions compared to the control group, supporting the premise that advance agreements can promote more consensual and less coercive care.

Other studies have surveyed relevant stakeholders’ opinions to determine expected outcomes of mental health anticipatory planning tools (Amering et al., 1999; Amering et al., 2005; Atkinson et al., 2003b; O’Connell & Stein, 2005; Srebnik & Brodoff, 2003). A survey of opinions on PADs showed that compared to clinicians, consumers’ held significantly higher expectations about the potential of PADs to improve their lives, where clinicians were somewhat skeptical about PADs being an effective mechanism for directing treatment options and helping the consumer stay well (Swanson et al., 2003). In the same survey, the majority of the consumers perceived the function of PADs as a means to avoid future involuntary treatment, whereas less than two thirds of the clinicians held that view.

Regardless of whether an AdA impacts the amount or length of involuntary admissions, the activation and utilisation of AdAs within the mental health system is proposed to: reduce unwanted interventions and enable more effective intervention, improve crisis management and timely access to a voluntary treatment, provide a tool for sharing information across different settings, assist clinicians in vigilantly monitoring a consumer’s treatment adherence and recovery process, and reduce emergency admissions through encouraging early intervention (Atkinson et al., 2004; Gallagher, 1998; Swanson et al., 2000). Thus, AdA’s could assist professionals in meeting standards of practice and regulatory requirements, such as the principle of least restrictive care. For instance, AdAs
could specify methods for de-escalating a crisis, thereby minimising the use of methods such as seclusion or restraint (Srebnik & Brodoff, 2003). Also, consumers’ recovery may be assisted by the knowledge that their mental health is being attended to in a way they have agreed to (Mental Health Alliance, 2005). More broadly, utilisation of AdAs and knowledge that this type of document is an option for individuals suffering a mental illness may reduce stigma within society that individuals with mental illness are incapable of being involved in their treatment and care programs (Swanson et al., 2000; Winick, 1996).

2.2.4 Education and Collaboration

Underpinning the stages of developing an AdA, and associated benefits, are the processes of psychoeducation and collaboration. The process of psychoeducation conveys the central message that treatment decisions should be informed. Acquiring a greater depth of knowledge about mental illness and treatment could enable consumers to gain more insight, and be more meaningfully involved and confident about their preferences (Atkinson et al., 2004). Consumers may not, however, always respond positively to education and information. If psychoeducation is not delivered sensitively, a consumer could perceive that the information is being forced upon them, leading to tension and resistance. Hence the importance of providing balanced information in a supportive and therapeutic environment. In addition, arriving at decisions for future mental illness treatment and care can be complex and difficult. To assist in these difficulties, the AdA is developed through a mutual alliance with a clinical manager, and in collaboration with significant others (Gallagher, 1998). In addition to reaping the general benefits of a
positive relationship with a key worker and others, forming mutual alliances could aid the development of a valuable AdA and successful implementation.

It has been suggested that with the establishment of a positive alliance between consumer and case worker, the consumer will experience the relationship as therapeutic regardless of the psychological intervention (Martin, Garske, & Davis, 2000). A therapeutic alliance entails a cooperative relationship and willingness by both individuals to invest in the therapy process and agree on treatment goals and tasks (O'Brien & Golding, 2003). Most literature demonstrating the outcomes of a positive therapeutic alliance has focused on some form of therapy, where individuals have actively sought treatment and display some degree of internal motivation to recover. In contrast, AdAs are being applied to a population of individuals experiencing serious mental illness, who are case managed within a community mental health setting on both a voluntary and involuntary basis. In addition, many individuals in case management have psychotic illnesses and may lack social skills necessary for the development of a stable and productive alliance (Howgego, Yellowlees, Owen, Meldrum, & Dark, 2003). Thus, while some unique challenges accompany the psychiatric population targeted by this research, establishing a positive alliance is considered conducive to attaining the goal of case management.

Desirable outcomes for case management entail medication adherence, reduced hospitalisations, reduced symptom severity, improved quality of life, and improved consumer satisfaction with treatment. Central to these outcomes is building and maintaining positive therapeutic relationship with treatment providers. A study conducted
by Frank and Gunderson (1990) demonstrated the importance of a positive therapeutic
alliance for individuals with non-chronic schizophrenia. Results demonstrated that
patients, who formed a healthy alliance with their therapists within the first six months of
treatment, were more likely to remain in psychotherapy, adhere to their medication, and
achieve improved outcomes after two years (Frank & Gunderson, 1990). Another study
demonstrated that clients and case managers showed a high degree of alliance after two
years of service (Solomon, Draine, & Delaney, 1995). An analysis revealed a positive
association between this alliance and quality of life, reduction in symptomatology,
attitudes favorable to medication adherence, and satisfaction with mental health treatment
(Solomon et al., 1995).

Drawing these findings together, the literature suggests that a healthy therapeutic
relationship is related to decreased perceptions of coercion, psychological wellbeing, and
general positive outcomes. Furthermore, it has been claimed that the most rewarding
therapeutic relationships are those that are characterised by mutual decision making
(Ritchie, Sklar, & Steiner, 1998). In a qualitative study of PADs, some participants
rejected a cooperative approach as they did not believe they would be able to, or it would
be difficult to, obtain agreement to their wishes (Atkinson et al, 2003b). Despite this,
AdAs provide an ideal forum for addressing such concerns, enhancing the therapeutic
relationship and experiencing mutual decision making.

One approach for mental health professionals to build their relationships with consumers
is by explicitly demonstrating that they are taking the consumer's concerns into
consideration. Through this, AdAs support the change in the dynamics of the doctor-patient relationship from a paternalistic fiduciary one to a more contractual one, allowing patients to assume more power in the relationship through increased responsibility and control over treatment decisions (Atkinson et al., 2003a; Miller, 1998). One potential barrier to this shift was identified from the results of a survey indicating that psychiatrists, compared to other groups, were significantly less convinced of the need for advance directives, and less likely to agree that services need to change in the direction of increasing service user control over their care and management (Atkinson et al., 2004). Nonetheless, it is proposed that AdAs could assist mental health professionals in gaining idiosyncratic knowledge thus shaping treatment and care to the individual, and also assist in the guidance of clinical decision-making during a crisis (Srebnik & Brodoff, 2003).

The philosophy behind AdAs also entails encouraging consumers to involve family members and friends. AdAs may provide a forum for family/carers and consumers to discuss each others role in the consumer’s life and potentially improve these relationships (Srebnick & La Fond, 1999). While there is growing evidence postulating that social support facilitates coping and competence for individuals with schizophrenia, a review of the literature concluded that evidence is lacking methodological and conceptual consistency (Buchanan, 1995). In general however, individuals with social support cope better with negative or stressful life events compared to individuals who lack social support (NAMHC, 1996). Studies have shown that higher levels of social support have also been positively correlated with a lower relapse rate, less frequent hospitalisations, and success and maintenance of treatment gains (NAMHC, 1996). Furthermore, it is
recognised that the amount of perceived social support could play a more influence on mental health and wellbeing, compared to the amount of support actually sought or received (NAMHC Report, 1996). AdAs provide a forum to assist with initializing, or activating, available social support through identifying treating team members, planning for relapse prevention, and working through preferences for significant others.

In summary, the operational and conceptual model for developing AdAs presented above described several phases and underlying mechanisms involved in developing an AdA, in order to provide an initial explanation for previously reported outcomes. Table 1 provides a summary of the outcomes proposed to be related to each stage or process of developing an AdA. These outcomes can also be conceptualised as targeting three groups: intrapersonal outcomes (consumer), interpersonal outcomes, and systemic outcomes (Table 2).
Table 1. Outcomes relating to each stage and process of developing an AdA

<table>
<thead>
<tr>
<th>Stages of developing an AdA</th>
<th>Outcomes</th>
</tr>
</thead>
</table>
| Providing the Option       | • Promote active consumer participation  
                            | • Demonstrate professionals value consumers perspectives  
                            | • Promote autonomy and responsibility  
                            | • Individualised treatment  
                            | • Build sense of control  |
| Contemplating              | • Stimulate consumer ownership and responsibility  
                            | • Incentive to employ preventative framework and adhere with a treatment plan  |
| Psychoeducation            | • Facilitate informed consent  
                            | • Increase a consumer’s insight into mental illness  
                            | • Enhance sense of confident in choices  |
| Choices and Decision-making| • Increase consumers understanding of options  
                            | • Enhance investment and motivation for a treatment plan  
                            | • Promote autonomy and control  
                            | • Develop problem-solving skills  |
| Collaboration              | • Develop the therapeutic relationship  
                            | • Increase social support  
                            | • Decrease perceptions of coercion  |
| Relapse Prevention Plan    | • Increase consumers sense of control  
                            | • Reduce relapse rates  |
| Document and Utilisation   | • Empowerment  
                            | • Reduce amount and length of involuntary hospital admissions  
                            | • Sharing information  
                            | • Reduce stress associated with anticipating a relapse  
                            | • Support principle of least restrictive care  
                            | • Improve crisis management  
                            | • Assist clinicians in monitoring treatment adherence  |
| Development                | • Maintain motivation  
                            | • Maintain the individualised nature of the document.  |
Table 2. Outcomes relating to specific groups

<table>
<thead>
<tr>
<th>Consumer outcomes</th>
<th>Interpersonal outcomes</th>
<th>Mental health system outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Increased sense of autonomy, individualization, empowerment, control</td>
<td>• Increased communication with significant others</td>
<td>• Reduced amount of involuntary hospitalisations</td>
</tr>
<tr>
<td>• Increased adherence to treatment program</td>
<td>• Minimise family burden in proxy decisions making.</td>
<td>• Reduced length of stay in hospital</td>
</tr>
<tr>
<td>• Reduced stress associated with anticipation of future relapse</td>
<td>• Enhanced therapeutic alliance and relationship with mental health system</td>
<td>• Improved crisis management, timely access to voluntary treatment and mobilizing resources</td>
</tr>
<tr>
<td>• Increased trust and confidence in the system and relevant stakeholders</td>
<td></td>
<td>• Tool to share information across different settings</td>
</tr>
<tr>
<td>• Ownership and responsibility re mental illness management</td>
<td></td>
<td>• Assist clinicians to be more aware and monitor adherence to treatment programs</td>
</tr>
<tr>
<td>• Reduced stigma and “sick role”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2.3 Competence and Insight

The validity of an AdA relies strongly on the prerequisite that, when developed, the consumer had a reasonable level of insight and competence to make decisions. Developing an AdA requires that consumers have an accurate understanding of their illness and the AdA concept, and an ability to articulate their preferences (Swanson et al., 2000). Many authors recommend some form of assessment for insight and competence prior to developing an AdA. The chief criteria however, is that a consumer acknowledges that he or she has a mental illness for which treatment is required (Miller, 1998).

In general, insight is considered the degree to which an individual considers him or herself to be mentally unwell, and how he or she understands the illness (Van Meijel, Van Der Gaag, Kahn, & Grypdonck, 2002). Poor insight into a psychiatric illness has been defined as “a multidimensional construct composed of unawareness of symptoms, denial/minimization of illness related consequences, and a failure to recognise the need for treatment” (Goldberg, Green-Paden, Lehman, & Gold, 2001, p. 138). Considering insight as dimensional, rather than categorical, is helpful as partial insight into illness is more common and does not necessarily negate a consumer from developing an AdA (Johnson & Orrel, 1995). Furthermore, insight is considered to fluctuate over time and is more related to symptom severity than a specific diagnosis (Goldberg et al, 2001). Once some insight is present, the process of creating an AdA is appropriate and may aid the consumer in gaining a deeper understanding and awareness of their mental illness.
Closely intertwined with insight is the notion of competence. Broadly speaking, competence is the state of being adequately or well qualified to perform a particular ability (The American Heritage, 2000). Not surprisingly, acute episodes of mental illness frequently cause impairment in an individual's ability to contribute towards decisions relating to his or her own treatment and care. Sometimes, however, this inference is generalized to the entire population of individuals who have a mental illness, regardless of diagnosis or stage of illness (Holloway & Szmukler, 2003). The MacArthur Treatment Competence Study provides a comprehensive collection of information regarding the abilities of individuals with mental illness to make decisions relating to psychiatric treatment (Appelbaum & Grisso, 1995; Grisso & Appelbaum, 1995; Grisso, Appelbaum, Mulvey, & Fletcher, 1995). Overall, the study challenged the assumption that mental illness renders those afflicted with it unable to engage in rational decision-making (Winick, 1996). The findings demonstrated that although the decision-making capacity of individuals with mental illness is sometimes severely impaired, they are not necessarily unable to make rational treatment decisions.

Determination of competency is usually based on a legal or clinical judgment. Bayliss (2002) identified competency as a “clinical decision and turns on the question of whether the patient understands the nature and purpose of the treatment to which they are being asked to consent” (p. 6). In the US, four legal standards for determining competency have been identified (Appelbaum & Grisso, 1995). Firstly, the individual must hold the capacity to communicate a choice. Secondly, they must hold the capacity to understand information relevant to making a choice. Thirdly, they must display an appreciation of
the situation and its likely consequences. This requires the recognition that one is suffering from a mental illness, where the generally accepted risks and benefits associated with particular treatments apply to one’s own situation. And lastly, they must show the capacity to apply the information and decision making to their own individual situation. This involves the ability to manipulate information presented in a rational manner, such as the process of weighing risks with benefits (Appelbaum & Grisso, 1995; Miller, 1998). Similar standards have been outlined in UK courts (Beever, 2002).

Developing an AdA requires consumers engage in activities (e.g. decision-making) that would plausibly establish they have an appropriate level of competency. These activities occur in collaboration with a mental health professional, who can monitor a consumer’s competency to understand and engage in the decision-making process. Competency is not a static quality either within or between individuals and thus, should be determined on an individual basis and according to particular tasks. A consumer is also presumed to be competent to make decisions regarding their future treatment, where a diagnosis of mental illness is not a sufficient reason for deeming an individual incompetent to make decisions. If a competency judgment is questionable or under debate, possible solutions include seeking second opinions or documenting the rationales for preferences to aid in understanding a consumer’s decisions. The principles regarding competence described above, along with the guidelines for determining levels of competency, are adopted by the current project.
Concerns relating to the concepts of insight and competency are vital requirements for developing a valid AdA. It is probable, that apprehensions exist around the accuracy of judging insight and competency, and are based on the concern that the AdA may not represent a consumer’s true or appropriate preferences. In this case, when the AdA is activated it may not necessarily encapsulate the best interest of the consumer, and has the potential to result in harmful outcomes. Ritchie et al (1998) provides specific guidelines to optimise the means for ensuring competency concerns in clinical practice, such as the consumer and case manager providing signatures to verify agreement. Furthermore, the current project aimed to safeguard these concerns through educating mental health staff on insight and competence, along with implementing a collaborative and educational model for AdAs. Additionally, regardless of whether an AdA exists, decisions made by professionals on behalf of the consumer are still bound by the Mental Health (treatment and care) Act (1994).

2.4 Issues and Considerations Impacting on Implementation

The appeal of anticipatory planning is intuitive, and the proposed model for AdAs paints a promising picture. It has, however, been commonly observed that progress towards implementing such initiatives in community mental health settings has not kept up with enthusiasm (e.g. Amering et al., 2005). A recent study showed that only 4 to 13 per cent of psychiatric outpatients in five US cities had completed a PAD; however between 66 and 77 percent reported wanting to complete one if given assistance (Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006). In addition to factors that impact on consumer involvement in TCP, there are specific issues that are proposed to impact on the
implementation of AdAs. Issues and considerations relating to AdAs can be conceptualised under five broad and overlapping domains: ethical, legal, practical, economic and medical.

2.4.1 Ethical issues

A primary goal of AdAs is to decrease coercive practices commonly experienced within the mental health system. There is, however, potential for AdAs to be misused or produce situations that may unintentionally increase a consumer's perception of coercion. For instance, the relationship between consumers and mental health professionals may have a history of power imbalance in favor of the professional. Developing an AdA is a collaborative process, and could place the consumer at risk of undue pressure or influence to follow paternalistic recommendations, rather than the expression of authentic preferences (Swanson et al., 2000).

Further ethical dilemmas that are reported in the literature concentrate on the period when an AdA is activated. The ethical practice of activating and utilising an AdA is a heated topic, given the potential of negative consequences for consumers if their AdA is not adequately used, or if their current views are discounted or ignored. Not surprisingly, the above scenarios could result in consumers feeling deceived and disempowered. Fortunately, early research has suggested that when a PAD is implemented in a crisis, consumers' wishes are honored (Backlar & McFarland, 1996). Despite this, research has shown considerable unease among professionals who believe that consumers expect their plan to be honored, and if it is not honored then this could be damaging to the consumer,
their relationships with professionals, and erode their confidence in the mental health system (Atkinson et al., 2004; Backlar & McFarland, 1996; Srebnik & Brodoff, 2003). Professional concerns around the ethical practice of AdAs are plausible and reflect a desire to protect consumers from harm. At the same time, professional concerns could lead to hesitations about AdAs and form a barrier to implementing AdAs. Developing safeguards against malpractice, and around the utilisation of AdAs, could assist in addressing professional concerns.

2.4.2 Practical issues

Practical issues highlighted in the literature are related to three aspects of an AdA: information contained in an AdA, developing the document, and activation and utilisation of the AdA. The core practical issue relating to the content of the AdA is the level of instruction or information that should be documented. The impossibility of foreseeing all future circumstances or knowing all the aspects that influenced an individual’s preferences, is one notable problem with documentation (Gallagher, 1998). To tackle this issue, Gallagher (1998) suggested finding a balance between addressing specific circumstances and providing general guidance.

Practical concerns expressed on the development of an AdA highlight that anticipatory planning can be lengthy, time consuming, and place pressure on staff (Backlar & McFarland, 1996; Srebnik & Brodoff, 2003). A study by the Mental Health Foundation (MHF, 2004) found that, given the time consuming nature of gathering information and considering preferences, developing advance statements required a high level of support,
and this feature considerably influenced the uptake of the statements. Adopting forms to reduce the complexity of AdAs, and the provision of staff support, are two apparent solutions. Further practical issues regarding the development of an AdA entail the processes and practicalities of ensuring that a consumer has an adequate level of insight, competence, knowledge, and experience of mental illness to develop a valid and reliable AdA (Atkinson et al., 2003a; Srebnik & Brodoff, 2003; Swanson et al., 2000).

Practical issues relating to the utilisation of AdAs entail the processes of activating, considering, and honoring or overriding an AdA. Issues include how the AdA could be activated and the circumstances when professionals should honor or override an AdA. One study found that the uptake of advance statements was limited because they were not incorporated into existing policy, and thus could be easily overlooked in clinical practice (MHF, 2004). MHACT has not yet developed policies and procedures to guide the practical application of AdAs. A general guideline, however, for the utilisation of an AdA was discussed with participants as part participation in the pilot project. This guideline drew on suggestions from previous literature. For instance, Miller (1998) suggests that a consumer should not be held to an AdA that is not in their current interest. Furthermore, he suggested that professionals should adopt a lower threshold for honoring preference changes in the direction of assent to treatment, rather than in the direction of treatment refusal. Other authors have suggested that staff should be educated on their role in developing (e.g. level of involvement) and utilising an AdA (e.g. where to access AdA) to safeguard against unintentional coercion, and guarantee the AdA is considered,
honored and applied consistently across as many cases as possible (Srebnik & Brodoff, 2003; La Fond & Srebnick, 2002).

2.4.3 Legal considerations

The amount of legal weight or enforceability an AdA should possess is a complex issue, with benefits and drawbacks associated with both a complete lack of status and a complete binding document (Howe, 2000). For example, one study indicated that many participants believed that psychiatrists would not take notice of an AdA with no legal status (Atkinson et al., 2003b). Another concern is that clinicians may more readily apply for an involuntary order so that they can avoid being constrained by, or rely upon, an AdA. This decision may be driven by clinicians' apprehension that the AdA may restrain their clinical autonomy or increase their vulnerability to legal liability (Atkinson et al., 2003a; Swanson et al., 2003). Furthermore, participants in a study by Atkinson and colleagues (2004) expressed concern that if the document was legally binding this could potentially slow the delivery of treatment.

At present, the authority provided by mental health legislation takes priority, allowing the system to legally override an AdA and treat without a consumer's consent (Papageorgiou, et al., 2002). Australian state and territories currently have guidelines for the legal status of healthcare advance directives, although no specific legal guidelines for a psychiatric population (Biegler, Stewart, Savulescu, & Skene, 2000). Despite this, the availability of mental health anticipatory planning tools is supported by the common law which preserves the autonomy of adult persons of sound mind with respect to their bodies where
the "legal requirement of consent to bodily interference protects the autonomy and dignity of the individual and limits the power of others to interfere" (Bayliss, 2002, p. 2). Clarifying a consumer’s expectations around the legal status of AdAs, and providing staff with good faith immunity against legal liability are two suggested strategies to safeguarding legal complications (Beever, 2002; Miller, 1998).

2.4.4 Economic feasibility

Economic feasibility is another noted consideration when developing and documenting preferences. Ensuring that preferences are economically realistic will assist in the likelihood of honoring of preferences. For instance, a consumer may prefer a private psychiatrist, or prefer to trial an expensive experimental medication. If such preferences are not compatible with mental health systems resource limits then they are less likely to be honored (Atkinson et al., 2003b; Swanson et al., 2000). Regardless, given a services current resources, staff should be educated in how to deal with anticipatory plans that are regarded as economically unfeasible (Srebnik & Brodoff, 2003).

2.4.5 Medical feasibility

Medical feasibility refers to whether a consumer’s preferences adhere to the accepted standards of psychiatric care, and whether the preferences mirror a consumer’s best interest (Swanson et al., 2000). A dilemma for treating professionals arises if there is a conflict between their perceived view of what is in the consumer’s best interest, and their obligation to support a consumer’s preferences for treatment and care (Swanson et al., 2003). Due to the nature of serious mental illness (such as fluctuating symptoms, effects
on cognitive processes, mood, social interaction, and adverse side effects of treatments) developing an AdA that reflects a consumer’s preferences and best interests may be complicated (Swanson et al., 2000). Furthermore, research has shown that professionals can be concerned that the AdA is not current, suggesting that regular reviews should be encouraged (Srebnik & Brodoff, 2003).

2.4.6 Revoking preferences or refusing treatment

Revocation of preferences or refusing all treatment poses challenging ethical, practical and legal situations. Even during an episode of mental illness and impaired competency, a consumer’s current expressed wishes need to be considered and this could potentially result in a desire to restate one’s own preferences (Gallagher, 1998). With respect to applying AdAs in MHACT, Bayliss (2002) suggests that in the same way an incompetent individual cannot develop an AdA, nor can they revoke an AdA. Moreover, the current project adopted the philosophy as outlined by Swanson et al., (2000) who concluded that PADs may serve as a reasoned expression of an individuals intentions regarding future treatment but should not substitute for listening and giving consideration to persons suffering from acute mental illness, perhaps especially during their times of greatest distress (p. 171).

Refusing treatment is another controversial topic. Presumed to be a valid implementation of autonomy, choosing to refuse all treatment during an episode of mental illness and impaired competency may not be truly autonomous (Van Staden & Kruger, 2003). In the US, although courts will consider a consumers preference to refuse treatment, these
refusals are overridden in more than 90% of cases (Miller, 1998). Research has demonstrated that very few consumers employ anticipatory planning documents to refuse all treatment (Amering et al., 2005). Atkinson and colleagues (2003b) identified that some consumers expressed a desire to state a refusal for particular treatments that could not be overturned by mental health legislation. Countering this view was a concern expressed by professionals who believed such legal status would make the directive less workable and that they would not want to be held accountable for service users who refuse treatment. Atkinson and colleagues (2003b) further investigated the implications of refusing treatments. It was found that the view was commonly based on a consumer’s previous negative experiences (e.g. in relation to ECT) and mistrust of the services. This finding is promising and indicates that the treatment itself may not be the cause of refusal. Advance agreements provide a forum to openly discuss treatment refusal, implications and previous negative experiences. Thus advance planning can be viewed as an opportunity to discuss treatment options and secure the cooperation of relevant stakeholders.

In summary, previous literature and research have highlighted a plethora of intertwined and legitimate ethical, practical, legal, economic and medical issues and considerations, that all have the potential to impact on the implementation of a successful AdA service. Furthermore, most literature has provided possible solutions to questions that are raised (e.g. Amering et al., 2005; O’Connell & Stein, 2005; Swanson et al., 2003; Srebnick & La Fond, 1999). Some authors have extended their suggestion to trials in research. For instance, Sherman (1998) developed a computer program called “AD-Maker”, which
educates consumers with serious mental illness about advance directives, tests their knowledge, and then assists them creating one. Sherman (1998) found that two thirds of the sample was able to complete an AD, where completion was dependent on educational and reading ability levels. Sherman, (1998) concluded that the AD-Maker is a cost-effective solution to educating and assisting consumers to make plans for the future. In general, suggestions provided for the appropriate and meaningful implementation of anticipatory planning tools consisted of supplying resources, training, education, legal counseling, clear manuals and documents, policies and procedures.

2.5 Research Methodology

2.5.1 Qualitative methods

Thomas and Cahill (2004) suggested that past empirical studies on advance agreements have lacked qualitative information on operations and outcomes. They commented that the concept, process, and implementation of an AdA are complex, and would be best investigated through action research projects. Similarly, Amering et al. (2005) noted that “a good deal of trial and error is needed before workable, culturally congruent practices are arrived at” (p. 251). The current project is a preliminary investigation into AdAs as an initiative within MHACT. Thus, the project aims to provide broad recommendations for AdA implementation, processes and outcomes. Given the above comments, qualitative methods are considered to be the most suitable means of initially investigating AdAs within MHACT.
In general qualitative approaches are concerned with “exploring, understanding, and describing personal and social experiences of participants and trying to capture the meanings particular phenomena hold for them” (Smith, 1996, p. 418). Thus, the goals of qualitative research are to holistically understand concepts and phenomena in natural settings, giving emphasis to participants’ experiences and views (Elliot, Fischer & Rennie, 1999; Hudelson, 1994; Pope & Mays, 1995). Qualitative methods are also useful for exploring previous research findings, such as initiatives that were not successfully implemented in clinical practice (Haines & Jones, 1994). Overall, qualitative methods are particularly suited for projects implementing programs at a local, idiosyncratic level, and provide a good foundation for future quantitative research. Fundamentally, by adopting a naturalistic approach, the current project intended to implement AdAs within MHACT in a manner that would reflect real clinical practice as closely as possible. This is proposed to enable an accurate and realistic understanding of AdAs within a particular setting. This project is best described as an action research project and predominantly utilises semi-structured interviews, focus groups, and questionnaires to investigate the subject matter.

2.5.2 Action research

Action research is an iterative process of inquiry involving a problem diagnosis, planning action intervention, implementing, evaluating outcomes, reflective learning and re-planning, whereby research informs practice and practice informs research (Avison, Lau, Myers, & Nielsen, 1999; Kemmis & McTaggart, 2003; McNiff, 1988). The above research process is conducted in a collaborative manner, by the researcher, those who experience the problem, and the relevant stakeholders. Contemporary forms of action
research "aim at making change and learning a self-generating and self-maintaining process in the systems in which the action researchers work" (Elden & Chisholm, 1993, p. 125). Elden and Chisholm (1993) identified five minimum characteristics of action research. Firstly, the purpose of action research is scientific inquiry and practical problem solving where a researcher holds some "vision of how society or organisations could be improved and uses the research process to help bring this desired future state into existence" (1993, p. 127). The second characteristic is that action research is a context-bound inquiry, where the process and solution are equally important products. Thirdly, the data is made sense of and drives changes within the project. Fourthly, the research process entails participation, and finally the knowledge is diffused to the local and scientific community. Lastly, the diffusion of knowledge by identifying general learnings, and relating them to existing literature, is a vital part of the research.

2.6 Summary

The current project combined the knowledge and suggestions generated in previous literature and research on mental health anticipatory planning, to develop a conceptual and operational model of AdAs. This model was implemented and evaluated within MHACT using an action research framework. The objective of the project was to pilot AdAs, and to collect feedback from consumers, staff and carers on AdAs and consumer involvement in TCP. In this regard, the project endeavored to generate specific knowledge for implementing AdAs as a consumer involvement initiative within MHACT. More generally, the current project sought to contribute to the growing knowledge on anticipatory planning documents relevant to the practice of clinical management in mental health services.
CHAPTER THREE

Study One

Developing, Implementing and Evaluating Advance Agreements with

MHACT Consumers and Clinical Managers

3.1 Aim

The overall objective of this study was to pilot the implementation of Advance Agreements (AdA) with mental health consumers in the Australian Capital Territory (ACT). The goals of the project were to develop, implement and evaluate a service tailored for Mental Health ACT (MHACT) that offered a formal method for consumers to plan for future periods of impaired competency, and enhanced meaningful consumer involvement in individual treatment and care planning (TCP). Additionally, the project intended to support one objective outlined by the Clinical Review Committee that aimed to “establish advance agreements as a routine component of care planning” (ACT Government, 2004, p. 74). To achieve the above goals, the project followed an action research protocol with several specific aims to:

- Increase knowledge and promote awareness of AdA’s within MHACT
- Develop, and provide feedback on, AdA materials
- Provide feedback on the stages and processes involved in developing an AdA
- Report the outcomes associated with developing and possessing an AdA
- Report anticipated beliefs around the activation and utilisation of an AdA within MHACT
- Identify general issues and barriers for implementing an AdA within MHACT
• Provide a summary of recommendations, gathered from participants and discussion of
  the data, for implementing AdAs in MHACT

3.2 Method

3.2.1 Participants

Participants were consumers of MHACT and their respective clinical manager
(CM) employed by MHACT or key worker, such as private psychiatrist. The
acronym ‘CM’ will be used to depict either clinical manager or key worker. For
this project, a consumer refers to an individual who utilizes MHACT services and
who has, or has experienced an episode of moderate to severe mental illness.
MHACT is committed to providing quality services to all residents of ACT
delivered in partnership with consumers, carers and other service providers (ACT
Government, 2003). One chief practice underpinning the development of an AdA
is collaboration between a consumer and CM. Consequently, the project required
that consumers who wished to participate were currently being clinically case
managed by a staff member within MHACT. Consumers of MHACT that were not
receiving clinical case management from MHACT, but who expressed interest in
developing an AdA, were eligible if they could nominate a qualified staff member
to collaborate with.

There are four adult community teams within MHACT that encompass four
regions of the ACT. During the initial phase of recruitment only two of these teams
were available to participate, due to another research study being conducted at the
same time. Additionally, there are specialized services within MHACT, such as Older Persons Mental Health and intensive treatment teams, and one long term rehabilitation facility (Brian Hennessy Rehabilitation Center) that provide care for consumers that may be suitable for AdA’s. Other individuals that may have been involved or influenced the development of a consumers AdA included significant others, psychiatrist, GP etc. To accomplish the aims of the project, it was suggested that 30 consumers, and their respective CM, would be sufficient to draw out common themes relating to the experience of developing and utilising an AdA.

3.2.2 Study design

The project progressed through five main phases, as depicted in Figure 2. **Phase One** entailed identifying and targeting relevant stakeholders and establishing their interest. Given that introducing a formal method of anticipatory planning into MHACT was in the very early stages of development, resources were limited and the stakeholders targeted were predominantly employees and consumers of MHACT. General practitioners, non-government organisations, and other government services were not intentionally approached or targeted. **Phase Two** involved assembling the materials required for the research. This included creating, and gaining feedback for, an AdA template, an AdA workbook designed to assist the completion of the AdA template, and an AdA manual for CMs. **Phase Three** consisted of disseminating the project within MHACT and other community organisations. This phase entailed creating a campaign of posters, fliers, and education sessions tailored to specific populations, aiming to increase knowledge, awareness, and to promote the project. **Phase Four** involved implementing and trialing
the AdA service, and consisted of recruitment, further education, gaining consent, implementing the research materials to develop an individualised AdA, and utilising the MHACT database to store the AdA. The Final Phase involved evaluating the implementation of AdAs. This was achieved by formulating two evaluation tools, an AdA questionnaire completed by consumers and CMs prior to developing an AdA, and a semi-structured interview, conducted on completion of developing an AdA.

The AdA project aimed to introduce and pilot a more formal method for developing and documenting a consumer’s preferences for future treatment and care, and to commence the move towards AdAs forming a routine component of care planning. Introducing the initiative entailed an action research design that progressed through five main phases. Often, information was collected throughout each phase of the action research design, and integrated as feedback where appropriate, resulting in modifications within the same or different phases. Therefore, while the phases logically flow downwards, some also occurred concurrently and overlapped, as the project was dynamically shaped by information and feedback was collected.
Figure 2. The Action research design for piloting Advance Agreements in MHACT

3.2.3 Procedure

**Phase One – Liaising with relevant Stake Holders**

The first phase of developing and implementing any program was to liaise with relevant stakeholders, aiming to gauge their interest and gain support. The initial interest in anticipatory planning documents arose from consumer advocates, and management and staff within MHACT. Interest was fuelled by the movement towards meaningful
consumer involvement in individual TCP and relevance of anticipatory planning methods. A working party within MHACT was formed following the November 2001 Family Sensitive Training for MHACT staff. This working party began to gain support from consumers and MHACT as an organisation, along with outlining the philosophy, aims, and initial proposals for a pilot project on AdAs. The working party met monthly during the year 2002 and consisted of MHACT staff and consumer representatives. In early 2003 the working party approached the Australian National University (ANU) School of Psychology to join forces and collaborate on the project. Following this, a Doctor of Psychology (Clinical) student was appointed as a primary researcher to work closely with a MHACT consumer representative to develop the project proposal to be presented to the ethics committee and relevant stakeholders within MHACT. The consumer representative was a paid employee of MHACT and had been an influential force and advocate driving the establishment and progress of the AdA working party within MHACT. The consumer representative’s central role in the project was to have a significant input and participate during all phases of the action research design, offer a consumers perspective and provide an essential link with consumers and individuals with mental illness.

Phase Two – Developing the research materials

Advanced Agreement (AdA) Template and Workbook

A survey of the literature was conducted in order to gain an idea of existing materials, layout, language, and content of anticipatory planning documents for psychiatric population (e.g. Beever, 2002; Judge, 2003). As described previously, the term advance
agreement was employed to represent the anticipatory planning documents implemented within MHACT, as it refers to an agreed plan of a consumer’s preferences towards future treatment and care. The initial draft AdA document drew primarily upon influences from existing materials along with recommendations provided by the consumer representative. The workbook endeavored to be consumer friendly through utilising simple and concise language, a problem solving framework, clear layout, and the use of clip art pictures. The draft document was reviewed by two consumer focus groups, conducted by the consumer representative on two separate occasions. The focus groups worked through the AdA draft workbook providing feedback and suggestions on the suitability of the language, content, and layout.

Following the focus groups, the consumer representative and primary researcher collaborated to discuss the feedback and agree on amendments to the AdA workbook. Prior to finalizing the document, the primary supervisors were consulted and the workbook and summary AdA template were presented to the Mental Health executive board, team leaders, and staff at an inpatient unit. Once again, feedback and amendments were extensively discussed between the primary researcher and consumer representative and the document was edited accordingly. The finalized document was trialed with participants recruited during the first round of Phase Four of the project. Following the evaluation of participants’ experiences, gained through the semi-structured interview, feedback regarding the workbook was considered and resulted in slight modifications. The resulting AdA document was then implemented with a second round of participants, and again feedback on the workbook was collected during the semi-structured interviews.
Advanced Agreement Manual for Clinical Managers

Given the practice of AdAs was being formally introduced into MHACT, an AdA manual was compiled and provided to CMs undertaking an AdA with a consumer. The manual served as an educational reference, and as a guide for directing the practicalities of developing an AdA. Comments and advice offered during Phase One of the project, along with a thorough literature review, guided the information contained in the manual. Common issues and questions from CMs were anticipated and addressed in the manual, for instance, what is the legal status of AdA? And, how is competency judged? The draft manual draft was reviewed by the primary supervisors, a MHACT team leader, a social worker, and a psychologist. Following feedback from these individuals the draft was extensively discussed with the consumer representative, edited, and finalized.

Phase Three – Dissemination strategy

The dissemination strategy proposed to increase awareness and educate relevant stakeholders about AdAs and the project operating in MHACT. Promotional materials and education sessions were created and targeted towards specific groups e.g. consumers, CMs. The primary researcher designed and delivered the AdA education sessions, and the consumer representative was often present. The sessions were delivered through a Power-Point presentation tailor-made for each relevant stakeholder group and conducted in a top-down manner from MHACT management, to team leaders, to mental health professionals, and lastly to consumers and carers (see Appendix A for an example). The education sessions occurred in this top-down fashion primarily so MHACT staff would
be equipped and prepared to assist consumers or carers queries about AdAs. Advertising for involvement in the project independently targeted consumers and CMs. Fliers, pamphlets and posters were distributed to the four main community mental health facilities; two main psychiatric inpatient units based in the ACT; one rehabilitation centre; the crisis and assessment team (CATT); and community centers and organisations including the Richmond Fellowship, the Schizophrenia Fellowship, and The Rainbow (See Appendix B for examples of information pamphlets). During the course of the project, AdAs were briefly mentioned to new employees during the MHACT orientation session. Additionally, the project was advertised in the Co-Morbidity/Dual Diagnosis Monthly Newsletter published by ACT Health (2005).

Approximately mid-way through the project, after several participants had completed an AdA, a second round of education sessions and promotion was conducted. A minimum of one refresher education session was conducted at each community team, all psychiatric inpatient units, and CATT. Additional presentations were provided to the Recovery Focus Group, the MHACT Consumer Network Group, and consumers housed in Villa C at Brian Hennessey Rehabilitation Center. During the second round of refresher sessions to the community teams, the importance of trialing and receiving feedback on AdA’s was emphasised. Each CM was asked to approach several consumers, aiming for the goal of each CM gaining experience with developing an AdA and to increase participation in the project. Agreement for this initiative was sought within each individual team.
Time was allocated during all education sessions for participants to ask questions about AdAs, and provide suggestions for the implementation of the project. Information on the awareness and promotion of the project were collected from participants who completed an AdA during the semi-structured feedback interviews.

**Phase Four – Implementation of AdAs**

Both consumers and CMs were able to initiate contact with the primary researcher or consumer representative to express interest in participating in the project, and nominate their respective partner for the study. Following initial interest the researcher arranged an appointment with the individual and respective consumer/CM either individually or together. The meeting generally lasted one hour and involved education on AdAs, the provision of an AdA template and workbook, the provision and discussion of the information sheet and consent form (see Appendix C), an opportunity for potential participants to make inquiries, and an opportunity for the researcher to confirm participants understand the AdA document and the processes involved in developing an AdA. Following this, the consumer/CM decided to either consent to participate in the project or take time to consider participation.

Once both participants (consumer and CM) provided informed consent to engage in the project they were given a brief pre-AdA questionnaire to complete (outlined in Phase Five). Following this, the pair could begin developing an AdA utilising the template/preference sheets and workbook. A general guide on how participants could collaborate and develop the AdA was provided in the AdA manual for CMs. Participants
could however develop the AdA in a way that they considered meaningful and effective. An estimated time limit of four months was given to complete an AdA. During that period, both consumer and CM were contacted regularly by the primary researcher to obtain updates on the pair’s progress, answer questions, or assist with any difficulties encountered during the development of the AdA. Once the pair had finished the AdA, the CM entered the summary AdA template/preference sheet information into the MHACT shared database. Each participant was then contacted by the primary researcher to organize an appointment for the semi-structured evaluation interview.

**Phase Five – Evaluation**

**Data collection**

Information was collected from several sources including the Consumer Pre-AdA Questionnaire, CM Pre-AdA Questionnaire, demographics obtained from the MHACT database called “MHAGIC”, and individual semi-structured interviews. Each participant was de-identified, where numbers (1 to 33) were allocated to consumers and a letters (A to J) were allocated to CMs. The data collected was analysed primarily to evaluate the process of developing an AdA and associated outcomes, along with identifying central issues and barriers influencing an AdA program.

**Evaluation tools**

A brief CM Pre-AdA Questionnaire and consumer Pre-AdA Questionnaire were developed for participants to complete prior to developing an AdA. The aim of the CM questionnaire was to briefly assess CMs prior experience with anticipatory planning
documents, how CMs believe the AdA would benefit the consumer and themselves, and to estimate the CM’s perception of the consumer’s current management of his or her mental illness. The aim of the Consumer questionnaire was to elicit information on the consumer’s perceived ability to manage his or her mental illness, along with identifying useful aspects of treatment and care. Initial drafts of both questionnaires were created and pre-tested with the consumer representative, primary supervisors and peers. The questionnaires were administered to participants following consent to engage in the pilot project, prior to developing an AdA.

A semi-structured interview was constructed to gain feedback from participants who completed an AdA. The technique of semi-structured interview was chosen to balance flexibility and reliability. In this way, the same topics could be addressed consistently across participants, while allowing for probing questions aimed at elaboration and eliciting further explanation. The interview questions were predominantly open-ended and assembled around the aims and goals of the pilot project. The draft interview questions were piloted within the research team, and with professional peers. Following amendments, a final edition of the interview was generated. The interviews were conducted following completion of an AdA. The primary researcher administered all of the semi-structured feedback interviews lasting for approximately 30 to 50 minutes. Interviews were conducted at the ANU, MHACT community centers or at a consumer’s residence. The interviews were transcribed by the primary researcher.
Analysis

This project adopted a primarily qualitative and descriptive analysis approach with the data collected including a rigorous analysis of interview manuscript, database information, and questionnaire data. Consumer Pre-AdA Questionnaire data was stored using the Statistical Package for Social Sciences for Windows (SPSS version 13.0). Descriptive statistics were performed to summarise and report the information. The CM Pre-AdA Questionnaire Data was stored in Microsoft Word and the responses to the open-ended questions were summarised.

The bulk of the findings were the product of a rigorous content analysis of each participant’s interview manuscript. In general, content analysis is a systematic examination of text by identifying, grouping themes and developing categories (Pope & Mays, 1995). Several methods of content analysis were considered (Burnard, 1991; Lee & Peterson, 1997; Mayring, 2000; Schilling, 2006). Furthermore, tactics for generating meaning, testing and confirming findings were utilised (Miles & Huberman, 1994). The method of content analysis adopted for the current project was based on Schilling (2006) who described a detailed method based on a spiral process that moves through five main levels.

The first level of content analysis, as described by Schilling (2006), entails transcribing the raw data. The semi-structured interviews for the AdA project were transcribed verbatim, including most sounds, such as “um” and “uh”. Other audible behaviour (such as coughing, laughter), pauses, changes in tone etc. were not transcribed unless they were
required to understand the context of the language. Participants were given anonymity in the transcripts by replacing names said during the interview with labels or acronyms, such as ‘C’ for consumer; ‘x’ to denote another e.g. Dr ‘x’. A proportion of the transcripts were listened to a second time to ensure accurate transcription. The second level of content analysis, as described by Schilling (2006), entails transforming the raw data into condensed records. The process of condensing records aims to reduce the material, while preserving the essential contents. For this project, units of analysis were defined as ranging from single words to a paragraph, where a meaningful unit in this sense would mean a “segment of text that is comprehensible by itself and contains one idea, episode, or piece of information” (Tesch, 1990, p.11 cited in Schilling, 2006 p. 31). This level entails paraphrasing the text, followed by generalizing and reducing the paraphrasing. Table 3 provides an example of paraphrasing, and then generalizing/reducing the text.

Table 3. An example of paraphrasing, generalizing and reducing the text

<table>
<thead>
<tr>
<th>Original Text (Cons. 25 p.1)</th>
<th>Paraphrases</th>
<th>Generalisation and reduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had such negative experiences with my past admissions that I kind of wanted to, in every time I got admitted to hospital, the lack of control over the whole process is humiliating, its disarming and so I guess I figured this would be a way to have some kind of input, some kind of say into the process of being admitted</td>
<td>Negative experiences with several previous admissions Hospital admission process experienced as humiliating and disarming AdA as a way to have input and say into hospital admission</td>
<td>Negative experiences Hospital admissions Experienced as humiliating Disarming AdA is a method to be involved and have input</td>
</tr>
</tbody>
</table>
The third level of content analysis entails changing the condensed data to structured protocols and developing a preliminary category system. In this level each statement is attached to one of the defined dimensions. For example, 'negative experiences' may be assigned to a dimension titled 'motivation to develop an AdA'. To ensure reliability of the structured category system the statements can be coded and then independently rated by another individual or re-coded by the same person. The fourth level of content analysis consists of identifying coded protocols from the preliminary category system, where it is essential to build the categories as close to the material as possible. For the AdA project, given the transcripts were all based on a semi-structured interview that was guided by theory and the aims of the project, some of the categories were obviously apparent. Other categories and topics were identified through an inductive process of analysis during all stages of data analysis. Similar to level three, this level requires an iterative process of revising the material, checking the categories, and formulating new categories when required. Finally the fifth level entails concluding the analysis and providing an interpretation. When relevant, results obtained from the consumer responses remained separate to the group of CM responses and the term ‘participants’ referred to the pooled consumer and CM groups. Results attempt to capture ideas, opinions and beliefs made by all participants, highlighting common themes and ‘deviant cases’.

3.3 Results

The results section will report feedback, products and outcomes associated with each phase of the action research design. The majority of results were obtained during Phase Five, and are predominantly based on the content analysis of the semi-structured
interview transcripts. Additionally, a portion of the data collected during Phase Five evaluated processes and products outlined in earlier phases of the action research design, and will be reported within those corresponding phases.

3.3.1 Phase One: Liaising with relevant stakeholders

As outlined in the methods section, liaising with relevant stakeholders resulted in a significant amount of interest and support for piloting AdA’s and the subsequent establishment of a joint project between MHACT and the ANU. Approval was received from MHACT executive board to seek ethics approval, which was granted from both institutions (see Appendix K). The completion date for the pilot project was then estimated for 30 to 36 months later. The primary researcher (ANU representative) and consumer representative from MHACT worked closely to implement the initial four phases. Approximately mid-way through the course of the project the consumer representative resigned from MHACT. Following this, another consumer representative was not appointed to the project. Thus, the second recruitment phase and evaluation was conducted by the principal researcher.

3.3.2 Phase Two: Developing AdA research materials

The Advance Agreement Workbook and Supplementary Sheets

Process results

Initially, the AdA workbook consisted solely of different aspects of treatment and care that a consumer could state specific preferences for e.g. preferences for medication, treatment facility and so on. These aspects were presented to the consumer in a workbook
that guided the consumer through structured problem solving steps to arrive at decisions for their preferences under each aspect of treatment and care. Several benefits were proposed for employing a structured problem solving approach, including teaching and practicing decision making skills, assisting difficult and complex decisions, and ensuring the AdA documented the consumer's true preferences through informed consent. Additionally, the workbook also provides education on process of developing an AdA, including information on relapse prevention planning and decision-making skills. The initial draft AdA workbook and summary template were discussed within consumer focus groups conducted by the consumer representative. The main recommendation was that the AdA document should encompass a more preventative focus. Subsequently, a relapse prevention plan was added, along with stating preferences according to different stages of mental illness, conceptualised as ranging along a continuum of mental illness from mild to severe.

Feedback, through semi-structured interviews, was collected from the first group of participants' who completed the workbook to arrive at preferences and the summary AdA template. Feedback from this group of participants was applied to modify the original format from a single workbook and summary template, to separate preference sheets with a supplementary workbook to guide the process of completing each preference sheet, analogous to a 'tax pack' arrangement (see Appendix D and E for preference sheets and supplementary workbook). The preference sheets and supplementary workbook are almost identical to the original workbook and template, with minimal changes to the layout and no changes to the information contained. The major changes were that
consumers could complete the shorter summary preferences sheets/template and refer to
the workbook for further information, rather than progress through the workbook to
arrive at decisions and then completing the summary. Thus, the AdA Workbook was used
by consumers who required further information or assistance as an informational source
and guide to create an AdA and arrive at preferences for different aspects of treatment
and care.

Product
The final AdA workbook comprises five sections. The first part consists of an
introduction that outlines the general philosophy of AdA’s, the Mental health continuum,
making decision, structured problem solving, information placed on the database,
collaboration, scheduling appointments, storing information, revisions and modifications,
legal limitations, expiration date. The second section is titled ‘Treating Team’.
Information stored in the ‘treating team’ section includes a list of the key individuals the
consumer gives permission to form part of their team, i.e. the consumer, CM, GP. This
section also includes contact phone numbers, and the option of each treating team
member to sign agreement with the AdA. The third section entails an individual relapse
prevention plan. This plan is individually tailored and entails the consumer listing
individual early warning signs and a four-stage progressive action plan. Part four
encloses the bulk of the workbook, guiding the consumer through problem solving steps
to arrive at decisions for preferences in different aspects of future treatment and care. The
aspects of treatment and care are medical treatment, treatment facility, emergency
interventions, mental health professional/s, and significant others. Additionally,
consistent with a relapse prevention framework, the preferences for medication, treatment
facility and emergency interventions are further subdivided to include preferences for
each stage of anticipated decline in mental health e.g. mild, moderate or severe. The
original workbook had a “statement of agreement” (Judge, 2003). The purpose of the
statement was so the consumer could articulate that the AdA is a genuine representation
of their preferences and is not intended to make the AdA legally binding. This was
excluded from the final workbook to keep the workbook as short as possible as it was
evident that not many consumers utilised the statement.

The AdA preference sheets are one-page sheets that cover one aspect of the AdA
workbook, i.e. the treating team, the relapse prevention plan, preferences for medical
treatment and so on. Each preference sheet refers the consumer to the page in the
supplementary workbook for further information or help with arriving at decisions. The
information contained on the preference sheets corresponds to the information documents
on the MHACT database. It is likely that the AdA will be referred to by MHACT staff
when the consumer is experiencing a moderate to severe episode of mental illness and
impaired competence to be meaningfully involved. The AdA is intended however to be
utilised by the consumer and CM during a period of declining mental health as a means
of relapse prevention.

*Overall Evaluation of the workbook*

Feedback by participants who completed the AdA workbook and template was collected
using semi-structured interviews during the Phase Five. All participants provided positive
feedback on the workbook. Comments indicated the workbook had an appropriate level of language and thorough information, making it clear and simple to complete. Two sections particularly favoured by participants were the ‘medication preferences’ and ‘relapse prevention plan’. Overall, participants identified the logical structure and decision-making steps useful for deciding preferences, but suggested making the AdA as brief and succinct as possible. Participants expressed the opinion that the appearance of the AdA needs to be kept simple because paperwork can be daunting and overwhelming, and as a result of mental illness many consumers suffer cognitive deficits and residual negative symptoms. One CM captured this point when stating:

One factor that a lot of our clients have are the negative symptoms...they may not quite have the motivation...and when they’re quite well, they’re not thinking about their illness as much...that’s why to make it as simple and succinct as possible will help. (CM, C. p.3-4)

It was also noted by some CMs that consumers may have difficulty filling out forms or impaired organisational skills, and for those consumers the CMs should expect to play a significant role in facilitating completion of the forms. Further suggestions regarding the information or content that could be added to the AdA are summarised in Table 4, and included proving more information on treatment options, and providing a functional role description on treating team members.
Table 4. Suggested Additions for the AdA Workbook

Suggestions provided by participants

- Provide more information on hospital choices e.g. including interstate options
- Include methods for staying well
- Provide a letter/s for treating team members to explain their role
- Include a statement on the MH database that refers professionals to the workbook for more detailed information on the rationales for preferences
- Provide a section on measuring level of risk and when to activate the AdA

The AdA Manual for Clinical Managers

Process

The AdA Manual for Clinical Managers was developed to educate CMs on AdAs and provide practical guidelines to assist them in collaborating with a consumer to develop an AdA. Following feedback collected during the pre-test, a final draft was produced and provided to CM who engaged in the project. Given that reading or using the manual was not a requirement for the study, overall evaluation information was not collected.

Product

The AdA Manual for Clinical Managers (see appendix F) consists of a general introduction, an outline of the content included in an AdA, information on the processes involved in creating an AdA, a section on relapse prevention, information on the administration of an AdA, an introduction to competence and insight, an outline of the limitations associated with AdA, and lastly a section on support available for CMs and consumers during the duration of the project.
3.3.3 Phase Three: Dissemination strategy

During the first dissemination strategy the education sessions were initially conducted in a top-down order. Midway through the project refresher education sessions were organised around the convenience of each specific target group. A range of approximately three to ten individuals attended each education session. Over the course of the project, 30 education sessions or reviews were presented to relevant stakeholders. The number of sessions (n) were broken down as follows: MHACT executive team (n=1); MHACT Clinical Review Committee (n=1); MHACT team leaders (n=1); Clinical managers within the four MHACT community teams (n=8); the Crisis and Treatment Team (n=2); Psychiatric Services Unit, The Canberra Hospital (n=5); 2N Psychiatric Unit, Calvary Hospital (n=1); Brian Hennessey Rehabilitation Centre (n=3); The Recovery Focus Group (n=1); consumers in Tuggeranong and Civic areas (n=4); consumers at The Rainbow community centre (n=2); and carers at Carers ACT (n=1).

Education sessions also functioned as a forum for professionals, consumers and carers to express their opinions, suggestions, and influence the service. It was evident from the education sessions that while the vast majority of stakeholders appeared to hold positive opinions and interest in utilising AdAs, they also had many questions regarding the legal status, practical use, and ethical issues.

Feedback obtained from the semi-structured interviews identified that of those individuals who initiated contact with the project all but one became aware of AdA’s through education sessions provided. The other participant learned about AdA’s through a poster displayed in a psychiatric inpatient unit.
3.3.4 Phase Four: Recruitment and implementation

Sample Information

Thirty-three consumers provided consent to participate in the AdA project. Fourteen consumers completed an AdA, equivalent to 42% of the sample. Data was collected from all consumers who completed their AdA. Of those who completed the AdA, participation in the project was initiated equally by clinical managers and consumers. For the consumers who completed the AdA, eleven CMs consented to participate in the project. Seven MHACT clinical managers, one MHACT psychiatrist, two non government organisation workers and one private psychologist collaborated with a consumer to develop the AdA. Of those CMs that data was collected for, one CM completed an AdA with three consumers and another CM with two consumers. Attempts were made to collect pre-AdA questionnaires and conduct the semi-structured interview with all participants. Table 5 summarises the data collection. Overall, all consumers engaged in the semi-structured interviews. Three consumers, however, did not complete the pre-AdA questionnaire; and two CMs did not complete the pre-AdA questionnaire and interview.

Of consumers who completed an AdA, all reported previous experience with hospitalisation and case management for mental illness. Information collected from the database and self-reports indicated the primary diagnoses were schizophrenia (n=8), major depressive disorder (n=3), bipolar affective disorder (n=2) and borderline personality disorder (n=1). Seven consumers had experienced no hospitalisations during
the one-year prior to engagement with the project, four had one hospitalisation and two consumers reported two hospitalisations.

Table 5. An Indication of CM and Consumers who completed the project measures

<table>
<thead>
<tr>
<th>Key: CM (n=11) ■ and Consumer (n=14) ▲</th>
</tr>
</thead>
<tbody>
<tr>
<td>■</td>
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<tr>
<td>▲</td>
</tr>
<tr>
<td>Questionnaire</td>
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<tr>
<td>Interview</td>
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<tr>
<td>■</td>
</tr>
<tr>
<td>Questionnaire</td>
</tr>
<tr>
<td>Interview</td>
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</tbody>
</table>

Reasons for withdrawal from the project

Nineteen consumers were either withdrawn from the study by the researcher, or decided to withdraw from the study themselves. Eight consumers were withdrawn by the researcher as the consumers were unable to be contacted following their initial interest. Reasons cited by participants, both CM and consumers, for the eleven consumers who withdrew from the project were: the consumer being discharged from clinical management (n=2), the consumer relocated (n=2), the consumer experienced a relapse of mental illness (n=2), the consumer reported a change of mind providing no specific reason (n=2), an AdA was not considered a priority by the CM (n=1), the consumer did not anticipate a relapse (n=1), and the AdA was experienced as too confronting (n=1).
One CM observed that the reason why one consumer dropped out of the study was because

...she was keen to do it initially...but as we worked through the document she got angrier and angrier at the reality of the process of what she’s confronted with when she gets unwell, and her option and the medications...it bought up issues for her, around her past experiences... (B. CM, p. 1)

_Reasons for deciding to develop an AdA_

Reasons provided by consumers for deciding to develop an AdA were collected from the semi-structured interviews (n=14). The most frequent, and obvious, reason consumers reported for deciding to develop an AdA was to document their preferences for future treatment and care. For many consumers, previous negative experiences with hospitalisations, medications, and other aspect of treatment and care plans (TCP), provided the motivated to express their preferences. Some consumers associated these negative experiences with feeling a lack of control, humiliation, and disempowerment. For instance, one consumer reported that

I had such negative experiences with my past admissions...the lack of control over the whole process is humiliating, its disarming and so I guess I figured this would be a way to have some kind of input, some kind of say into the process of being admitted. (Cons. 25, p. 1)

Consequently, the general or broad reasons that consumers provided for developing an AdA entailed employing the AdA to state individual preferences and provide input when
unwell. Most consumers developed their rationales further to describe that AdA’s would additionally assist them to strive towards three major goals: increased consumer involvement, enhanced communication, and better outcomes in the future. Enhancing self-involvement in one’s TCP was a frequent rationale for developing an AdA. Some consumers reported beliefs that involvement is a basic consumer right, relating involvement to benefits including the opportunity to provide informed consent, reflect on and discuss past experiences, gain more control and power regarding choices, and demonstrate to mental health staff that the consumer has knowledge, experience, insight, and acceptance of their mental illness. For example, “the AdA seemed to be a way to illustrate that I have insight to my illness and some acceptance of being treated voluntarily” (Cons. 16 p. 1). Enhancing communication with mental health professionals was another frequently cited reason, and in particular, clarifying and communicating individual preferences, where MH professionals and significant others can use the AdA as a guide to make decisions that best meet the consumers needs. ‘Better outcomes’ for the future treatment and care were reported as a broad reason for developing an AdA and was associated with the expression of one’s preferences and provision of treatment in the consumers best interest. For instance, the AdA would act to guide professionals and prevent the dispersion of incorrect medication, increase voluntary treatment methods, and facilitate alternative treatments e.g. relaxation.

Rationales provided by CMs for developing an AdA were extracted from the CM semi-structured interviews (n=10) and Clinical Manager pre-AdA questionnaire (n=10). Many CMs reported that relapse planning and ascertaining a consumer’s preferences was part of
routine practice, although not in the way of a formal agreement. CM responses are summarised in Table 6 and have been conceptualised into three main functions (not necessarily mutually exclusive), each with related objectives. AdAs were viewed as functioning as: a therapeutic tool, a method of including and liaising with others, and as a method to guide clinical decision making, including facilitating access to services and voluntary treatment. One CM, who identified employing the AdA as a therapeutic tool, explained that “the workbook itself enabled me with [consumer] to go through a process that would actually change the way he saw admission” (A, p. 2).

Table 6. CM Rationales for developing an AdA with a consumer

<table>
<thead>
<tr>
<th>Function</th>
<th>Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic tool</td>
<td>• Increase sense of empowerment</td>
</tr>
<tr>
<td></td>
<td>• Increase ownership, responsibility and control of TCP</td>
</tr>
<tr>
<td></td>
<td>• Increase understanding and awareness of illness, including early warning signs</td>
</tr>
<tr>
<td></td>
<td>• Address related issues e.g. negative past experiences</td>
</tr>
<tr>
<td></td>
<td>• CM can reflect on their own role</td>
</tr>
<tr>
<td></td>
<td>• Challenge consumer to break patterns</td>
</tr>
<tr>
<td>Method of including others</td>
<td>• Opportunity to learn about consumer’s wishes for TCP and better meet their needs</td>
</tr>
<tr>
<td></td>
<td>• Gain consent from consumer to liaise with others – aid monitoring and reduces load on CM by dispersing responsibilities to others</td>
</tr>
<tr>
<td></td>
<td>• Bridging the gap between significant others and consumer</td>
</tr>
<tr>
<td>Method of facilitating treatment</td>
<td>• Tool for relapse prevention planning</td>
</tr>
<tr>
<td></td>
<td>• Use AdA to look at alternative options for treatment and care</td>
</tr>
<tr>
<td></td>
<td>• Facilitate early access to services</td>
</tr>
<tr>
<td></td>
<td>• Clear direction and plan to assist and guide the clinician and other MH professionals</td>
</tr>
<tr>
<td></td>
<td>• Remind client, when unwell, of their preferences to assist voluntary treatment</td>
</tr>
</tbody>
</table>
Results associated with the process of developing an AdA

The semi-structured interviews captured a range of information about the processes involved in developing an AdA. This section will report results on time to complete an AdA, psychoeducation, collaboration, involvement of significant others, challenging and easy aspects of developing an AdA, and the end product.

Time to develop an AdA

All consumers reported having enough time to complete their AdA. Time to complete an AdA ranged from 30 minutes (one session) to 15 hours over several months. While most CMs reported they had enough time to complete the AdA, they commented on the difficulty of time management. CMs attributed difficulties with time management to heavy case loads, consumer's relapsing, consumers having other commitments, note documentation, and finding time in private practice. There was mixed opinion among participants regarding the length of time an AdA should take to complete, some stating 30 minutes, others stating several sessions. Most participants recognised the process was highly dependent on the individual consumer, who should complete the AdA “in their own time and their own way” (D. CM, p.3). Some related the length of time a consumer needs to complete an AdA to consumer attributes, such as motivation, time available, and self knowledge. For instance, a consumer who already knows their preferences may take less time compared to a consumer who requires psychoeducation or needs to address issues that impact their preferences. Despite the emphasis on the individualised process, some participants commented that reducing the amount of time to develop an AdA would
increase the uptake of the documents, while other participants commenting they could have taken longer with it.

_Psychoeducation_

All participants reported possessing enough knowledge, or there was sufficient information provided in the workbook, to complete their AdA. Participants’ utilised personal experience and knowledge, other mental health professional’s knowledge, and resources such as the mental health database, books and Internet. One consumer reported they would have like greater access to information in relation to methods of treating mental illness. Several participants identified types of knowledge a consumer should have in order to develop an AdA. Knowledge on individual diagnosis, treatment, and the mental health system were common responses. Questions to elicit information on the association between psychoeducation and potential benefits were not consistently asked. At least one consumer however, linked psychoeducation with feeling empowered.

_Collaboration_

Questions on collaboration resulted in participants’ reporting on the level of input, frequency of disagreements, style of collaboration, role of CM, and personal attributes that facilitated positive collaboration. Eight consumers reported that they had _more_ input into developing the AdA compared to their CM. Five consumers stated they had _equal_ input and one stated they had _less_ input compared to their CM. These reports corresponded strongly with CM responses, indicating a strong consensus within each consumer-CM pair relating to the amount of perceived input each had. All CMs reported
feeling satisfied with the amount of input their consumer had; and thirteen out of 14 consumers reported feeling satisfied with the amount of CM input. One consumer reported a preference to complete the document without a CM while at the same time acknowledging the assistance was helpful. Another consumer reported 'somewhat dissatisfied' with CM involvement, attributing this to the difficulty in realising they had to agree with specific treatment and care, and that they could be treated for mental illness regardless of whether consent was provided. All consumers and most CMs were satisfied with their own involvement. Several consumers identified that their input was limited by the nature of the mental health system e.g. legislation, limited choices in ACT etc. CM identified the main barrier to their own level of involvement was time limitations impacted by heavy case load, leave from work, and pressure to discharge consumers.

The majority of participants reported no disagreements with their consumer/CM, and the majority of consumers reported having an open honest relationship with their clinical manager and that they could raise issues. One consumer admitted that if they did disagree with their CM, they would keep it to themselves and expressed the belief that in reality they have little control over decisions for treatment and care. One consumer described the collaboration with the CM as

If you feel the person is genuinely concerned about you, or caring about you...even if I don't agree with some things that he might say I'll take them on board because I have respect for him and he treats me as an equal...he has different ideas to what I have but the main thing is that he's concerned about me and where its in his power to do so, he will do things to help me. (Cons. 31, p 2)
Of those CMs who reported disagreements with their consumer, the “disagreements” were considered more as important points of discussion rather than an argument, where the disagreement did not cause significant conflict within the relationship. Points of disagreement were resolved through open discussion, giving the consumer space, gently challenging but not pushing the idea, compromise, and acknowledging difference of opinion “what I think is right and good might not be right and good for the client” (CM. B, p. 5). Another CM linked utilising the workbook examples with a technique of collaboration that facilitated consumer empowerment, reporting that

the actual explanations and suggestions were useful to give him [consumer] some idea of what techniques are available…it also gave him the idea that he was actually discovering instead of me saying what he should be doing. (CM. G, p. 1)

Preliminary styles of collaboration were drawn from the analysis, indicating that collaboration appeared to differ on the type of approach (flexible, ad hoc, structured), level of support (directive versus non-directive), and level of teamwork (tasks completed individually versus together). For instance, some pairs worked through the AdA workbook together during scheduled appointment times, whereas other pairs initially allocated the AdA to the consumer to complete and arranged appointments to review the AdA.

Consumers identified several roles that CM held in the collaboration such as organising the process, scribing, helping the consumer to articulate preferences, sharing knowledge
on the consumer's clinical presentation, clarifying the meaning of statements, providing psychoeducation, encouraging the notion that treatment is required for mental health, facilitating decision-making, and reducing distress or addressing trauma issues that may be triggered. Additionally, participants frequently reported particular attributes within their respective partner that facilitated a positive collaboration (see Table 7).

**Table 7. Attributes identified by participants that facilitate a positive collaboration**

<table>
<thead>
<tr>
<th>Consumer Attributes</th>
<th>Clinical Manager Attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Committed</td>
<td>- Trustworthy</td>
</tr>
<tr>
<td>- Motivated</td>
<td>- Good at listening and empathy</td>
</tr>
<tr>
<td>- Competent and insightful</td>
<td>- Talkative and social</td>
</tr>
<tr>
<td>- Place effort, thought and reflection into AdA</td>
<td>- Supportive and encouraging</td>
</tr>
<tr>
<td>- Include key worker</td>
<td>- Positive</td>
</tr>
<tr>
<td></td>
<td>- Knowledgeable</td>
</tr>
<tr>
<td></td>
<td>- Professional</td>
</tr>
<tr>
<td></td>
<td>- Honest and upfront</td>
</tr>
<tr>
<td></td>
<td>- Respect consumer views</td>
</tr>
</tbody>
</table>

**Involvement of Significant Others**

Four consumers reported they directly involved at least one significant other, and half of the consumers reported that they included a significant other but did not directly involve them in the process. Participants reported several reasons and related outcomes of involving significant others, summarised in Table 8. Two common reasons for involving significant others was to enhance communication and increase knowledge so significant others can better understand their role in the consumers TCP or better advocate on the consumers behalf.
Table 8. Reasons provided for including significant others

<table>
<thead>
<tr>
<th>Reason</th>
<th>Reported Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Significant others felt ‘traumatised’ by previous experiences with acute mental illness</td>
<td>Clearer understanding of role and awareness of plan if a future crisis occurs</td>
</tr>
<tr>
<td>Significant others are a ‘resource’ and hold valuable knowledge about the consumers individual symptoms and early warning signs</td>
<td>Consumer could demonstrate to others they are being active and ‘taking control’</td>
</tr>
<tr>
<td>Increase significant others sense of control and involvement</td>
<td>Significant others can demonstrate they do care for the consumer</td>
</tr>
<tr>
<td>Increase communication and networking between significant others to reduce the ‘burden’ on any one individual</td>
<td>Significant others can help monitor EWS</td>
</tr>
<tr>
<td></td>
<td>Significant other is equipped to advocate for the consumers best interest</td>
</tr>
<tr>
<td></td>
<td>MHS is more likely to contact and involve significant others during a crisis – reassuring for significant others</td>
</tr>
</tbody>
</table>

One CM commented on link between consumer and significant others by stating

It’s the consumer saying ‘what about me? My needs need to be met’ and the family of origin saying ‘well what about us? We need to have our needs met too and we’ve had enough’ and its sort of trying to bridge that that [sic] gap. (CM. H, p. 3)

Challenging aspects of developing an AdA

Consumers reported a myriad of challenging aspects with developing an AdA. A few consumers did not readily report any challenging aspect, however, a further analysis of interview transcripts often identified at least one aspect that could be considered challenging. Responses have been clustered into three main aspects: reflecting on one’s mental illness, deciding preferences, and parts of collaboration. Examples provided by
consumers relating to each theme are provided in Table 9. It should be noted that collaborating with a CM was also identified by some consumers as the easiest aspect of developing an AdA.

Table 9. Challenging aspects of developing an AdA as reported by consumers

<table>
<thead>
<tr>
<th>Main Theme</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reflecting on mental illness</td>
<td>Reflecting on difficult past experiences</td>
</tr>
<tr>
<td></td>
<td>Triggering of ‘traumatic’ memories</td>
</tr>
<tr>
<td></td>
<td>Fear of hospitalisation</td>
</tr>
<tr>
<td></td>
<td>Confronted with the possibility of relapse and loss of control</td>
</tr>
<tr>
<td></td>
<td>Realising the need for medication</td>
</tr>
<tr>
<td></td>
<td>Accepting mental illness</td>
</tr>
<tr>
<td>Deciding preferences</td>
<td>Researching information</td>
</tr>
<tr>
<td></td>
<td>Making decisions without assistance</td>
</tr>
<tr>
<td></td>
<td>Thinking ahead to cover the range of future possibilities</td>
</tr>
<tr>
<td></td>
<td>Finding suitable medication</td>
</tr>
<tr>
<td>Collaboration</td>
<td>Trusting mental health staff</td>
</tr>
<tr>
<td></td>
<td>Acknowledging the views of others</td>
</tr>
<tr>
<td></td>
<td>Being honest with oneself and others</td>
</tr>
<tr>
<td></td>
<td>Organising the treatment team and gaining agreement</td>
</tr>
</tbody>
</table>

One consumer response regarding the challenges of collaboration was based on the belief that mental health staff “don’t respect my wishes, and that I can’t feel that I can really open up to because they aren’t on my side” (Cons. 26, p. 4). Another consumer reflected in mental illness where the difficulty was “accepting that, you know, I’m not like other people, my life’s not completely controlled by me” (Cons. 28, p. 3).
Challenges reported by CMs could be grouped into two broad clusters of challenging aspect: collaborating with a psychiatric population and administration tasks (see Table 10 for examples).

Table 10. Challenging aspects of developing an AdA as reported by CMs

<table>
<thead>
<tr>
<th>Main Theme</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborating with a psychiatric population</td>
<td>Helping the consumer to identify early warning signs</td>
</tr>
<tr>
<td></td>
<td>Clearly sharing CM observations of the consumer’s illness</td>
</tr>
<tr>
<td></td>
<td>Judging competency and validity of consumer responses</td>
</tr>
<tr>
<td></td>
<td>Knowing whether the consumer understood, was ‘on the same page’ or ‘on board’</td>
</tr>
<tr>
<td></td>
<td>Helping consumer imagine experiencing a relapse</td>
</tr>
<tr>
<td></td>
<td>Sensitivity to rejection</td>
</tr>
<tr>
<td>Administration</td>
<td>Creating time</td>
</tr>
<tr>
<td></td>
<td>Liaising with treating team members</td>
</tr>
<tr>
<td></td>
<td>Time consuming paperwork and documentation</td>
</tr>
</tbody>
</table>

One CM reported the following about a consumer

...he [consumer] wasn’t actually able to put himself in the mindset of what if he were severely unwell...that would be almost obviously like letting go of control....it could be that maybe the memory of being severely unwell is distorted so maybe its hard for them to imagine being back there, maybe its hard to imagine what they need or to accept what they may need. (CM. A, p. 2-3)
Easy aspects of developing an AdA

The most commonly reported easiest aspects of developing an AdA from consumers was the filling in AdA paperwork and knowing one’s preferences. Collaborating with family or the CM was the next most cited easy aspect. In align with consumer responses, the most common CM response was the document itself and the consumer being self-motivated, driven, and committed to the process. The latter point is captured by a CM who replied

I think ‘consumer’s’ energy to keep going with it, because he’d just keep chugging on. I mean he’d be quiet for a couple of months…and then all of a sudden he’d come in with all the papers and we’d go off, so that’s great, so I didn’t have to hound him about it. (D, p. 4)

The finished AdA product

Half of consumers reported they felt able to, and did, express and document their true preferences. The other half reported that most of the AdA truly represented their true preferences, where limitations to documenting ‘true’ preferences were raised. One consumer identified working with mental health staff and being honest as a limitation. Despite this, the consumer reported that “it’s good to know that they [mental health professionals] kind of do want to know what I want” (cons. 26, p. 5). Consumer responses on the limitations to documenting one’s ‘true’ preferences were grouped under three key boundaries. Firstly, current options and services available within the mental health system e.g. limited choices available, unable to state preferences for interstate options. Secondly, current mental health legislation restricts the amount of power
consumers can hold. Some consumers questioned their ability to truly choose treatment, and that there are certain decisions the consumer cannot control. Thirdly, consumer opinions may hinder accurate information, for instance, the consumer may prefer not to have a mental illness or be on any medication, or considers the AdA as a ‘wish list’, therefore preventing the consumer to state true preferences.

All CMs indicated that they believed the AdA adequately represented the consumer’s true preferences. Many articulated the significance of documenting a consumer’s “true” wishes for treatment and care. As two CMs summed up, “At the end of the day, what I think’s [sic] right and good for a client might not really be right and good for the client” (CM. A, p.5) and

The way I see it being used as, somebody being sat down and discussing what the true options are, not what the case manager says is appropriate…if it’s used for the latter…it’s not an advance agreement, it’s a treatment plan (CM. J, p. 5-6)

CMs also verbalised several barriers to gaining a consumer’s ‘true’ preference. Firstly, the options on offer by MHACT and what the consumer would actually like can be two conflicting options. For instance, a consumer may prefer to wonder the streets, or may prefer herbal supplements; however neither are considered or encouraged as viable options by MHACT. One CM expressed this first point by commenting that

If I look at preferences for medication, ah, it’s rather an odd presentation considering really she’s [consumer] going to, you know, need whatever they [psychiatrists] prescribe…and so there aren’t really, its not really a set of
preferences...she's really just listing what she's been given when she's acute...I know, for example, that she'd like natural remedy so she doesn't have to take lithium at all, but you know that doesn't count as treatment (CM, I. p. 2)

The second barrier cited was that due to mental illness or personality traits, or both, some consumers frequently and rapidly change their mind. Thus raising the issue of ensuring the AdA has current validity. Thirdly, it was recognised that some consumers are not assertive or effective at verbalising their views. And lastly, consumers may have a tendency to agree with CM opinions or could feel coerced into agreeing.

Overall, participants' main suggestion for ensuring valid preferences was regular reviewing and opportunities to edit preferences.

3.3.5 Phase five: Evaluation

Products

Pre AdA Questionnaires

The consumer pre-AdA questionnaire consists of two parts (see Appendix G). Part A contains five questions that elicit information about the consumer's perceived ability to detect early warning signs and intervene. Part B contains questions on (i) involvement and medication preferences during their last period of being mental illness (ii) perceived helpfulness of particular aspects in treatment and care (iii) current perceived competence in managing their mental illness and (iv) beliefs around the impact of having an AdA.
The CM pre-AdA questionnaire consists of two parts (see appendix H). Part A poses three open ended questions regarding their previous experience with AdAs and benefits. Part B consists of questions to estimate a consumer’s level of independence, control, motivation, confidence, and empowerment towards managing his or her mental illness, using a 5 point Likert scale of not at all through to completely. None of the CM reported having previous experience with AdA’s or other anticipatory planning tools. Other results obtained from the CM questionnaire have been integrated into the results for rationale to engage in the project and develop an AdA.

Semi-structured interview for evaluating AdA’s

The semi-structured interview for consumers and CMs consists of a mixture of thirteen open and closed questions (see Appendix I). Interviews for the CM and consumer followed the same sequence of questions. The questions chosen were based on the main research goals and focused on collecting feedback on the workbook, processes involved in the development of an AdA, benefits associated with developing or possessing an AdA, the impact of an AdA on managing one’s mental illness, anticipated utilisation of an AdA, and other comments.

Results from the Pre-AdA Questionnaires

Eleven out of 14 consumers completed the pre-AdA questionnaire. Results indicated that half of the consumers perceived they were able to identify early warning signs more than half of the time (n=5), with fewer consumers stating they were actually able to intervene during those times (n=4). More than half of consumers reported that during their last
hospitalisation for mental illness they were not involved, nor did they receive preferred medication (n=6). Most consumers reported that over the past year they found psychoeducation and medication to be the most helpful aspects of managing mental illness. Consumers reported a spread of ratings for perceived sense of current management of mental illness in terms of independence, control, confidence, and empowerment. More than half of the consumers reported feeling extremely or completely motivated towards managing their mental illness (n=8).

Ten out of 11 CMs completed the pre-AdA questionnaire. None had previous experience with developing AdAs or similar anticipatory planning documents. CM responses for how they believed developing an AdA would benefit themselves and the consumer were reported in section 3.3.5.

A comparison of consumer and CM Pre-AdA ratings of a consumer’s current level of psychological functioning in managing one’s mental illness is summarised in Table 11. The comparison indicates a strong consensus with ratings, although CMs may be slightly overestimating the consumers who rate their perceived level of psychological functioning as none or not at all.
<table>
<thead>
<tr>
<th>Psychological factors</th>
<th>Rating (n= number of responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
</tr>
<tr>
<td>Independence</td>
<td></td>
</tr>
<tr>
<td>Consumer</td>
<td>3</td>
</tr>
<tr>
<td>CM</td>
<td>0</td>
</tr>
<tr>
<td>Control</td>
<td></td>
</tr>
<tr>
<td>Consumer</td>
<td>1</td>
</tr>
<tr>
<td>CM</td>
<td>0</td>
</tr>
<tr>
<td>Motivation</td>
<td></td>
</tr>
<tr>
<td>Consumer</td>
<td>1</td>
</tr>
<tr>
<td>CM</td>
<td>0</td>
</tr>
<tr>
<td>Confidence</td>
<td></td>
</tr>
<tr>
<td>Consumer</td>
<td>2</td>
</tr>
<tr>
<td>CM</td>
<td>0</td>
</tr>
<tr>
<td>Empowerment</td>
<td></td>
</tr>
<tr>
<td>Consumer</td>
<td>2</td>
</tr>
<tr>
<td>CM</td>
<td>0</td>
</tr>
</tbody>
</table>

**Results from the Semi-structured Interviews**

Results obtained during the interviews that relate to different phases of the action research project are reported in those relevant phases. This section primarily focuses on reporting results relating to suitability criteria for AdA’s, outcomes, anticipated benefits, issues, barriers, and suggestions.

**Suitability criteria and conditions required for developing an AdA**

The interview format did not contain a question inquiring about suitability or criterion required to develop an AdA, however during the interview this topic frequently rose or was posed as an additional question. Therefore, some participants mentioned criteria or attributes that make some consumers more suitable candidates for developing an AdA
compared to others. One obvious criteria was that the consumer desired to express their preferences and subsequently that they are willing to participate. The ‘stage of mental illness or disorder’ was frequently cited as a criterion to consider. There was some consensus that an AdA could be initiated when a consumer has an adequate level of insight and competence, which usually occurs when the illness is resolving or in complete remission. Hence in general, an AdA is suitable when the consumer is well, robust and equipped to deal with issues that may arise. This criterion however, was accompanied by difficulties. The main difficulty noted, with developing an AdA while a consumer is in complete remission, was that the consumer is generally ‘moving on’, and thinking about mental illness or developing an AdA may not be a priority. Additionally, there may be pressure to discharge the consumer from the mental health service. Alternatively, a few CMs identified AdA as suitable for new clients or early onset, where the AdA is utilised to build rapport, collect information, and provide education on the mental health system and ‘demystify’ hospitalisation. Again, CMs cautioned that this would have to be implemented with care as the AdA could be misleading and too confronting if introduced too early. For instance on CM commented that

"It's my belief that it takes people actually a few episodes before they actually begin to believe there's something wrong with them...the sooner the better but it takes people time to be ready for it" (cons 27. p. 7)
Other criteria or areas that participants' suggested to consider when deciding whether a consumer is suitable for an AdA included:

- Type of mental illness e.g. suitable for episodic illnesses and consumers who are relatively well functioning between episodes or with minimal residual inter-episodic symptoms
- Consumer's personal attributes - suitable for consumers who have energy, motivation, social conscious, educated/intelligent, respectful of others views, and empathic
- Consumer's previous experience with treatment and care - suitable for consumers who have a history of negative experiences, such as negative side effects of medications
- Availability of social support and level of trust within relationships

A few participants briefly commented on the general suitability of AdAs applied to a psychiatric population, where the inherent nature of mental illness (impact of symptoms, medication etc.) render consumer participation difficult. One consumer highlighted how lack of trust with mental health system and low self esteem can impact on a consumer engaging in an AdA:

If you'd have introduced this to me ten years ago I'd have had great doubts what are they going to do with the information...the most important distrust is, distrust of myself, I'm not sure if I do this, if it goes wrong I blame myself, if I do it and its successful I blame myself for being stupid about it...sort of afraid to win and afraid to lose. (Cons. 31, p. 6)
One CM expressed the opinion that if a consumer really had insight they would recognise that if they became severely unwell then ‘wouldn’t anything that would get their psychosis in control be worth a go?’ (CM. A, p. 3)

*Outcomes for psychological factors in managing mental illness*

During the semi-structured interview participants were asked whether developing or possessing an AdA impacted four psychological aspects towards managing one’s mental illness: independence, control, motivation, and confidence. Table 12 outlines the number of consumers and CMs who rated less, more, or no change, for each psychological factor in relation to managing one’s mental illness. Some participants provided elaborations on the questions around managing mental illness. Each psychological factor will be briefly reported, and where relevant compared with consumers pre-AdA ratings collected from the questionnaire.

**Table 12. Post-AdA ratings of changes in consumer management of mental illness**

<table>
<thead>
<tr>
<th>Psychological factors</th>
<th>Ratings (n= number of responses)</th>
<th>Less</th>
<th>No Change</th>
<th>More</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Independence</strong></td>
<td>Consumer</td>
<td>1</td>
<td>5</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>CM</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td><strong>Control</strong></td>
<td>Consumer</td>
<td>0</td>
<td>5</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>CM</td>
<td>0</td>
<td>3</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td><strong>Motivation</strong></td>
<td>Consumer</td>
<td>0</td>
<td>6</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>CM</td>
<td>0</td>
<td>4</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td><strong>Confidence</strong></td>
<td>Consumer</td>
<td>0</td>
<td>7</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>CM</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>2</td>
</tr>
</tbody>
</table>
Consumers who rated themselves as ‘more’ independent (n=8), attributed this to the AdA increasing their knowledge of options available and feeling more independent during periods of mental illness. All consumers who reported ‘no change’ (n=5) had rated their sense of independence as moderate (n=1), extreme (1), and complete (n=2) prior to developing an AdA. One consumer reported feeling less independent because they realised how much power the CM and other professionals have over the hospital admission procedure. Some CMs reported that the increased sense of independence arose with an improvement in general mental health, however, commented that AdA’s played an important role. CMs identified that independence was enhanced by giving a consumer time to think about and discuss their mental illness, and encouraging the consumer to make own choices. Thus a few CMs operationalised ‘independence’ as gaining ownership of choices and having input during periods of illness.

All five consumers who reported ‘no change’ in their level of control in managing their mental illness had pre-AdA ratings of feeling in control ‘half of the time’ (n=2), ‘most of the time’ (n=1), or ‘all of the time’ (n=2). Consumers attributed an enhanced sense of control to increased knowledge and control over medications. A few participants cautioned that a high sense of control can be counter-productive. For instance, if the consumer becomes the “controller” to a degree that wasn’t appropriate, or if a consumer with a high level of control becomes unwell they may be deemed too highly functioning for mental health system.
Another CM related the AdA to an enhance sense of control, stating that

I think its probably a process that’s clarifying to them that they are in control that they are controlling the medication that they’re taking now, that its keeping them well, that they know the signs that they are becoming unwell, the whole process I feel is concreting that they actually are managing their illness. …so I think over time and experience it is overall making them more confident that they are driving the bus (CM A, p. 4)

All consumers (n=7) who reported the AdA either did not impact their motivation to manage their mental illness or they were not sure, five consumers indicated pre-AdA motivation levels as ‘extremely’ (n=1), or ‘completely’ (n=4) (missing data n=2). Some consumers stated they felt more motivated to seek help and support if they noticed early warning signs. Additionally, CM identified consumers as more motivated to comply with a treatment plan, attributing this to psychoeducation, a greater acceptance of MI, and acknowledgment of the benefits of treatment.

Half of the consumers reported the AdA did not change their level of confidence towards managing their mental illness. Out of these, only one consumer however, reported no confidence prior to developing an AdA. One CM reported heightened level of confidence towards going into the future, while another reported the consumer felt more confident in being effective with managing mental illness. One CM identified education as impacting level of confidence stating that the AdA “gave him [consumer] a lot of education about his illness because he, initially when I first picked him up, he wasn’t even confident in saying he had a mental illness” (CM. G, p. 4). Only one CM reported the consumer’s
confidence had declined, attributing this to the consumer’s frustration with difficulty accessing services.

*Reported outcomes associated with the process or possession of an AdA*

The interview format did not contain direct questions inquiring about the benefits or outcomes associated with process of developing an AdA. Throughout the interviews, however, participants identified numerous benefits and outcomes related to the process of developing and possessing an AdA. Analysis lead to clustering these benefits into three groups: consumer benefits, interpersonal benefits, and professional or system benefits (see Table 13). The main benefits identified for consumers entailed increased involvement in one’s TCP, and increased sense of understanding and empowerment. Interpersonal benefits included significant others developing a greater understanding of the consumer and their role in the consumers TCP. Benefits reported for CM and the mental health system included clarification of the CM role and the AdA guiding clinical decisions, along with the AdA program supporting the shift towards a consumer involvement and multidisciplinary framework for TCP.

One consumer summed possessing an AdA as follows, “I feel its like, what a relief... to have the agreement filled out, so long as in the event I go back to hospital it’s abided” (Cons 5, p. 3). Additionally, one consumer reported that AdA can aid understanding of mental illness in the broader community “the more that people with mental illness come out and say how they feel, the better the community will be better able to handle it, especially carers and family” (Cons 31, p. 1) and “the more the community gets to know
that people are person with a mental illness, they aren’t a mental illness walking around” (Cons 31, p.3). One CM reported that simply possessing an AdA could be therapeutic if utilised as

A reminder to someone that there was a phase in their life when they were able to, with fully informed consent, map out their future...Some people might benefit from being reminded of that and it may actually activate their capacity to do it again. (CM, F. p. 4)

### Table 13. Outcomes reported by participants related to the process or possession of an AdA

<table>
<thead>
<tr>
<th>Consumer outcomes</th>
<th>Interpersonal outcomes</th>
<th>Systemic and professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Increased involvement in TCP</td>
<td>• Increased others understanding</td>
<td>• Gathered meaningful information on the consumer</td>
</tr>
<tr>
<td>e.g. helped the consumer realise</td>
<td>of the consumers mental illness and experience</td>
<td>• Outlined CM role</td>
</tr>
<tr>
<td>that they do have choices</td>
<td></td>
<td>• Clarification and awareness of own presumptions about the consumer</td>
</tr>
<tr>
<td>• Empowering</td>
<td>• Provided the opportunity for consumers and CM to discuss and communicate preferences in context and detail</td>
<td>• Facilitated movement towards multidisciplinary TCP</td>
</tr>
<tr>
<td>• Improved insight, understanding and knowledge of mental illness, treatment and the system</td>
<td>• Rapport building</td>
<td>• Aid in shifting attitudes around the importance, possibility, and benefits of consumer involvement</td>
</tr>
<tr>
<td>• Confronted and addressed other issues</td>
<td>• Recognised support system, or lack of support system, and increased liaison between all members</td>
<td>• Demonstrated that the MHS is consumer focused</td>
</tr>
<tr>
<td>• Relief regarding future periods of unwellness (aware of what will happen)</td>
<td>• Gave CM and consumer a focus in case management</td>
<td></td>
</tr>
</tbody>
</table>
Many participants linked aspects of the process of an AdA to outcomes, for instance:

There was a whole lot of psychoeducation…it wasn’t just a case of ‘answer this question for me’…it probably means that I get to understand ‘consumer’ a bit better (CM. E, p. 3)

And

It was a learning process for him [consumer] about his early warning signs…and also ways to empower him to actually identify when to seek help” (CM. G, p.1)

And

The more information [CM] give me the more empowered I am in just being aware of what’s going on. Whereas the real power of deciding which drugs…there wasn’t really a choice there, its just a nice idea that there was a choice (Cons. 25, p. 4)

And

The process of contributing [to] my good mental health is better than fighting the system when I have come to realise that I live a better quality of life while receiving treatment." (Cons. 16, p. 2)

Beliefs and anticipated benefits associated with activating an AdA

Some consumers identified that their AdA was no different to their usual treatment. For those consumers, gaining agreement, clarifying the procedures for a future mental health crisis, and being aware that mental health staffs want to seek their preferences, however, was reassuring. Consumers who reported that their AdA would not make much difference in TCP in the event they become unwell attributed this to a variety of reasons. One
consumer stated that the AdA was "a bit of a wish list...there are certain things like not having private health cover, which means I can't chose a facility of my liking" (Cons. 27, p. 5). Other consumers reported that they already have provided consent for their TCP, or that their psychiatrist already takes into consideration their best interests considers the consumers preferences. Others reported a low expectation that mental health staff will refer to their AdA, or the belief that staff will override the AdA.

In light of the above, all consumers anticipated at least one of the following positive outcomes if their AdA was considered, implemented, or both:

- Early intervention and access to services e.g. remind consumers to identify symptoms and seek voluntary treatment
- Hasten recovery
- Self-calming and reassuring to have a 'voice' when unwell
- Guide clinical decisions to be in align with consumer needs
- More 'humane' and positive experience of T & C by receiving pre-specified and consensual preferences for treatment and care e.g. keep away from male patients, prevent 'mistakes' with medication
- Faster activation of support network as the 'connecting' work has already been done and so significant others can help monitor decisions made by MH professionals
The last benefit is captured well by this consumer who commented that

Just the idea of a psychiatrist having to explain what he was doing to a family
member, you know somebody who was sane and competent, it just makes them
aware that their actions are being observed and um, there's some power in that.

(Cons. 25, p. 5)

CMs responses were clustered into two broad anticipated benefits for consumers who
posses an AdA in the event they become mentally ill. Firstly, if activated early, the
AdA's focus is prevention of acute illness through family involvement and faster access
to service. And secondly, if acutely unwell the AdA will improve hospital admission,
intervention and recovery through enhanced communication, avoiding mistakes, and
receiving consented for treatment and care. Only one CM expressed concern that the
consumer may not fully comprehend how the AdA would be used if activated,
commenting that

I think what she [consumer] thought was that we would all be rushing to her
side...if she ever went to PSU [Psychiatric facility] and we'd be there advocating
and lobbying for her to say no she needs this medication, she needs this music,
she needs this kind of massage. (CM. H, p. 2)

CM identified three benefits for themselves in the event an AdA is activated. Firstly, the
AdA will guide clinical decisions aiming to better meet the consumer's needs.
For instance, one CM commented that

I think it is going to be an important written report that is accessible to all mental health service staff about what his preferences are, and I think that can only add getting him through a crisis. (CM. D, p. 6)

Secondly, the AdA can act as leverage or a reference point for reminding a consumer, who may be exhibiting declining insight, of their TCP. And thirdly, the CM can more readily contact and involve significant others if the consumer has provided permission in the AdA.

*Relapse rates and Utilisation of AdA’s*

During the semi-structured interview, each participant was asked whether their AdA had been activated. Only one consumer had been hospitalised during the development of their AdA, and as the AdA had not been completed it was not ready to be activated by mental health staff. Another consumer reported they had successfully implemented the relapse prevention section of their AdA during a difficult life event. A different consumer reported that their AdA may be activated in the near future to demonstrate that the consumer no longer requires an involuntary patient treatment order.

*General Issues and Barriers*

Three broad and ongoing themes that impact on the uptake, development and utilisation of AdA’s in MHACT became apparent throughout the interviews. These themes were the impact of current mental health legislation, current mental health system practices, and
consumers perceived negative experiences of the MHS. Many participants questioned how much control or power the consumer actually has over preferences for future TCP, referring to the MHS legislation and power to override consumer preferences during an acute episode of mental illness. Linked to this issue was the belief that voluntary treatment is not really voluntary, as one consumer reported that

Voluntary doesn’t mean voluntary at all, because you ask to leave and they go “right, ship you over to involuntary”...I said I wanted to leave and they thought I was manic (Cons. 33, p. 3)

One consumer who raised a similar issue expressed that it was still a ‘nice idea’ to be given a choice, and that AdA’s are an opportunity to even the power imbalance. Another consumer emphasised the importance of autonomy and the right to chose:

I thought that if the patient wants something that’s what should happen because it’s their bodies, it’s their lives...it’s their happiness. They should be allowed...to do what treatment and medications they want, when they want. (Cons. 26, p. 3)

Several participants noted that overriding an AdA can be detrimental to consumers, particularly those who have invested time and energy into their AdA. Furthermore, one CM expressed how presenting consumers with a service that enhances autonomy, control and power can be confusing, overwhelming, and ironic given the MHS ultimately has the decision-making power during a mental health crisis:

The biggest problems is you’ve got two models happening, you’ve got that medical model where I’m the professional...like you will do what you’re told.
And then you get another school of thought that is about self empowerment, consumer driven work with clients… from a clients perspective it could be quite confusing …. So in one sense the system says well no you’ll do what we say, we know best, we’re the specialists …and then in the next breath we say well you’re better now. Or you know, it’s all, you can have all your power back now, work it out yourself. (CM. B, p. 7)

Here, a few CMs commented that they had to remind the consumer of the role and obligation the MHS has in caring for individuals experiencing mental illness.

Comments around this issue were not all negative, for example one consumer stated that

If I got to a certain point he [CM] would take over and I don’t have a problem with that…sometimes you’re the last person to know you’re, well to recognise that, or to admit I suppose, that you’re not well (Cons. 30, p. 3)

The second issue entails comments on the current MHS with respect to services available. Many participants remarked on the limited options for treatment and care, and the difficulty accessing services, resulting in the questionable use of the word ‘choices’. For example, regarding hospitalisation one consumer commented that “I don’t have private health cover so it’s really, I don’t think it’s a choice for me where I go” (Cons 27. p. 2). Additionally, a few participants queried whether consumers should be given the right to choose medications, given they are not qualified professionals.
Discussion about the MHS also revolved around the current status and function of clinical case management. Participants commented on the long waiting lists, heavy case loads, difficulty accessing and receiving case management, and CM stability i.e., staff changing roles or going on leave. Issues around the current function of clinical management were also raised. Current clinical management was viewed to be ‘crises’ driven, available predominantly for consumers who are acutely unwell, and addressing immediate issues as opposed to underlying psychological problems. Consequently, it was pointed out that if a consumer is clinically managed, they are assumed to be fairly unwell, and by definition not at a suitable stage for developing AdA’s. For instance,

If she [consumer] had a case manager she would be prioritised for services, but to get a case manager you’ve got to be acute....the system caters for people who are acutely unwell whilst talking about managing people within the community...they’re not managed in the sense of return to work, ah social education, motivational interviewing, ah housing issues, because to address those the persons got to be functioning, once they get functioning they don’t need a case manager. (CM HB p. 4)

The third common theme drawn from the analysis was the significant impact previous negative experiences with mental health services seemed to have on attitudes and beliefs towards AdA’s and TCP. Many consumers expressed defeatist attitudes and cynicism, reflecting a culture of hopelessness and helplessness amongst participants regarding being listened to, having choice, control and power over decisions relating to their individual TCP. It was emphasised that memories of such experiences may be traumatic
or distorted and therefore could influence a consumers desire to participate. For instance, a consumer may feel suspicious and consider the AdA as a ‘trick’. Also evident were some consumers reporting beliefs or misunderstanding around medication and hospitalisations that would obviously impact a consumer’s level of comfort in providing consent for treatment e.g. medication by injection causes paralysis.

In summary, the three issues outlined above are considered broad and ongoing matters of contention among consumers and CM, and undoubtedly influence the uptake, implementation and activation of individual AdA’s.

Other suggestions

During the semi-structured interviews many issues and questions were raised and frequently followed by suggestions. A few common examples include:

- Improve the cooperation of psychiatrists by making AdA’s part of standard practice and mandatory to consider
- Reduce the possibility of coercion during the uptake and development of an AdA by employing an independent project manager
- Increase staff awareness and activation of AdA by having an alert system on the database or giving treating team members copies.
- Debrief significant others after a crisis and review how the consumers AdA was utilised
- Emphasise to professionals that consumers need time to build trust, and therefore professionals need to be patient and understanding
- Emphasise the preventative focus e.g. by integrating AdA’s with collaborative therapy
- To increase uptake of AdA’s, educate all staff and consumers on benefits of AdA’s

Recommand AdAs to other consumers

All participants reported that they would recommend developing an AdA to other consumers of MHACT. The main reason identified for recommendation was to enhance awareness that consumers can be involved, have choices, and should provide informed consent for TCP. More specifically, one consumer identified AdA as an opportunity for consumers to tackle their issues around mental illness and treatment, while another recommended it as a tool to empower significant others. While all CM reported they would recommend developing an AdA, key workers from the private sector and non-government bodies identified barriers to developing AdA in their line of work, where AdA’s are viewed as ‘public health agreements’ and are not typically offered by their service. In particular, with private practice the main issue was whether the service of AdA’s was financially feasible, where for the NGO the main issue was that the organisation is not equipped for intensive supportive roles and so staff do not have access to appropriate support.
3.4 Discussion

The discussion is organised according to each specific aim of the project.

3.4.1 Aim: to increase knowledge and promote awareness of an AdA service within MHACT

The project was disseminated extensively its duration. Liaising with relevant stakeholders and the dissemination phase were both aimed to enhance awareness of AdA service, along with increase knowledge and gain support. A secondary function of the education sessions was to provide a forum for participants to express opinions and offer suggestions. This function is considered imperative for the implementation of an effective, successful and consumer oriented service. The education sessions were more successful in recruiting participants, where more passive methods, such as posters and fliers, were not as effective. The key difficulty encountered during this phase entailed reaching out and accessing all staff members and consumers. This is mainly attributable to the inherent problems of allocating the responsibility of service-wide dissemination to one, or even two, individuals. Given this scenario, the momentum of the project was blunted due to the incapability of the project to deliver multiple service-wide education sessions to each target group in a timely fashion. Consequently, the project relied heavily on fliers, posters, and CMs who attended the education sessions to communicate with consumers and raise awareness regarding AdAs and engaging in the project. Additionally, during the beginning of the study two areas of MHACT were deemed unavailable to participant in the project, further reducing consistent service-wide implementation.
Refresher courses targeted to relevant stakeholders on AdA’s and the associated benefits were deemed important for maintaining the liveliness, and sincere implementation, of AdAs. For reasons unknown, the original working party disbanded and the project was disseminated by the primary researcher and consumer representative, and then during the latter half by the primary researcher. Re-adopting a shared responsibility framework for implementing the AdAs is one solution for reaching and capturing a wider audience. Previous literature (E.g. Amering et al., 2005) also suggests that invitations to develop an AdA could be initiated whilst a consumer is in hospital, the availability of staff to discuss the option of an AdA, and encouraging families to participate, are all important for enhancing the likelihood of engaging consumers.

3.4.2 Aim: to provide recommendations on the AdA Materials

The AdA materials received positive and constructive feedback and are considered to be an excellent foundation to guide the process of developing an individual AdA. One of the challenging aspects regarding developing an AdA was the time-consuming nature of the AdA and associated documentation e.g. progress notes. The format of the resulting individual preference sheets is considered to be optimally structured, clear and succinct, enabling consumers to create their AdA in an individualised fashion. The resulting version of the AdA preference sheets also has the potential for consumers to complete some or all preferences in one sitting, on the proviso that they know their preferences and do not require any additionally education or counselling. The supplementary workbook successfully functioned as a tool for providing further information on developing a
relapse plan, and structural problem solving. Overall, the provision of AdA materials was
regarded as a useful base and source that balances general guidelines with specific
instructions, forming one solution to the impossibility of foreseeing all possible future
scenarios (Gallagher, 1998). The AdA Manual for CMs was not formally evaluated, as
reading or using the manual was only suggested and was not a requirement of the study.
It is, however, considered an essential tool for answering important and common queries
about AdAs. The provision of extra information on methods for staying well, along with
functional descriptions of treating team members roles are two suggestions for improving
the AdA materials.

3.4.3 Aim: to provide feedback on the stages and processes of AdAs

Results of the project, particularly the interview data, support the conceptual and
operational model outlined in Chapter Two, detailing the stages, processes and outcomes
entailed in developing an AdA. To reiterate, the stages move from offering, or being
offered, the opportunity to develop an AdA and deciding whether to engage; to
contemplating mental illness and past treatments; to problem solving and decision
making; to documenting the preferences and gaining agreement. Across all these stages
the processes of collaboration and psychoeducation were hypothesised to assist the
consumer and CM to achieve completion. The project reinforced the notion that
developing an AdA is an individualistic process, where some consumer will move
through the stages at greater speeds or in less depth compared to others.
Providing the opportunity

At present, MHACT is technically the sole provider of the AdAs in the ACT. Given ethical and logistical limitations, the project was unable to directly target all consumers to provide them with the opportunity to develop an AdA, thus relying heavily on MHACT employees to educate consumers and offer the opportunity. During the second round of education sessions to community mental health teams, particular emphasis was placed on the value of being involved in the project for providing feedback to MHACT to determine continued implementation of AdAs.

The project anticipated that more CMs than recruited would utilise AdAs as part of clinical management and TCP. Several reasons may explain the relatively low uptake of AdAs by CMs. Some CMs may have not offered AdAs to consumers for personal reasons (beliefs, attitudes) or because they did not consider any of the consumers were suitable candidates; alternatively, some CMs may have offered the service and the consumer decided not to engage. One noteworthy belief, expressed by a few CMs during education sessions, was the belief that AdAs should be “consumer driven - staff collaborative”. For instance, it was noted on many occasions that some staff believed consumers should initiate the process of developing an AdA (consumer-driven) with the CM. One reason provided for this view was to protect the consumer from the AdA being perceived as a “coercive” practice, “pushed” by a CM. It is likely that staff holding this opinion would be less inclined to provide the consumer with the opportunity. Given this, the project also recognises the importance of a consumer-driven service in order to ensure that the AdA service remains an honest representation of consumer rights and method of meaningful
involvement in TCP. The strict adoption of this view, however, is considered counterproductive and can have serious implications for the promotion and provision of the AdA service to consumers who, as explained previously, are difficult to reach. Additionally, while staff fears of coercive practices are plausible, the AdA service by nature requires that staff emphasise to consumers that the AdA is a documentation of their individual preferences and therefore they have the power to decide whether to engage and participate.

Overall, providing the consumer with the opportunity, through the provision of information and the availability of staff to discuss and offer the service, is considered to be an essential step for engaging and committing to AdAs.

Deciding to develop an AdA

Evidently, the rationale for developing an AdA is intimately linked to benefits one hopes to gain. Additionally, understanding why consumers or CMs desire to develop an AdA can help promote AdAs to other potential users, along with shape the goals they wish to achieve from completing an AdA. This study marked the beginning of collecting knowledge and gaining insights into a participant’s reasoning for developing an AdA, which have not been documented in previous studies. The analysis indicated that a consumer’s motivation to document his or her preferences for future treatment and care predominantly stemmed from a history of negative experience/s with mental illness, treatment or the system. Thus, developing an AdA formed part of the solution by increasing meaningful involvement in one’s own TCP and communicating one’s
preferences, with the optimistic hope for better outcomes and more positive experiences in the event of a relapse.

As developing an AdA is collaborative process, the rationales for CMs to engage in the process are also imperative to understand. Although expressed in differing language, CMs essentially identified reasons that were aligned with consumers. CMs viewed an AdA as functioning as a therapeutic tool, a way of including others, or as a method of facilitating treatment. These functions are not mutually exclusive or refined. They do, however, provide a preliminary system for conceptualising the function of AdAs from the CMs perspective. These insights could prove useful as promotional information for attracting, or encouraging, CMs to offer, develop and utilise AdAs.

*Contemplating mental illness, past treatments*

Results indicated that consumers moved faster through stage two, the contemplation stage, compared to others. Some consumers seemed to place a significant amount of effort into thinking and dealing with issues related to mental illness and past treatments, while other consumers stated that they already knew their preferences and thus there was little need to address related issues. For those consumers who did spend time contemplating, reflecting on one’s own mental illness was often reported to be a challenging aspect of developing an AdA. Memories of “traumatic” experiences, fear of hospitalisation, the confrontational nature of relapse, and accepting one has a mental illness, were all reported to be challenging aspects. The opportunity to reflect, however, did not necessarily produce negative outcomes, and was often perceived to be
accompanied by substantial CM support. While all consumers reported at least one positive outcome associated with AdAs, the data seemed to indicate a positive relationship between amount of time and effort placed into ‘contemplating’ issues around mental illness, with detailed AdA and reported gains. Considering these results, it is recommended that AdAs could be utilised as a forum for CMs to counsel consumers on sensitive topics, such as negative experiences, to assist them in addressing and resolving issues that are likely to negatively influence their perception of mental illness, treatment and care, and the mental health system.

Deciding on preferences

Stage three of the AdA model (i.e. choosing preferences) outlined a strategy of problem-solving to assist consumers in making decisions and enhance the sense of informed consent and investment in the AdA. Structured problem solving did not appear to be strictly utilised by all consumers, as many already knew their preferences or flowed through the steps of decision-making more automatically without a conscious awareness. Additionally, working through the outlined steps of problem solving was reported by some participants as time-consuming and repetitive. For the preferences that did require some problem solving, some consumers reported that reaching a decision was a challenging aspect of developing an AdA. Researching information, deciding on actual preferences, and making thorough decisions that cover the range of possible future scenarios, were all reported difficult aspects. Two proposed suggestions to remedy this are the provision of psychoeducation and the assistance from CMs in searching for information and decision-making techniques. Regardless of the extent of decision-making
that occurred, the premise behind individuals making decisions is that they are more likely to follow-through with the decision, performing the decision more effectively and with greater motivation. Thus, while the strategy outlined in the workbook was not always strictly followed, educating and practicing problem-solving techniques are still considered essential and beneficial tools for any individual making important decisions. Future research could investigate more comprehensively the techniques consumers adopt to decide on their preferences, the need for teaching consumers techniques, and the effect of decision-making and benefits associated.

The finished document

The fundamental feature of an AdA, compared to other TCPs, is that it is a true representation of a consumer’s preferences for future treatment and care. Ensuring an AdA is an accurate and “true” representation of a consumer’s preferences is a vital ethical component of developing an AdA, and is not always explicitly raised in the literature. All CMs, and the majority of consumers, reported that their AdA was a genuine representation of their preferences. Participants identified barriers to recording an accurate AdA, which provide useful points for future participants to be mindful of when developing an AdA. The two predominant barriers were the reality of limited options and services offered by MHACT, where the medical model and medication was perceived to dominate a significant portion of TCP; and the current status of legislation and power held by treating professionals, where participants questioned a consumer’s capacity to truly choose preferences.
Optimistically, only one consumer reported hesitation in being honest with mental health staff, expressing that they felt inclined to agree with the CMs suggestions. This issue has been raised as one of the ethical problems associated with collaborative anticipatory planning. Given this, the problem recognized in previous literature stating that mental health professionals are concerned about consumers “giving in”, or making decisions under the influence of others, was not identified as a major problem in this study. Additionally, issues around competence and insight in relation to the validity of the document were rarely commented upon. It appeared that determining the validity of an AdA was based on general personal judgment, arrived at by acknowledging the complex interplay between the consumer, CM and system, and trusting that the consumer was honest and open. Future research could investigate more specific characteristics that might modulate the validity of an AdA, such as diagnosis, and acceptance of mental illness.

The range of time-frames that participants required to complete an AdA further supports the notion that the process is individualistic. CMs frequently reported time pressure and constraints as challenging aspects of developing an AdA. Some participants warned that if AdAs are considered as too time consuming by CMs then they are less likely to be offered or developed. A CM’s attitude that AdAs are too time consuming may be stemming from other factors, such as pressure to discharge a consumer, rather than a belief that there is little value in spending time developing an AdA. Thus, while developing an AdA may be considered by the CM as important, discharging a consumer from the service may be considered the priority. Addressing concerns regarding the
“time-consuming” nature of AdAs and underlying factors may be important for enhancing the probability of CMs offering AdAs to consumers.

**Collaboration**

**Collaboration between consumer and CM**

As examined in Chapter Two, a positive alliance between consumer and CM can be experienced as therapeutic. Previous literature has identified several positive outcomes associated with a therapeutic alliance, including a decreased sense of coercion, medication adherence and psychological wellbeing. A therapeutic alliance entails a cooperative relationship and willingness by both individuals to invest in the process and agree on goals and tasks. Each pair had a unique relationship and style of collaboration, mostly built around trust and mutual respect. Participants were, overall, satisfied with the collaboration and agreed on goals and tasks for the AdA, which is a good indication that a therapeutic alliance was either established or developed. In general, the collaboration was considered as positive where the CM played a variety of roles. Most consumers in the study reported that they had more input into their AdA, indicating a high degree of consumer ownership of the AdA. To assert further, it is plausible that ownership is associated with informed consent and reduction in coercive practices. To draw conclusions for other outcomes, such as medication adherence and psychological wellbeing, requires longitudinal objective measures not covered in this study.

Challenging aspects of collaboration were also identified, highlighting the intricacies of working with a psychiatric population who often have a history of unstable relationships,
reduced social skills, and other enduring influences of mental illness. Challenges identified by clinicians appeared to link closely with consumer reports, potentially flagging an important issue to be addressed. For example, if a CM identified difficulty with helping a consumer imagine a future relapse, this could be an indication that the consumer is fearful of a relapse, thus providing a good opportunity to address the issue. Such challenges highlight the importance of CMs being vigilant in assuring that their consumers are comfortable and able to be honest, otherwise the AdA runs the risk of being a treatment plan driven by the clinician rather than the consumer.

Involvement of significant others
Over half of the consumers included their significant others in their AdA. Only four consumers, however, reported that the inclusion entailed direct involvement or collaboration. The small amount of direct inclusion of significant others may reflect population characteristics i.e. individuals with schizophrenia tend to have smaller social networks; and specific research goals i.e. the research could have placed greater emphasis on encouraging significant other involvement, only one section of the AdA directly required significant other inclusion; and individual decisions not to include significant others. Participants identified a range of positive reasons they decided to include or involve significant others, along with a range of positive outcomes, such as clarifying roles, improved communication, and to advocate better on a consumer’s behalf. These results add to the growing literature on the importance of, and benefits associated with, involving significant others.
3.4.4 Aim: to report the overall outcomes associated with developing or possessing an AdA

The qualitative information provided by participants provided considerable support for the positive outcomes flowing from AdAs. Consumers' perceptions of their ability to manage their mental illness were assessed by subjective evaluations of motivation, control, independence, and confidence. Prior to developing an AdA, high motivation levels were consistently reported across participants, indicating that motivation may be an important factor for developing an AdA. The majority of participants rated most of the psychological factors as remaining the same or improving after completing the AdA. For consumers who indicated that the AdA did not impact on their perceived ability to manage mental illness, pre-AdA ratings indicated that they already had high levels of independence, control, motivation and confidence.

Participants often made direct connections between parts of the AdA process and changes in a specific psychological construct, such as education and an enhance sense of control. Other times, the change was considered to occur in conjunction with a general improvement in mental health, where it was uncertain how much the AdA impacted on the generated outcomes. In any case, the results provide preliminary evidence that developing and possessing an AdA can assist one's subjective sense of managing one's own mental illness. Additionally, the results indicate that perceived high levels of independence, control, or confidence are not a prerequisite for developing an AdA.
Other benefits related to the process of developing an AdA or to the possession of an AdA were derived from the data. All participants were able to identify at least one benefit that they experienced from completing an AdA. However, the significance or impact that a benefit had on one’s life appeared to differ among participants. Nonetheless, the analysis generated a range of benefits that could be conceptualised in the same categories developed from the literature review, lending further support for the conceptual and operational model of AdAs (refer to Table 13 for a summary of the benefits). Almost all the benefits identified from the analysis were parallel to those described in the literature. Understandably, concrete outcomes discussed in the literature, such as reduced amount of involuntary hospitalisations and reduced length of stay in hospital, were not identified from the analysis and would require a lengthier study. Additional benefits relating to the mental health system or professional were drawn from the study. These benefits included being able to clarify a CM’s role, gather idiosyncratic information, facilitate the move towards multidisciplinary care, and assist the cultural shift towards meaningful consumer involvement. Clearly, further work needs to be done to establish causal links between the process of developing an AdA and the benefits reported.

3.4.5 Aim: to report beliefs around the activation, and utilisation, of an AdA within MHACT

For the duration of the project none of the consumers with completed AdA’s had experienced a relapse that required intervention. Only one consumer activated the relapse prevention plan section of their AdA during a stressful life event, and this was considered
to successfully function as a preventative measure. Thus, feedback was collected on anticipated benefits and beliefs associated with the activation and utilisation of an AdA.

Identification of anticipated benefits for consumers and CMs provides a useful source of information for education, promotion, and outcome measures for future studies. One consistent finding was that many consumers expressed a low expectation that their AdA would be referred to or honoured by mental health staff. Though disconcerting, the study demonstrated that holding this belief was not sufficient to prevent consumers from developing an AdA. Two plausible reasons for consumers holding this belief to continue with developing an AdA are because they are gaining other benefits, or because they are hopeful that their expectation will not be realised. Further analysis was able to identify possible grounds for the low expectations, such as the concern that staff in an emergency situation may not be aware a consumer possesses an AdA. The reasons behind a participant's low expectation were often followed by useful suggestions, such as utilising an alert system to increase awareness.

It is likely that gaining a more comprehensive understanding, of the processes and issues regarding the activation and utilisation of an AdA, will happen over time. Investigating the activation and utilisation of AdAs relies on real clinical circumstances to arise, where a consumer who possesses an AdA requires it to be activated, and thus suits a longitudinal research design.
3.4.6 Aim: to identify general issues and barriers to implementing AdAs within MHACT

Specific challenges relating to the stages and processes entailed in AdA have been discussed in previous sections of this chapter. Participants’ responses regarding general barriers to implementing AdAs could be grouped into three extensive issues. These issues are complex, and all contain a multitude of sub-issues or problems that could all be suggested to either directly or indirectly impact the implementation of an AdAs in MHACT. The three broad issues are connected by an overarching theme questioning the extent that consumers are able to be meaningful involved in TCP, which is impacted upon by current mental health legislation, the model of treatment and care, and consumers’ previous experiences within the system.

The legal enforceability of an AdA when activated within MHACT is unclear, thus limiting a consumers AdA to have mandatory influence towards clinical decisions. Furthermore, participants raised concerns around the mental health legislation and current powers held by professionals to override an AdA. Comments collected from the interviews also raise questions about the validity of voluntary treatment and the provision of consent. The problem identified relating to the idea of voluntary treatment was that some consumers are under the impression that treatment will be administered through involuntary measures, regardless of if they refuse consent to voluntary treatment and care. This opinion has implications for the validity of an AdA, as some consumer may be simply “agreeing” with professional’s advice. Furthermore, if this opinion is plausible, and the practices of “convincing” or “blackmailing” consumers into accepting voluntary
treatment is commonplace, then a deeper ethical issue regarding service provision has been identified and is beyond the scope of this paper to address.

Issues related to the current model of treatment revolved primarily around the notion of "choice", where choices the system offers are limited and this consequently can limit the AdA. The third common theme was the impact of mental illness experiences on attitudes and beliefs, where specific attitudes and beliefs identified often highlighted areas a CM could address with a consumer, such as beliefs around medications.

Overall, the broad issues expressed by participants are congruent with those discussed previously in the literature on consumer involvement in TCP and anticipatory planning. Each issue is evolving; existing within a multifaceted interplay between ethical, legal and practical responsibilities, along with the reality that mental illness encompasses a diverse and complex array of disorders, disabilities and experiences. A thorough discussion to address each issue is beyond the scope of the study. The central point, however, is that AdAs are implemented within a systemic culture that is constantly changing and subjectively experienced by the consumer. Thus, a consumer is likely to benefit from a CM who is sensitive and knowledgeable about the broader issues that impact on a consumer's AdA, such as mental health legislation, and limited choices for treatment and care.
3.4.7 Aim: to provide a summary of recommendations for the implementation of AdAs in MHACT

The successful and effective implementation of AdAs entails the necessary involvement of multiple groups. Thus, not surprisingly, implementing and sustaining AdAs requires adequate resources and support from relevant stakeholders; continual dissemination through education and promotion; and the development of protocol, procedures and guidelines for developing and utilising AdA’s. The evaluation of this study resulted in rich context specific information from participants. Given this, most of the recommendations or suggestions flowing from the evaluation have been reported throughout the results and discussions sections of this chapter. Within each stage and process entailed in developing an AdA information was gathered that could assist with the continued implementation of a successful AdA initiative. For example, it is recommended that developing an AdA is a highly individualistic process and that CMs can take on several different roles, such as providing psychoeducation, facilitating decision-making, or scribing a consumer’s preferences. Further examples of recommendations resulting from this study are outlined in Table 14.
Table 14. Examples of recommendations for implementing an AdA service in MHACT

<table>
<thead>
<tr>
<th>Issue</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability of an AdA service</td>
<td>• Management to offer systemic support</td>
</tr>
<tr>
<td></td>
<td>• Collaboration and a shared responsibility between consumers and MHACT for resources and implementing AdAs</td>
</tr>
<tr>
<td></td>
<td>• Continued liaison with relevant stakeholders</td>
</tr>
<tr>
<td>Education and promotion</td>
<td>• Disseminate extensively across all teams and areas of MHACT</td>
</tr>
<tr>
<td></td>
<td>• Allocate an AdA representative within each team and community organization</td>
</tr>
<tr>
<td>AdA Materials</td>
<td>• Utilise Individual Preference Sheets and supplementary workbook</td>
</tr>
<tr>
<td></td>
<td>• Keep materials brief, succinct, and allow for individuality</td>
</tr>
<tr>
<td>Functions of an AdA</td>
<td>• Primary function is to increase consumer involvement</td>
</tr>
<tr>
<td></td>
<td>• Secondary functions include utilising AdA as a therapeutic tool or to involve significant others</td>
</tr>
<tr>
<td>Developing an AdA</td>
<td>• Assess suitability characteristics</td>
</tr>
<tr>
<td></td>
<td>• Individualise the process for consumers and CMs</td>
</tr>
<tr>
<td></td>
<td>• Utilise decision making techniques when required</td>
</tr>
<tr>
<td></td>
<td>• Ensure AdA is a true representation of a consumers preferences</td>
</tr>
<tr>
<td>Activating and utilising an AdA</td>
<td>• Develop an alert system on MHAGIC</td>
</tr>
<tr>
<td></td>
<td>• Share consumers AdA with all treating team members</td>
</tr>
</tbody>
</table>
3.4.8 Study Limitations

Sample size and recruitment

The sample size was considered adequate given the limited resources, time allocated to the project, and richness of the data collected. Recruitment for the project was challenging and a major limitation of the study. Considerable time and energy was required during the dissemination phase and the researcher/s had to work hard to recruit CMs and consumers. As noted by previous authors (e.g. Amering et al., 2005), low levels of recruitment and completion rates are not surprising given the well-documented obstacles to implementing AdAs. Furthermore, it was not possible to estimate the number of consumers in ACT who knew about AdAs or how many were suitable for the project, as education and promotion of AdAs targeting consumers relied heavily on individual CMs offering the option of developing an AdA to consumers being clinically managed.

The withdrawal rate was not unexpected given the population under investigation. Consumers with transient lifestyles or changing contact details, and pressure to discharge consumers from clinical management are not uncommon features in a mental health setting. Only a few of the reasons provided for withdrawal from the study mimicked those cited in previous literature, such as finding the AdA confronting or the consumer not anticipating a relapse. Future research should ensure that expectations for sample size and AdA implementation are realistic, and that measures are in place for increasing the researcher’s ability to maintain contact with consumers, address reasons for withdrawal, and increase participation rates.
Limitations with study design

One limitation of the study design was the lack of standardised protocols to measure the process and specific outcomes associated with AdA’s. If such measures were available the reliability and validity of the results could be strengthened. Nevertheless, the adoption of the qualitative methods for the project was considered appropriate and consistent with the goals of the project.

General limitations relating to qualitative research and research in a mental health setting is outlined in Chapter Six. The scope and depth of the qualitative analysis of the current study was limited given time and resources. The content analysis was conducted by the primary researcher, and the project was unable to access an independent rater to perform a secondary analysis of the data. Gaining an indication of inter-rater agreement for the content analysis would ultimately strengthen the validity and reliability of the results and conclusions drawn from the data. Additionally, given more time, the results drawn from the content analysis could be strengthened by deepening the scope of the analysis by employing techniques such as “If-Then” tests, and searching for and then testing relationships between variables (Miles & Huberman, 1994). Nevertheless, the content analysis of the interview data was conducted through an iterative process, where results were continually checked with the raw data to increase the accuracy and validity of conclusions proposed.
**Generalisability**

The consumer portion of the sample is considered to be moderately representative of the MHACT consumer population. Together, the consumer sample had a range of diagnosed mental illnesses, primarily schizophrenia. The sample, however, may also be relatively unique as indicated by high levels of motivation towards managing one’s mental illness, and the fact that half of the sample had not required hospitalisation one-year prior to engaging in the study. Anecdotally, it appeared that the majority of consumers who completed an AdA in this study had a high level of experience with their own mental illness and had experienced multiple episodes of mental illness in the past. These characteristics are relatively common in a mental health setting. Thus it is reasonably plausible to generalisable the results of the study to other consumers of MHACT, particularly those who are currently experiencing a period of relative mental stability.

Similarities in models for clinical management across mental health services in Australia would ease the generalisability of the results from this study to other community mental health settings. The relatively small geographical size and urban nature of the ACT allows for an easier implementation of a service wide initiative, compared to the difficulties associated with mental health services within other states and territories that deliver services across a larger geographical area of rural and urban settings. Relatively, MHACT is a more compact service, which allows for the potential of AdAs to be disseminated consistently and delivered service wide in a timely manner. Another feature that makes MHACT unique is the provision of a shared computer database, allowing the distribution of AdAs and increasing staff awareness of a consumer’s AdA in a crisis.
situation. Furthermore, given the relatively small geographical size of the ACT compared to other Australian states, the options for services regarding treatment and care are significantly limited. For instance, there is only one public psychiatric facility in the ACT, thus preferences for hospitalisation are obviously restricted. Nevertheless, the findings of the current study could be employed to influence and guide the implementation of AdAs into a different mental health setting. The intricacies of an implementation, however, will undoubtedly be context specific.
CHAPTER FOUR

Study Two

Consumer and Carer Focus Groups on Advance Agreements

4.1 Aim

Focus groups are commonly employed in action research to “empower” participants to become active in the process of feedback, research and data collection (Kitzinger 1995). They are suitable for identifying a range of opinions, ideas, or beliefs in a population (Hudelson, 1994) and can also facilitate the expression of criticisms and discussion of taboo topics, as the less inhibited members of the group initiate and generate discussion. Therefore, focus groups were conducted to strengthen and compliment the research evaluating the implementation of advance agreements (AdAs) in Mental Health Australian Capital Territory (MHACT). The purpose of the focus group comprising consumers, and the other comprising carers, was to gain an overview of attitudes, opinions, and advice on AdAs, and in particular to attain specific insights into how AdAs could be best implemented in MHACT.

4.2 Method

4.2.1 Participants

Participants were divided into two separate groups. The first was a Carer Focus Group (n=4) consisting of carers of individuals with mental illness, who have had previous experience with MHACT, and who utilise services provided by Carers ACT. The second
group pooled two separate Consumer Focus Groups (n=14) and consisted of consumers from the MHACT Consumer Network.

4.2.2 Procedure

The Carer Feedback Session was organized through Carers ACT. Carers were invited by an employee of Carers ACT to partake in the group. The carers who volunteered to participate were then contacted and given information on the purpose, dates, location of the session. The Consumer Feedback Session was organized by providing an initial meeting with consumers from the MHACT Consumer Network, and then through liaising with the manager of the MHACT Consumer Network. The consumer sessions were advertised through a flier displayed at the MHACT Consumer Network and in a local electronic journal disseminated to consumers of MHACT.

The Focus Groups were structured as follows:

- An information session on Advanced Agreements and the project currently being conducted in MHACT
- Consent to participate collected
- Semi-structured discussion
- Written feedback to open ended questions

The discussion was guided by set open-ended questions and often complimented with probing questions to obtain further information. The set of open-ended questions were:

*What information would you want in an Advance Agreement?; How do you think*
Advance Agreements would benefit consumers, carers, MHACT?; What are the reasons a consumer might not want an Advance Agreement?; How can Advance Agreements be implemented in MHACT?; What do you think are the main obstacles and concerns with Advance Agreements?; Overall, do you think Advance Agreements should be offered by MHACT?; and Any other comments or questions?.

The focus groups were tape recorded and transcribed for content analysis, following the same procedure described in Chapter Three. An initial summary of the results for each focus group was forwarded to the participants who attended that group. This provided participants with the opportunity to provide further feedback, clarification and confirmation of their views. Following any further feedback, amendments were made and a summary of the results were reported.

4.2.2 Analysis

A content analysis of the interview transcripts followed the procedure described in Chapter Three. The content analysis was conducted by the primary researcher in a rigorous and iterative fashion. General themes and, where relevant, individual opinions are reported. Furthermore, written comments were used to check the results drawn from the data and to further ensure the representativeness of the analysis.

4.3 Results

The results for the Carer Focus Group and Consumer Focus Group will be reported separately. Some of the discussion during the groups revolved around asking questions
about the current status of the AdA. If this occurred, information was provided and followed by a question to elicit discussion. For instance if a participant asked “how much legal status does an AdA have?”, information on the current status was provided by the researcher, followed by a probing question to facilitate further discussion, such as “what kind of legal status do you think it should have?”. The results section will report the main findings that support feedback gathered from the pilot project, along with other points relevant to the specific population and constructive suggestions. Thus, the information reported focuses on the anticipated benefits associated with an AdA program, specific issues and considerations, along with suggestions for implementing an AdA service in MHACT.

4.3.1 Carer Focus Group

Four carers participated in the Carer Focus Group, lasting approximately 85 minutes. The participants indicated that they each provided care for individuals who have a diagnosis of chronic mental illness and have received treatment and care from MHACT. Results on previous experience with AdA’s, specific carer issues and needs, along with benefits and barriers will be reported. All carers were somewhat familiar with the concept of AdA’s however none had previous involvement in the AdA project.

Function of an AdA

Carers reported that guidelines on the level of carer involvement, along with information for mental health staff to contact the carer when the consumer is mentally ill, would be especially important to document in an AdA. Some carers identified that AdA’s are a
means of including carers with informed consent from the consumer, thus avoiding the
danger of infringing on consumer privacy and litigation.

**Benefits associated with AdA’s**

Carers identified the purpose of AdA’s is to protect the consumer’s rights during a period
of mental illness, to increase consumer involvement and gain informed consent. A few
predicted that if a consumer agreed to carer input in the first place, the AdA would make
little difference, stating that

> if they’ve [consumer] agreed to do them...they’re agreeing to you [carer] having
> some input into the whole lot, so if they’re agreeing in the first place you haven’t
> really got a problem (Carer, p. 9).

Despite this, all carers agreed that if the AdA reflected the consumer’s wishes, and both
carer and CMs were involved, and there were supports in place to actually do and carry
out expressed wishes, then the AdA would be beneficial. Additionally, one carer
suggested that the AdA could be used as a tool to assist carer inclusion and relationship
building.

**Barriers and Issues**

Carers highlighted legal considerations, ethical concerns, and practical issues around
implementing an AdA program in MHACT. The degree of legal status AdA’s should
hold was discussed in length. One carer expressed that if AdA’s become legalized then
consumers may be deterred from developing one, reporting that “if you say to the
consumer ‘okay you make this agreement and it’s legal, you can’t change your mind when you’re psychotic’, then they’ll say ‘well I don’t want a bar of it’” (Carer, p. 4). Another point recognized was that AdAs do not protect individuals from involuntary treatment, or breaches of confidentiality to involve carers, if a consumer is mentally ill. The main ethical concern raised by carers involved ensuring that the AdA is a true representation of a consumer’s preferences, where impaired competence and the influence of others were highlighted as barriers. Practical issues identified concerned MHACT staff awareness of a consumer having an AdA, and how the AdA will be utilised, where some carers expressed the opinion that few psychiatrists are currently thinking in terms of AdA’s.

Other potential barriers identified to developing AdAs included the impact of mental illness on a consumer’s level of insight and competence, a lack of case management, and difficulty in empowering or collaborating with consumers. Some comments that demonstrate the above points included:

I don’t think many of them [consumers]...would have enough perception, maybe when they’re well, but especially when they’re unwell to even have a clue as to how much medication they should have (Carer, p. 6).

And

The clinical managers seem to change all over the place all...and I mean from my experience ... kids [consumers] wouldn’t have a bar of it, and even if they were willing to talk with their case manager they wouldn’t want their parent involved,
or some would want their parent involved but not anybody else, you know, we’ll just keep it between us sort of thing (Carer, p. 7).

General concerns raised relating specifically to the carer population included privacy and confidentiality laws that place limits on their involvement, the impact of deinstitutionalization and ‘flinging’ the consumer back to the community and carers without the appropriate resources, delayed contact from mental health staff during a crisis, and the perceived opinion that staff rarely take carers input seriously. For instance one carer believed that “there’s a medical attitude really that, if you as a carer are saying ‘look I’ve been observing this, this and this’ you’ll get, ‘oh where did you get your medical degree young man?”’ (Carer, p. 9).

**Carer suggestions**

Carers identified themselves as hard working and knowledgeable regarding the consumer and their needs, emphasising the necessity of their involvement, communication and sharing of knowledge. Carers supported the notion that the consumer should have the most input into their AdA and that the consumer should collaborate with a qualified mental health professional. Carers suggested that to promote AdAs, mental health staff should request an appointment with the carers for education purposes, and that this should form part of staffs’ job criteria when a consumer is admitted to hospital or during hospitalisation. They suggested that the AdA process should be initiated by staff in the hospital and that consumer should also receive education on the benefits associated with AdAs. If the consumer is considered ‘well enough’ the AdA could form part of the treatment within the hospital, otherwise the AdA could be developed in the community.
They also highlighted the need to produce complementary laws, policies, and procedures that guide the implementation of AdAs.

4.3.2 Consumer Focus Groups

Two consumer focus groups were conducted with a total of 14 participants. The results of the two groups were pooled. Each session lasted approximately 90 minutes. No demographic information was collected, however from observation it appeared that many of the consumers attending the focus groups were articulate and experienced advocates for consumers with mental illness.

Consumers identified that developing an AdA and implementing an AdA were two different processes. Consumers reported the following information was most important to document in an AdA

- Significant other involvement e.g. notification, consent to release information
- Preferences for psychiatric hospitals and alternative treatments
- Planning for anticipated changes of mind in preferences, or opting out of the AdA
- Documentation of differing opinions between consumer, CM, and significant others.

Benefits

Consumers identified developing an AdA as a means to be heard and involved in one’s own treatment and care plan (TCP). For instance one consumer noted that the AdA is “just one way to be heard when I’m in a state where people may discount what I’m thinking or saying” (Consumer, group 2, p. 8). Another stated that “it [AdA] helps the
consumer to feel safer, that their rights are being looked after” (Consumer, group 1, p. 4). Anticipated benefits associated with AdAs were reported and are presented under the categories of benefits for consumers, carers, and the mental health system (Table 15).

Several benefits for consumers were anticipated. Firstly, increased satisfaction with treatment and care, achieved through involvement and the provision of informed consent or voluntary care. The importance of this aspect was highlighted by one consumer who viewed that “currently in the ACT forced treatments are too readily invoked” (Consumer, Group 2, p. 14). Secondly, consumers reported that an AdA would assist in consumers’ empowering themselves, taking initiative, being influential and proactive in TCP rather than being passive vehicles of treatment and care. For instance, one consumer reported that an AdA “has the potential to be the instrument where the actual consumers’ become the major influence on their own care rather than…the subordinate influence on their own care” (Consumer, Group 2, p. 9). Another consumer stated that the AdA service would “help give a whole different consciousness or awareness of how they [consumers] can be proactive in their own [TCP], taking control” (Consumer, Group 2, p.9)

Consumers reported that the AdA was a legitimate means of involving significant others and could potentially lead to a heightened understanding of the consumer. This was suggested to assist advocacy on behalf of the consumer, where even “if the carer and consumer didn’t agree with what the consumer wanted, at least they’re knowledgeable about it, like you know, they’re more in the picture” (Consumer, Group 2, p. 10).
Potential benefits identified for the mental health system included the provision of a more individualistic, holistic and consumer centered service. One consumer noted that they did not believe “they’re [MH professionals] doing it for the good of them” (Consumer, Group 2, p.6). Another consumer reported that through meaningful consumer involvement in treatment and care planning “the person [consumer] feels like they’re doing treatment on their own terms, then trust can start to grow again” (Consumer, Group 2, p.15). Other consumers noted that AdAs could assist clinical decision making and result in greater cost effectiveness for the service, with one consumer noting that “the higher above should realize that it’s cost effective to have these things in place” (Consumer, Group 2, p.17), and another stating that

I think that [AdA] would be immensely helpful for them to know more about what that persons likes and dislikes and all that is... all work together for consumers getting well (Consumer, Group 2, p.10).

Table 15. Anticipated benefits identified by the consumer focus groups

<table>
<thead>
<tr>
<th>Consumer</th>
<th>CM and Significant Others</th>
<th>Mental Health System</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Provision of Informed consent</td>
<td>- Heighten carer awareness and understanding of a consumer’s mental illness</td>
<td>- Provide individual holistic care</td>
</tr>
<tr>
<td>- Increased satisfaction with treatment and care</td>
<td>- Better able to advocate for a consumer’s best interest</td>
<td>- Consumer centered and directed service</td>
</tr>
<tr>
<td>- Empowering</td>
<td></td>
<td>- Potentially cost effective</td>
</tr>
<tr>
<td>- Heightened sense of security and reduce stress associated with anticipated relapse</td>
<td></td>
<td>- Family sensitive service</td>
</tr>
<tr>
<td>- Increase self knowledge</td>
<td></td>
<td>- Guided clinical decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Reducing need for coercion</td>
</tr>
</tbody>
</table>
Rationale for not developing an AdA

The group reported several reasons that they or other consumers may not want to develop an AdA. These reasons were that:

- The consumer is feeling mentally healthy, does not anticipate a relapse, or is satisfied with management plan and decisions made by mental health staff
- The consumer may not want to collaborate with MHACT, carers or significant others
- The process takes time and effort
- No policies or procedures are currently in place, therefore the AdA is a ‘wish list’ and can be overridden
- Developing an AdA can trigger unpleasant thoughts or traumatic memories as the focus of being mentally ill and past experiences is under the microscope. For instance one consumer reported that
  
  You [consumer] might remember the traumas on the ward, and the nurse standing over you with this godforsaken medication that you don’t want to take because it tastes yucky, and sleep for hours and days and you don’t know what day it is because you’ve had this junk (Consumer, Group 1, p.6)

- Individual traits e.g. lack of confidence or skills to develop an AdA
- Some consumers don’t realize the advantages e.g. young consumers or individuals experiencing a first episode may believe they do not require an AdA or they may not be in the condition to be developing an AdA.
**Issues & considerations**

The group discussed several key legal, ethical and practical considerations regarding the implementation of AdA’s. The group expressed mixed opinions about the legal status of AdA’s. On the one hand, if the AdA is not legally binding then the treating team are not obliged to consider it. For instance, one opinion expressed was that AdA’s are “not a legally binding document. The treating team are not obliged to consider it, and it just becomes a wish list” (Consumer, Group 1, p.6). Others expressed concern that if the AdA was legally enforceable then some consumers “can be forced away from it because of the binding paperwork” (Consumer, Group 1, p.13). Regardless of how much legal power AdA’s hold, the group noted that current legislation allows psychiatrists and the Mental Health Tribunal to override the AdA, and the consumer may receive the same service they would have otherwise.

Ethical concerns raised involved how MHACT can ensure the AdA is a legitimate act of will from the consumer, a true representation of their preferences, and prevent negative consequences associated with the misuse or non-compliance with an AdA. Some consumers also expressed concern that the AdA has the potential to become another tool of control where

In many cases, especially with clinical managers, and where there’s community orders, the relationship between the clinical managers and, and [sic] the client are often hostile and confrontational by their nature. And the whole point about this is, when you’ve got that, kind of sitting at the bases of the relationship you know,
what the advanced agreement is, potentially another tool of control rather than a tool of emancipation (Consumer, Group 2, p.5)

And

If coercion’s involved and you keep to the situation of the advance agreement, you actually become complicit in your own abuse (Consumer, Group 2, p.7)

Thus the Focus Group emphasised the importance of consumers developing an AdA because they want to, and only if they feels able and competent to document their preferences.

The group also discussed variety of practical issues that entailed how MHACT will:

- Ensure awareness and communication of an AdA
- Provide resources to sustain an AdA service
- Support clinicians who are under pressure and working within a ‘crisis-driven’ system
- Determine consumer competency to develop an AdA
- Allow consumers without clinical managers to develop an AdA
- Activate and utilise AdA’s, and handle anticipated difficulties, such as revocation.

**Consumer Suggestions**

The Consumer Focus Group provided an array of suggestions, including that

- AdAs should be based predominantly on a biopsychosocial model of treatment and care planning, and prevention rather than focusing on acute care
• Policy and procedures need to be developed to safeguard many anticipated problems or issues e.g. alert system, mandates for treating professionals to consider AdAs

• Support the ‘cultural change’ through resource allocation and involve consumer organisations in the AdA service. For instance, one consumer commented that:

  I just get the tendency of that this whole thing, that advanced agreements at the moment is we’re gifting you this from our privileged position, its not coming from bottom as rights (Consumer, Group 2, p.6).

• Employ an advocate who could educate, encourage and support consumers to develop AdA’s. There was mixed opinion regarding whether this advocate should be a professional or consumer.

• Provide continual education on AdAs for all staff members, consumers and public

• Offer the AdA service to all consumers prior to being discharged from hospital or clinical management. The AdA should be offered on more than one occasion.

• Involvement of a second or third party, chosen by the consumer, to advocate for a consumer’s AdA when they are unwell, or to mediate disagreements between consumer and CM

• Regular reviews of the AdA to ensure the validity of the information

• The AdA should be developed in an environment where the consumer feels they have ownership

4.4 Discussion

The discussion will be arranged according to the main aims of the focus groups, giving particular emphasis on comparing the consumer and carer group, identifying similar
views and unique group considerations. Most of the results reiterate views and results collected during other phases of the project, providing additional support for opinions, issues, benefits and suggestions around AdAs. All individuals in the groups were observed to give AdAs serious consideration and thought. The opinions provided by each member of the group are considered to be honest representations, as each member appeared to respect diversity of opinions and discuss issues from a non-judgmental perspective. No participants reported they felt unable to express their opinions or that the group was an unsafe environment to express their thoughts.

4.4.1 Summary of the general opinions and anticipated benefits around AdAs

In general the carers considered that AdAs could function to ensure civil rights, to assist legitimate carer inclusion in a consumer’s individual TCP, and build carer-consumer relationships. They specified that important matters to document in an AdA are guidelines for the level of involvement a carer should have, along with information on how to contact the carer during a crisis are. The group questioned the impact of placing complete legal power on an AdA, commenting that this may deter consumers from developing an AdA. Carers also raised some issues that may form a barrier to general carer inclusion. These included the impact of deinstitutionalization and the perceived lack of support for carers from mental health services, along with the perceptions, based on previous experiences, that carer views and input are not valued by mental health professionals.
The consumer focus group identified several issues similar to those raised during the individual semi-structured interviews conducted in the pilot study of AdAs. Additional suggestions that the group had for improving AdAs included that the AdA could entail a clause for anticipating a change of preferences or opting out of the AdA, and that the AdA could document differing opinions amongst treating team members. Overall, the group believed that AdAs was one method of ensuring consumer rights and being heard. The group reported that this could result in consumers’ enhanced satisfaction with their TCP and a reduction in the need for coercive practices. The group results provide additional evidence for the current issues around implementing an AdA program, barriers to developing an individual AdA, anticipated benefits of AdAs, and support for making the documents part of routine practice.

4.4.2 Consumer and Carer Suggestions for Implementing AdAs in MHACT

Carers suggested that MHACT should encourage, support and facilitate carer and consumer involvement to develop an AdA. They suggested that this could be achieved through the development of policy and protocols, service wide and community education, and initialising the process of offering an AdA while a consumer is residing in hospital. The consumer group made several similar comments, along with unique suggestions that had not been heard during previous data gathering from the project. Once again, the most recurrent and accentuated suggestion was for MHACT to incorporate AdAs into policy and protocols. In addition, the group emphasised the need for allocating resources to AdAs if MHACT is to demonstrate support for the move towards consumer involvement, individualized TCP and the adoption of a biopsychosocial model of treatment and care.
Additionally, regular community education, the employment of a representative for AdAs, consumer education to be initiated whilst a consumer is in hospital, and the nomination of a third party to mediate disagreements or advocate for the consumer.

4.4.3 Limitations of the focus groups
The generalisability of the opinions and issues raised by the carer group is limited given the small sample size. Nevertheless, the carer responses appeared to re-iterate similar information on AdAs, and the role of the carer in an AdA, collected during the evaluation of AdAs (Study one, part A). The responses from the consumer focus groups also elicited similar points to the first study. Whether the opinions and concerns raised could be generalized to other consumers of MHACT is difficult to determine. It seemed that the vast majority of consumers comprising the Consumer Focus Groups were articulate, had extensive experience with MHACT and were long-term advocates for consumer rights. Thus, their opinions regarding AdAs may be biased. Despite the above cautions, all focus groups generated a range of opinions, along with some agreement on some topics. Participants appeared comfortable in expressing their own opinions, and while consumers and carers may have been biased towards AdAs, they were able to identify a range of complicated issues regarding implementing AdAs in practice.
CHAPTER FIVE

Study Three

The Consumer Involvement Questionnaire for Clinical Managers

5.1 Introduction

The primary goal of the Consumer Involvement Questionnaire for Clinical Managers (CIQ-CM) was to explore and identify current factors that impact on the uptake or practice of involving consumers of Mental Health Australian Capital Territory (MHACT) in individual treatment and care planning (TCP). The development of the questionnaire was prompted by preliminary findings and communications, with consumers and staff members within MHACT, which suggested that while there was a strong preference supporting meaningful consumer involvement through AdAs in TCP, the uptake of the AdA project was modest. Chapter one outlined four clusters of factors hypothesised to influence the uptake and implementation of consumer involvement in TCP. Organisational commitment, community service issues, professional attitudes, and consumer traits were all identified as encompassing several factors that impact on the level of consumer involvement. Previous literature on the necessary ingredients and obstacles for consumer involvement was applied to develop a questionnaire for mental health professionals. The CIQ-CM was designed to complement the AdA pilot project through gaining an understanding of MHACT staff’s knowledge, opinions, beliefs, and current practice of consumer involvement in TCP. Such information may be valuable in explaining the uptake of, and guiding the implementation of, consumer involvement initiatives in individual TCP.
5.2 Aim

The CIQ-CM was designed to be explorative, with the overall aim of identifying factors that may be inhibiting or enhancing current practice of involving consumers in TCP. The questionnaire endeavored to achieve this primarily by collecting information relevant to current practice, opinions, and beliefs about the anticipated outcomes. In addition, the questionnaire collected information on participant’s demographics, knowledge on current consumer involvement strategies in MHACT, and perceived level of systemic support for consumer involvement in TCP. While primarily explorative, the questionnaire aimed to:

- Identify the current level of importance mental health (MH) professionals attribute to involving consumers, along with the level of current practice
- Identify the perceived level of support provided by MHACT for consumer involvement in TCP
- Outline MH professionals’ current opinions regarding consumer involvement in TCP, identifying any opinions that may be hindering or assisting current practice
- Outline MH professionals’ perceived benefits associated with consumer involvement in TCP, identifying any beliefs that may be hindering or assisting current practice

5.3 Method

5.3.1 Participants

Participants consisted of MH professionals working within the four MHACT community teams, along with rehabilitation coordinators from Brian Hennessey Rehabilitation Centre in the ACT. The acronym ‘CM’ will be used to denote all participants.
5.3.2 Measure

The CIQ-CM was produced by conducting a literature review, creating a generic outline and then expanding the questionnaire, pre test and pilot test, and lastly, adjusting the questionnaire to maximize the response rate (Unpublished workshop, Ritchie, 2005). The questionnaire items are based on literature regarding consumer involvement, particularly for involvement in individual TCPs, and were influenced by existing surveys. Two relevant questionnaires that influenced the development of the CIQ-CM were the Opinions about Psychiatric Advance Directives Questionnaire (OPADQ; O’Connell, 2002 cited in O’Connell and Stein, 2005) and the Consumer Participation Questionnaire (CPQ; Kent & Read, 1998; Soffe et al., 2004). Both questionnaires are considered useful tools however they were not directly suitable for the purpose of the current study.

The pre-test entailed presenting the questionnaire to colleagues and supervisors. The pilot test utilised a sample of Mental Health staff from Queanbeyan Adult Mental Health (NSW), as this region was not involved in the project. The questionnaire was distributed to the twelve staff present during a team meeting. They were asked to complete the survey and note any difficulties or changes they believed would improve the questionnaire. Nine staff members completed the survey, including seven psychologists, one registered nurse and one occupational therapist. Following both tests the draft questionnaire was finalized and submitted to the ACT Health and ANU ethics boards where approval was granted.

The questionnaire is comprised of six sections, along with an information sheet and demographic questions (See Appendix J). Section one assesses participants’ knowledge of
current consumer involvement strategies utilised in MHACT. Section two asks the participant to estimate how important they believe consumer involvement is, and how many consumers on their case load are currently involved in aspects of TCP. Section three contains 17 opinion statements. Each statement was generated from a literature review of hypothesised and empirically supported opinions on consumer involvement that influence practice of involving consumers in TCP. Each item is conceptually categorized into one of four themes assessing opinions on Mental Illness, Consumer Involvement, Consumer Suitability for Involvement, and Professional Concern around involvement. Each item is rated along a five point likert scale ranging from strongly disagree to strongly agree. Overall scores for the four themes were computed by allocating numerical value to the scale, assigning one to strongly disagree through to five for strongly agree, and then adding the scores of the items attached to each theme. The range of scores computed for each theme are as follows: Mental Illness (8 to 40), Consumer Involvement (6 to 30), Consumer Suitability for Involvement (2 to 10), and Professional Concern around involvement (2 to 10).

Section four lists 15 potential outcomes of involving consumers in TCP. The outcomes were identified through the literature review, and can be categorised into three sub-types: Intrapersonal (consumer), Interpersonal (Consumer-professional), and System. Each item is rated along a five-point likert scale ranging from strongly decrease to strongly increase. Similarly to section three, items were transformed to range along a scale of one to five. The range of scores computed for each opinion type is as follows: Intrapersonal (7 to 35), Interpersonal (4 to 20), and System (4 to 20).
Section five lists five factors identified in the literature as important for the effective integration of consumer involvement in a Mental Health System. Participants are asked to indicate firstly, whether they believe the factor is provided in their workplace and secondly, whether they think it is adequate or should be improved. Lastly, section six poses three questions specifically related to Advanced Agreements (AdAs) to gauge a participant’s position on knowledge, priority and benefits of AdA’s. In addition, sections one, two, and six include space for written comments.

5.3.3 Procedure

The team leader within each MHACT region was emailed to introduce the questionnaire and gauge ideas for efficient implementation of the CIQ-CM. The researcher attended team meetings at all five workplaces, presented information and the CIQ-CM, and provided multiple copies of the questionnaire with an attached information sheet, an envelope for completed questionnaires, and a small incentive following completion of the questionnaire. Approximately one week following the initial drop off each team leader was sent an email to obtain an update of responses and if the response rate was low, the team leader was asked to remind CMs of the questionnaire. Additionally, during the process of data collection, a MHACT Consumer Consultant attended each of the teams, with copies of the questionnaire and a collection envelope, to further encourage completion. The questionnaires were collected between one and three weeks later. The survey was anonymous and it was assumed the respondent provided consent on return of the questionnaire.
5.3.4 Analysis

Survey data was stored using Statistical Package for Social Scientists (SPSS) version 13 and the analysis produced was primarily descriptive. Relationships between actual practice and opinions, beliefs, knowledge and years of service with MHACT were explored utilising Spearman’s Rho correlations.

5.4 Results

5.4.1 Response rate and sample characteristics

During the period of questionnaire distribution, it was estimated that MHACT had 53 clinical managers (CMs). The questionnaire was distributed to CMs across the service resulting in a response of 55% (n=29). Table 16 summarises respondents’ demographic information. The number of consumers, under each participant’s case-load, currently involved in several aspects of TCP was estimated. Responses ranged along a four point scale from none of their consumers being involved to all consumers. Results indicated that 48 percent of the respondents are currently involving most of their consumers in the medication aspects of TCP, while 48 per cent reported that none are currently being involved in anticipatory planning aspects of TCP (see Table 17).
<table>
<thead>
<tr>
<th>Profession</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered Nurse</td>
<td>13</td>
<td>(45%)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>8</td>
<td>(28%)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>3</td>
<td>(10%)</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>2</td>
<td>(7%)</td>
</tr>
<tr>
<td>Enrolled Nurse</td>
<td>2</td>
<td>(7%)</td>
</tr>
<tr>
<td>Rehabilitation Coordinator</td>
<td>1</td>
<td>(3%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other Demographics</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average number of consumers currently case managed</td>
<td>12 (9)</td>
</tr>
<tr>
<td>(missing data n = 4)</td>
<td></td>
</tr>
<tr>
<td>Average number of consumers in usual caseload</td>
<td>15 (8)</td>
</tr>
<tr>
<td>(missing data n = 6)</td>
<td></td>
</tr>
<tr>
<td>Length of work in profession (years)</td>
<td>15 (12)</td>
</tr>
<tr>
<td>Length of employment with MHACT (years)</td>
<td>7.6 (7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Aspect of TCP</th>
<th>Level of consumer Involvement</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>None</td>
<td>3 (10%)</td>
</tr>
<tr>
<td></td>
<td>Some</td>
<td>5 (17%)</td>
</tr>
<tr>
<td></td>
<td>Most</td>
<td>14 (48%)</td>
</tr>
<tr>
<td></td>
<td>All</td>
<td>4 (14%)</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Relapse Prevention Planning</td>
<td>None</td>
<td>2 (7%)</td>
</tr>
<tr>
<td></td>
<td>Some</td>
<td>7 (24%)</td>
</tr>
<tr>
<td></td>
<td>Most</td>
<td>6 (21%)</td>
</tr>
<tr>
<td></td>
<td>All</td>
<td>10 (35%)</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Anticipatory Planning e.g. AdA’s</td>
<td>None</td>
<td>14 (48%)</td>
</tr>
<tr>
<td></td>
<td>Some</td>
<td>5 (17%)</td>
</tr>
<tr>
<td></td>
<td>Most</td>
<td>3 (10%)</td>
</tr>
<tr>
<td></td>
<td>All</td>
<td>1 (3%)</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>4 (14%)</td>
</tr>
</tbody>
</table>
5.4.2 Knowledge of Consumer Involvement Strategies within MHACT

All participants (n=29) were aware that MHACT has a complaints procedure for consumers, and the majority demonstrated knowledge that it was simple to use (83%). Most CMs were also aware that MHACT seeks consumer input into the planning of services (83%) and will involve consumers in hiring decisions of staff members (62%). Fewer participants were aware that consumers are invited to participate in staff training meetings (38%), that MHACT routinely conducts consumer satisfaction surveys (17%), and that consumers do not participate in the provision of mental health services (17%).

5.4.3 The importance of involving consumers in TCP

The majority of participants thought it was extremely important to involve consumers in aspects of TCP: accommodation (90%, n=26), relapse prevention planning (90%, n=26), employment activities (83%, n=24), anticipatory planning (70%, n=20) and medication (66%, n=19).

5.4.4 Opinions

Table 18 reports the mean and standard deviation scores for the four opinion themes as described in section 5.3.2. The mean scores for opinions concerning Mental Illness and Consumer Involvement suggest that overall respondents held strong positive attitudes, conducive to involving consumers in TCP. On average, respondents rated that they disagreed that consumer traits would determine the suitability of particular consumers; or that their professional judgment is being questioned, or criticized, through involving consumers.
Table 18. Mean (SD) sub-scale scores for opinions on involving consumers

<table>
<thead>
<tr>
<th>Opinion</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Illness</td>
<td>30 (3.5)</td>
</tr>
<tr>
<td>Consumer involvement</td>
<td>22 (1.8)</td>
</tr>
<tr>
<td>Consumer suitability</td>
<td>4.7 (1.9)</td>
</tr>
<tr>
<td>Professional Concern</td>
<td>4.3 (1.2)</td>
</tr>
</tbody>
</table>

An item analysis revealed a high uniformity of responses on several opinions, with a high percentage of CMs reporting they either agree or strongly agree that consumer involvement is a priority in their line of work (90%, n=27), and that consumers have the skills to participate (86%, n=25). Similarly, a majority of clinicians disagreed or strongly disagreed that their professional judgment was being questioned by including consumers (86%, n=25), that consumers do not have knowledge to participate (86%, n=25), and that meaningful involvement is too time consuming or difficult (81%, n=24).

Eight opinion items generated a wider range of responses (see Table 19). There was a mixture of responses for whether individuals with mental illness are capable of being involved, whether consumer involvement is considered to be a primary objective of TCP, and whether there are some consumers who are more appropriate for involvement compared to others. Furthermore, CMs differed in the level of adoption for the opinion that mental health professionals are criticized for speaking on consumers’ behalf.
Table 19. Opinions that generated a mixture of responses

<table>
<thead>
<tr>
<th>Opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Mental illness decreases consumers’ motivation levels to participate in TCP</td>
</tr>
<tr>
<td>- Mental illness distorts consumers’ opinions regarding treatment</td>
</tr>
<tr>
<td>- Facilitating patient choice is the primary objective in TCP</td>
</tr>
<tr>
<td>- If a consumer does not agree with a professionals suggestion for treatment, then they are most likely in denial, lacking insight, and/or irrational</td>
</tr>
<tr>
<td>- Consumers who are mature and broadminded are more suitable to participate than consumers who are more difficult to work with</td>
</tr>
<tr>
<td>- Consumers who can easily articulate their views are more suitable for involvement than consumers who find their views difficult to articulate</td>
</tr>
<tr>
<td>- Consumers are capable of being involved in decision-making for TCP</td>
</tr>
<tr>
<td>- Mental health professionals are not criticized by their colleagues for speaking on the consumers’ behalf</td>
</tr>
</tbody>
</table>

5.4.5 Anticipated outcomes for consumer involvement

In order, means for intrapersonal, interpersonal, and system benefits were 27.6, 15, and 13.2 (SDs = 4, 2.4, and 13.2 respectively). These results indicate that on average, respondents’ held positive beliefs regarding the benefits of involving consumers in TCP.

An item analysis revealed that for anticipated Consumer Outcomes, out of the 29 respondents, a high percentage of clinicians believed that involvement would increase or strongly increase a consumer’s sense of sense of control (90%), empowerment (90%), motivation (69%), independence levels (79%), and perception of treatment choices and adherence to their treatment plans (79%). Item 15, a consumer’s perception of coercive treatment, generated a greater range of responses.
Results for Interpersonal Outcomes indicated that a high percentage of CMs believe that involving consumers would increase the quality of the therapeutic relationship (86%) and staff responsiveness to clients needs (76%). Clinician’s opinions significantly differentiated on whether the frequency of disagreements between themselves and consumers would be impacted.

All of the items assessing the Mental Health System outcomes resulted in a variety of opinions. There was an even distribution of responses on whether staff stress levels would decrease or increase; with approximately half of the clinicians (n=13) reported that involving consumers would lead to no change to staff stress levels. Nearly half of the clinicians (n=14) reported staff’s work efficiency should increase, while 35% (n=10) reported there would be no change. Regarding service efficiency, over half of the clinicians (n=17) reported an increase while 28% (n=8) reported no change. Nearly half of the clinicians (n=13) reported that involving consumers in TCP would lead to a decrease in the frequency of hospitalisations whereas 42% (n=12) believed there would be no change.

5.4.6 System support

More than half of the participants reported that there existed staff support, specific strategies and education for consumer involvement in TCP. With respect to stating whether supports were adequate, or require improvement, there was a significant number of missing responses (n=8 to 14 missing across the items). Of those who did respond, there were always approximately half of the CMs indicating that improvements are required if consumer involvement was to be successful. Table 20 summarises respondents’ perceived sense of
support, provided by MHACT, for staff support, financial resources, specific strategies, clear outcomes, education. The table also indicates the percentage of participants who believe support should be improved.

Table 20. Perceived support provided by MHACT

<table>
<thead>
<tr>
<th>Support Provided?</th>
<th>Staff Support</th>
<th>Financial Resources</th>
<th>Specific Strategies</th>
<th>Clear Outcomes</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>66</td>
<td>24</td>
<td>52</td>
<td>35</td>
<td>62</td>
</tr>
<tr>
<td>NO</td>
<td>17</td>
<td>38</td>
<td>24</td>
<td>31</td>
<td>10</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>10</td>
<td>31</td>
<td>17</td>
<td>28</td>
<td>21</td>
</tr>
</tbody>
</table>

5.4.7 Advanced agreements

Most participants (79%, n=23) reported that they knew a *little* or a *moderate amount* about Advanced Agreements (AdAs) and most participants (76%, n=22) rated the priority of AdAs as either *low* or *medium*. There was a mixture of opinion regarding how beneficial advanced agreements are in current practice with 76% of participants rating *somewhat* or *moderately* beneficial (48% and 28% respectively), and 17% (n=5) stating that AdAs are *extremely* beneficial.

5.4.8 Written comments

Nine participants wrote comments in the questionnaire, providing opinions on the suitability of individuals with mental illness to participate in along with specific comments on AdAs. Some CM commented on the suitability of involvement with a psychiatric population:

The level of empowerment a consumer feels is much more likely to be influenced by the attitudes of staff and the quality of interactions between consumer and staff. Few
consumers have the capacity or motivation to be fully involved in their TCP (participant #5)

It was identified that consumer involvement was more suitable for consumers who are managed in the community and are voluntarily accepting of treatment, with symptoms under control, however “it may increase levels of empowerment in all clients” (participant #5). Other factors that influence involvement included the consumer’s level of insight and motivation. In relation to AdAs, one CM was not aware that AdAs were offered by MHACT. Another reported that the AdA was a low priority as the Collaborative Therapy program was being implemented in MHACT, while other CMs stated that anticipatory planning was informally conducted as part of case management. Reported obstacles, identified by some CMs, to developing AdAs included time limits, the confronting nature of the AdA process, and the impact mental illness can have on an individual’s ability to participate. One CM suggested that it can take “a few relapses for clients to start thinking of Advanced Agreements’ (participant #8).

Another suggested that further education on AdA’s is needed. Summing up some of the points, one CM wrote that:

A solid and comprehensive relapse prevention plan developed with consumers really covers a lot of what is in a AA [AdA]. Clients I have talked to don’t think it is useful as they know it is not a legal document and find the length arduous. A few clients have also stated that when they are well, it is the last thing they would like to do – as it is confronting (participant #28)
5.4.9 Correlation analysis

Table 21 presents Spearman’s rho correlations between current practice of involving consumers in aspects of TCP and firstly, the perceived level of importance of involving consumers; secondly, opinions; thirdly, perceived benefits; and lastly, knowledge and years of employment with MHACT.

Reported involvement of consumers in the relapse prevention planning aspect of TCP was significantly positively correlated to both level of importance attributed to relapse planning ($r = .47, p < .05$) and anticipatory planning ($r = .46, p < .05$), and the level of interpersonal benefits participants attributed to consumer involvement ($r = .41, p < .05$). Additionally, the level of involvement in relapse planning was significantly negatively correlated to the number of years participants had worked within MHACT ($r = -.39, p < .05$). Current involvement in anticipatory planning, such as advanced agreements, was significantly positively correlated to level of importance attributed to anticipatory planning ($r = .45, p < .05$), and opinions participants had on consumer involvement ($r = .44, p < .05$). Consumer involvement in medication aspects of TCP was significantly positively correlated to overall knowledge of consumer involvement strategies offered by MHACT ($r = .47, p < .05$).
Table 21. The relationship between CMs current practice and the perceived level of importance, opinions, benefits, knowledge and years of employment (Spearman’s Rho)

<table>
<thead>
<tr>
<th>Current Consumer Involvement</th>
<th>Medication</th>
<th>Relapse Planning</th>
<th>Anticipatory planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall Knowledge</td>
<td>.47*</td>
<td>.05</td>
<td>.09</td>
</tr>
<tr>
<td>Years working MHACT</td>
<td>-.17</td>
<td>-.39*</td>
<td>-.17</td>
</tr>
<tr>
<td>Medication</td>
<td>.37</td>
<td>-.05</td>
<td>.09</td>
</tr>
<tr>
<td>Relapse Prevention</td>
<td>.31</td>
<td>.45*</td>
<td>.04</td>
</tr>
<tr>
<td>Anticipatory planning</td>
<td>.15</td>
<td>.46*</td>
<td>.45*</td>
</tr>
<tr>
<td>Level of Importance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Illness</td>
<td>.21</td>
<td>.19</td>
<td>.14</td>
</tr>
<tr>
<td>Consumer Involvement</td>
<td>.01</td>
<td>.29</td>
<td>.44*</td>
</tr>
<tr>
<td>Suitability</td>
<td>-.32</td>
<td>-.26</td>
<td>-.24</td>
</tr>
<tr>
<td>Prof. Concern</td>
<td>-.34</td>
<td>-.15</td>
<td>-.28</td>
</tr>
<tr>
<td>Opinions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumer</td>
<td>.23</td>
<td>.41*</td>
<td>.37</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>.11</td>
<td>.35</td>
<td>.33</td>
</tr>
<tr>
<td>System</td>
<td>.09</td>
<td>.27</td>
<td>.37</td>
</tr>
</tbody>
</table>

*correlation is significant at the .05 level (2-tailed)

5.5 Discussion

The CIQ-CM explored numerous factors that have been illustrated in previous literature to influence the practice of consumer involvement in TCP. This discussion will address each specific aim of the study and then consider limitations and recommendations for future questionnaires.

5.5.1 Aim: to identify the current level of importance and actual practice of consumer involvement in differing aspects of TCP

A substantial number of CMs perceived that involving consumers in all aspects of TCP was extremely important. Medication and anticipatory planning were considered comparatively
less important compared to other aspects of TCP. It makes sense to expect that current practice of consumer involvement would reflect this level of importance. Initial observations of the data lead to some questioning of this relationship as discrepancies were detected between perceived importance and actual practice. For instance, while 90% of CMs rated involving consumers in relapse prevention planning was extremely important, only 35% reported that all of their consumers were currently involved. Similarly for anticipatory planning, while 70% indicated it was extremely important to involve consumers, 48% indicated that none of their consumers were currently involved. Despite initial observation, correlation analysis indicated moderate significant relationships between importance attributed to involving consumers in relapse planning and anticipatory planning and respective practices. Importance of involving consumers in medication aspects of TCP was just moderately, but not significantly, correlated with actual practice.

Overall, some evidence for a moderate positive relationship between level of importance attributed to TCP and the number of consumers a professional involves in TCP was established. Given the limitations of the study, causal relationships were not analysed. It could be that professionals who involve consumers develop the stance that it is important to involve them, rather than it being a perceived importance motivating the practice. Additionally, the level of importance attributed to involving consumers is unlikely to be the only factor that influences actual practice. For example, knowledge of methods available to enhance consumer involvement could be one factor. This example could explain the reason why so many CMs reported almost none of their consumers were involved in anticipatory planning, given that a large majority of participants indicated a limited knowledge of AdAs.
Furthermore, the measure of “current practice” obtained by the CIQ-CM may not be an accurate representation of how often CMs involve consumers. For instance, consumers on a CM caseload may not be at the level of relapse or anticipatory planning, therefore for a CM who always involves consumers in relapse planning an indication of none would not accurately represent that particular CM’s usual practice. Another point to note is that many CMs do not “manage” the consumers’ medication aspects of TCP. Therefore, measuring this aspect of TCP may not be appropriate for a CM population.

Nevertheless, the findings optimistically indicate that a large majority of CMs believe that consumer involvement forms an important component of TCP, and that there is a moderate positive relationship between levels of importance attributed to consumer involvement in TCP and actual practice. Further investigations could invest energy into confirming this relationship and then exploring how CMs develop a stance of attributing a high level of importance to involving consumers i.e. does the stance come from positive experiences with practicing consumer involvement or is the stance based on opinions and beliefs about consumer involvement?

5.5.2 Aim: to identify the perceived level of support provided by MHACT for consumer involvement in TCP

Staff support, financial resources, specific strategies, clear outcomes, and education were identified from the literature as being important systemic factors necessary for successful consumer involvement in TCP. Most CMs perceived that staff support and education was provided by MHACT. Most participants were either unsure or did not perceive financial
resources and clear outcomes to be available. Regardless of the amount of support participants perceived MHACT to provide, for each factor approximately half of the professionals reported that the supports need to be improved if consumer involvement is to work effectively within MHACT. This lends support to the notion that meaningful consumer involvement requires more than simply a CM’s commitment. The findings suggest that specific systemic support for consumer involvement may be a necessary ingredient for facilitating CMs towards endorsing consumer involvement in current practice.

5.5.3  Aim: to outline CMs current opinions regarding consumer involvement in TCP
In general, respondents expressed positive opinions around mental illness and consumer involvement that would presumably, if anything, enhance the practice of involvement. Given the limitations of the study, individual item analysis may be more suitable than the four sub-factor scores. Item analysis also provides a more comprehensive understanding of CMs opinions. In general, CMs expressed positive opinions, which logically would be considerably conducive to the practice of consumer involvement. The majority of CMs believe individuals with mental illness are experts with invaluable experience, knowledge and skills to actively participate and make realistic and useful contributions to TCP. A high proportion indicated that consumer involvement is a priority in their line of work, not just a form of tokenism, where mental illness cannot be successfully diagnosed and treated by mental health professionals without consumer involvement. Additionally, a large majority reported that involving consumers was not too difficult or time consuming.
There was not one item, which CM demonstrated consensus for, that could be predicted to negatively impact the uptake of consumer involvement. These results are promising and offer a good illustration of the positive stance MHACT aspires to hold regarding involving consumers in TCP. Items that generated a wider range of responses may be more indicative of areas where opinions have a greater influence on consumer involvement in practice, compared to the items that gained consensus. Opinions about how mental illness impacts a consumer’s capacity to make decision, motivation levels, and opinions for their own TCP generated a spread of responses. All three items are considered essential for meaningful consumer involvement and may distinguish between CMs practices of consumer involvement. The implications of identifying opinions that hold stronger influences over consumer involvement are far reaching. For instance, strategies could be developed to target, test, and reframe opinions to guide CM in judging appropriate levels of consumer involvement, aiming to maximize involvement where possible.

Correlation analysis revealed some modest relationships between the opinion themes and current practice in three aspects of TCP. One significant correlation revealed that more positive opinions towards Consumer Involvement are related to a greater practice of involving consumers in anticipatory planning, however are barely related to current practice of involving consumers in medication aspects of TCP. While there was a general mild trend for other correlations, it was intuitively expected that higher correlations would exist between positive attitudes and practice; however given the limitations of the study it is unlikely there was enough power to uncover these relationships. Additionally, the difficulty with the measure of “current consumer involvement” as outlined previously would likely significantly
impact the results. Thus, these results should be considered with caution. Nevertheless, the primary aim of this section of the CIQ-CM was to explore CMs opinions that intuitively impact on the practice of consumer involvement. Overall, the items developed are based on strong theoretical grounds and offer a solid foundation for further research to continue uncovering firstly, whether opinions are connected to practice; secondly, causal relationships between opinions and practice; and thirdly, distinguishing which opinions are most influential.

5.5.4 Aim: to outline CMs perceived benefits associated with consumer involvement

In general, CMs strongly endorsed positive beliefs around the potential benefits for consumers and interpersonal relationship from consumer involvement in TCP, although there were considerable differences of opinions expressed regarding the benefits for the mental health system. These beliefs may highlight important areas to address if MHACT is to encourage consumer involvement. For instance, mixed beliefs regarding whether consumers perceptions of coercive treatment would increase or decrease may be the result of CMs trying to comprehend or balance the reality of the necessity of coercive practices in conjunction with facilitating consumer involvement. Staff stress levels are considered another important factor for the CM population, and was an item that generated a broad range of beliefs. Obviously, if a CM believes consumer involvement will increase their stress levels they will be less inclined to involve consumers. Favorably, however, most of the mixed responses were in support of either a positive outcome or no change. These results shed some positive light that CMs are recognizing the benefits associated with consumer involvement in
individual TCP, which intuitively would be linked with the actual practice of consumer involvement.

Mild to moderate relationships were detected between current practice of consumer involvement and all types of benefits. Benefits for the consumer were mildly related to involvement in medication aspect of TCP, however there was barely any relationship detected for other benefits and medication practices. Again, caution should be taken in interpreting these results given the study limitations. They do, however, provide an initial idea of some patterns that may exist, and a closer analysis of the relationships may reveal explanations. For instance, intuitively, Interpersonal Benefits are more likely to be associated with relapse prevention planning than with medication, given that relapse prevention often requires the assistance and cooperation of others.

Overall, the results support the notion that in general, CMs hold positive beliefs around the benefits of consumer involvement, especially benefits for the consumer and the relationship between consumers and CMs. Further investigation of differing beliefs among CMs may provide some clarification on the reasons why some CMs include consumers more than others.

5.5.5 Limitations of the CIQ-CM Study

The study attained a moderate response rate, capturing approximately half of the population being sampled. Efforts were made to increase response rate through keeping the CIQ-CM brief, providing multiple reminders and the provision of a small reward. Despite this, the
response rate was lower than expected. This could be due to a variety of factors related to characteristics of the population or the topic of the survey. For instance, CMs are regarded as a busy population and placing time aside for research activities may not be a priority. In addition, some CMs may not believe the topic was a priority to research or feel they could express opinions honestly. These barriers were anticipated, resulting in the presentation of the CIQ-CM during a routine intake meeting, and then leaving the CIQ-CM to be completed either during the meeting or in CM own time. One limitation to this method of recruitment was that not all CMs attended the intake meetings due to being on-leave, a recommended day off, or sick leave.

Another limitation of the study is that the CIQ-CM is not a standardised measure. It was however, based on a thorough literature review that enable the clustering of factors and concepts to assist in interpretation of the results. Additionally, given the small sample population, and that the aim of the questionnaire was explorative. Factor analysis and other quantitative techniques that could be useful for future investigations were not within the range of the study. With the application to a wider and larger sample size, standardisation, and refinement the questionnaire has the potential to explore and examine a range of factors impacting consumer involvement, and relationships between factors.

Generalisability of the results to other CMs within the same service, or CMs within other mental health services, may also be limited for several reasons. Firstly, the relatively strong support, and positive opinions and beliefs expressed, in favour of consumer involvement may signify a bias in the sample. CMs who advocate for consumer involvement may have been
more inclined to complete the survey, compared to CMs who defend or are satisfied with "usual" or current strategies of TCP. Ensuring anonymity was one way to reduce this bias. Secondly, given the general cultural push by MHACT towards enhancing consumer involvement, social desirability may skew the responses as participants, where CMs may desire to express a positive opinion about consumer involvement. Thirdly, caution should be taken in generalising the results to other mental health services. MHACT has some distinct features compared to other states and territories in Australia, which make generalisations and comparisons difficult. These features have been discussed in Chapter Three (Section 3.3.8). Nonetheless, the aim of the CIQ-CM was to gain a culturally specific idea of current opinions, beliefs and practice, held by CMs within MHACT. Lastly, a further limit impacting on generalisability of the findings is that the results represent a "snap shot" of time, and it is acknowledged that the construct being measured exists within an ever-changing cultural climate.

2.4.6 Recommendations

The CIQ-CM identified that CMs held positive opinions and optimistic beliefs around and allowed a preliminary identification of factors that may be enhancing or inhibiting consumer involvement in TCP. This finding lends further support to findings from previous research on consumer involvement (e.g. Kent & Reads, 1998). While the power of the findings should be considered within the context of the study limitations, sharing the findings with CMs of MHACT could reassure staff members that consumer involvement is a valuable venture, and encourage further movement towards the uptake of consumer involvement initiatives. Given the general positive stance, future research would benefit from exploring particular opinions and beliefs that distinguish between CMs and the level of consumer involvement. Gaining
meaningful and applicable results will also be assisted by clarifying the concept of consumer involvement as existing along a continuum; acknowledging the factors that cannot be absolutely controlled, such as acute mental illness or a consumer’s preference not to be involved; and the investigation of other factors such as the relationship between CM and consumer. Additionally, given the complexity of the topic, qualitative methods in conjunction with questionnaires such as the CIQ-CM are considered appropriate tools for collecting culturally specific information. Overall, the CIQ-CM is considered theoretically sound, and with further standardization has the potential to identify factors within and between mental health professionals that influence consumer involvement in TCP.
CHAPTER SIX

General Discussion

The objective of the current study was to develop and pilot a tool for anticipatory planning as a component of treatment and care planning (TCP) within clinical management for consumers of Mental Health, Australian Capital Territory (MHACT). The term Advance Agreements (AdAs) was adopted to embrace the collaborative nature of anticipatory planning. The study employed an action research framework and qualitative methods to develop, implement and evaluate AdAs and consumer involvement in TCP. On the basis of the overall findings, the project established that AdAs are a valuable strategy for anticipatory planning, as part of individual treatment and care planning (TCP). Furthermore, the studies support AdAs as a useful method for promoting meaningful consumer involvement in TCP, a goal consistent with the current national and territory mental health plans. The project gained valuable insights into the operations of implementing an AdA service within MHACT, along with the individual process of developing an AdA. This discussion will emphasize the main findings of the project, limitations, recommendations and future directions for the provision of AdAs in MHACT.

6.1 Summary of the findings

6.1.1 Stakeholder support for AdAs

It is evident, from the development and evaluation of the project, that there is considerable support for AdAs among relevant stakeholders. Expressions of interest for
the availability of anticipatory planning, and support for the worthiness of AdAs, were
documented throughout the duration of the project. MHACT articulated organisational
support for AdAs under Action 27 of the ACT Mental Health Strategy and Action Plan
2003-2008, subsequently assigning one consumer representative to assist in the initial
development and implementation of the project. Strong evidence supporting the value of
AdAs was collected from participants who completed an AdA. All participants identified
positive outcomes associated with AdAs, and established that they would recommend
AdAs to other consumers of MHACT. Participants from the consumer and carer focus
groups also indicated a strong preference for the availability of AdAs.

Previous studies have reported a difficulty in “convincing” clinical staff of the
importance of psychiatric advance planning (e.g. Papageorgiou et al., 2002). The
Consumer Involvement Questionnaire for Clinical Managers (CIQ-CM) revealed that the
majority of CMs who completed the questionnaire believe that involving consumers in
TCP is extremely important. Furthermore, the general adoption of positive opinions and
beliefs around consumer involvement provides a strong indication that Clinical Managers
(CMs) value the philosophy of consumer involvement in TCP. In relation to AdAs,
however, the CIQ-CM indicated that the majority of CMs did not prioritise AdAs in TCP.
Thus, the level of priority CMs attribute to AdAs may be a more influential factor in CMs
utilising AdAs compared to the level of importance. Nevertheless, this finding coincided
with a reported limited knowledge on AdAs, indicating a promising prospect that further
education on AdAs, to assist CMs in understanding the function and benefits of AdAs,
could facilitate increased implementation.
6.1.2 Support for the model on AdAs

The qualitative data, gathered from participants who completed an AdA, offers considerable support for the conceptual and operational model of AdAs. A detailed discussion regarding the stages and processes entailed in developing an AdA is presented in Chapter Three (Section 3.4.3). Overall, the project supports the notion that developing an AdA is highly individualistic and potentially therapeutic process. Consumers appear to approach the task of completing an AdA in differing ways, and progress through several stages of developing an AdA at varying rates.

The analysis of feedback collected from Study One and Two support the reality that AdAs may not be applicable for all individuals with mental illness, nor do all individuals with mental illness wish to develop an anticipatory plan. The current research identified a range of reasons why consumers may not desire to develop an AdA. Interestingly, reasons often reflected motivations expressed by others to develop an AdA. For instance, anticipating that the AdA may be confronting and elicit traumatic memories was one reason provided for declining to develop an AdA. Similarly, one frequent motivation for developing an AdA, was to address previous negative experiences and prevent the likelihood of them occurring in the future. Furthermore, reasons for declining to develop an AdA may signal a serious issue and require attention, for example lack of case management, or harmful past experiences. Consequently, a declined offer to develop an AdA could provide the CM and consumer with a forum to discuss serious issues that could be potentially impacting negatively on a TCP. For example, a consumer may
believe that possessing an AdA would not be beneficial. Further discussion may reveal a belief that mental health professionals would not acknowledge the plan, and that this belief is based on past experienced of one’s opinions being discounted. This scenario could provide a CM with a therapeutic window of opportunity to address previous negative experiences, reframe, motivate the consumer to engage, and facilitate the chance of a more positive experience.

Once engaged, AdAs require a consumer to be meaningfully involved and to genuinely express his or her preferences for future treatment and care. Consistent with previous studies, this research provided strong evidence that some consumers have the capacity to be active agents on their own treatment and care (e.g. Barnes & Shardlow, 1997). Participants who completed an AdA in this study reported differing styles of collaboration and levels of “active” involvement. Moreover, all consumers reported satisfaction with their level of involvement with developing their AdA. Two observations can be drawn from these results. Firstly, the extent or level of consumer involvement in developing an AdA within TCP is variable, supporting the notion that involvement is best understood as ranging along a continuum, as described in Chapter One (Section11.2). Secondly, a consumer’s perception of meaningful involvement and satisfaction with collaboration is derived from subjective individual experience. Combined, these observations about consumer involvement could assist the realistic application of meaningful consumer involvement and expected outcomes. For instance, CMs may reasonably assume that to achieve meaningful consumer involvement, the consumer should be highly active and independent in the process of developing an AdA. The
current findings however, suggest that there is no standardized level of meaningful consumer involvement for developing an AdA. Furthermore, past research has demonstrated that CM and consumers may hold different perceptions about consumer needs and level of assistance received from a CM (Crane-Ross et al., 2000). Thus, negotiating the level of consumer involvement should be determined on an individual basis, and in a collaborative manner between consumer and CM.

Content analysis of the feedback from Study One and Two identified several suggested factors for consumers and CMs to consider when determining the level of involvement. These factors included mental illness factors (e.g. insight, competence, motivation), stage of illness (e.g. remission, first episode), personal attributes (e.g. willingness, intelligence), and context factors (e.g. relationship with CM). Furthermore, most factors were generally not considered to be static, thus requiring the level of involvement in TCP to be flexible, and reviewed over time. These characteristics lend support for the added suggestion, that to promote an accommodating and ethical clinical management practice, consumers could be offered the choice of developing an AdA on more than one occasion.

Intrinsically linked with consumer involvement is collaboration. In general, collaboration is an essential component of case management, assisting CMs to advocate for consumers and provide individualised treatment and care. Contrary to other anticipatory planning tools, developing an AdA required collaboration between a consumer and CM. Collaboration has been associated with rapport building and experiences of a therapeutic alliance, which has been associated to positive outcomes such as medication adherence
and a reduction in perceived coercion (e.g. Solomon et al., 1995). The findings of Study One indicated support for the existence of positive alliances between CM and consumer pairs and reported outcomes, such as rapport building and a reduced sense of coercion. Furthermore, most participants across all studies of the current research recognised that each stakeholder had unique expertise and knowledge to share, where mutual recognition of values and knowledge is considered essential for a positive collaboration.

Several functions and outcomes associated with AdAs were drawn from the data. While the functions and outcomes extracted from the analysis are not all mutually exclusive or easily distinguished, they can be categorised into three primary targets: the consumer, interpersonal relationships and the Mental Health system and professional (see Table 22). While one primary aim of AdAs is to enhance autonomy and empowerment, AdAs also need to function as useful tools for the mental health system given that the system is currently the main provider of AdAs in the ACT. As indicated in Table 22, AdAs were primarily identified by participants to function as ethical and therapeutic tools for the consumer. Furthermore, AdAs were frequently cited to cover more secondary interpersonal or systemic functions such as assisting the inclusion of significant others, sharing knowledge, providing holistic care, and facilitating voluntary treatment.

While it is clear that AdAs can take on a variety of functions, they are not considered to function as a “miracle” cures or have the exclusive capacity to function to solve complicated issues. Many of the positive outcomes associated with AdAs could be attributed to aspects or processes entailed in developing an AdA, such as collaboration, or
decision-making skills. Additionally, many alternative methods exist that propose to address similar purposes to AdAs such as crisis cards (Srebnik & Brodoff, 2003; Sutherby & Szmuckler, 1998), joint crisis plans (Henderson et al., 2004), and collaborative therapy (ACT Government, 2006). Thus, AdAs were not hypothesised to benefit all consumers, nor were they anticipated to benefit consumers in the same way.

Findings from the project suggested that the type and extent of benefits anticipated or gained from AdAs was highly individual. Some participants were more readily able to identify direct benefits, or placed more weight and emphasis on reported benefits, compared to others. On the whole, the diversity of outcomes anticipated or gained from completing an AdA for the consumer, CM, and mental health system, offer encouraging support for value and future use of AdAs.

In summary, the project results provide information on the intricacies of consumer involvement and collaboration, lending support for conceptualising consumer involvement as ranging along a continuum, and the notion that “meaningful” involvement is perceived and judged by the individual. The results highlight the significance of the process of developing an AdA, as well as the resulting document. The current project was unable to clarify the underlying mechanisms instrumental in directly causing the outcomes. Nevertheless, the findings add to the growing literature that highlight the significance of the process entailed in developing an AdA for producing beneficial outcomes.
Table 22. A summary of the functions and outcomes associated with AdAs

<table>
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<tr>
<th>Function</th>
<th>Consumer</th>
<th>Interpersonal</th>
<th>Mental health system/CM</th>
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<tr>
<td></td>
<td>• Ensure consumer rights</td>
<td>• Share knowledge</td>
<td>• Provide holistic care</td>
</tr>
<tr>
<td></td>
<td>• Facilitate consumer involvement</td>
<td>• Assist significant other inclusion</td>
<td>• Consumer centered service</td>
</tr>
<tr>
<td></td>
<td>• Have a 'voice' when unwell</td>
<td>• Gaining consent to liaise with treating team members and significant others</td>
<td>• Family sensitive service</td>
</tr>
<tr>
<td></td>
<td>• Therapeutic tool</td>
<td>• Relationship building (with CM, significant others, etc.)</td>
<td>• Facilitating voluntary treatment</td>
</tr>
<tr>
<td>Outcomes</td>
<td>• Empowerment</td>
<td>• Increase others understanding</td>
<td>• Facilitate early access to services</td>
</tr>
<tr>
<td></td>
<td>• Insight</td>
<td>• Significant others better able to advocate</td>
<td>• Direct clinical decision making</td>
</tr>
<tr>
<td></td>
<td>• Satisfaction with TCP</td>
<td>• Develop or maintain therapeutic relationship</td>
<td>• Ensure decisions meet individual consumer needs</td>
</tr>
<tr>
<td></td>
<td>• Increased ability to manage mental illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Sense of security</td>
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<td></td>
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6.1.3 Summary of Issues and Considerations

The project results elicited a myriad of specific questions and concerns regarding the development, activation, and utilisation of AdAs. These questions or concerns could generally be placed into one or more of the five categories: ethical issues, practical issues, legal considerations, economic feasibility, and medical feasibility (described in Chapter two, Section 2.4). For instance, two common practical and ethical issues reported concerning the aspect of developing an AdA were how to ensure the AdA is a legitimate act of will of the consumer, and how to judge consumer competency and insight to ensure an AdA is valid. One example of a practical issue raised connected to the aspect of
activating an AdA concerned the practicalities with ensuring mental health staff are aware of a consumer’s AdA. Another common practical question entailed how an AdA would be utilised once activated.

Given that the AdA service within MHACT is a relatively new initiative, it is not unreasonable to expect a range of opinions, beliefs, concerns and questions around the use and usefulness of AdAs. The provision of education sessions about AdAs and the project was considered to be a successful strategy to increase knowledge, address concerns, raise awareness, and provide advice. Many participants from the pilot and focus groups suggested that regular education sessions may assist the uptake of AdAs in clinical management and sustain effective implementation.. Participants recommended that the education sessions should provide information on the function of AdAs, address concerns, and provide guidelines on developing and utilising AdAs. Furthermore, results from the CIQ-CM indicated that while most of respondents reported that MHACT provides education regarding consumer involvement in TCP, many of these stated this aspect could be improved. Previous research has also hailed community education and training as essential for the successful implementation of AdAs (O’Connell & Stein, 2005). One suggested activity to assist education on AdA consisted of asking professionals to draft their own AdA. Amering and colleagues (1999) recommended this is a fruitful way for professionals to gain perspective of being a recipient of forced treatment and form an opinion on the benefits and limitations of AdAs.
In addition to specific issues and questions relating to the practical application of AdAs, the current research identified more general issues that impact are likely to influence the implementation of AdA. The legal status of AdAs was one complex issue that generated a mixture of opinions, concerns and questions. Many consumers in the study expressed concerns regarding the “ease” that mental health professionals could invoke the power of current mental health legislation to override an AdA. Some participants expressed the necessity for AdAs to be legally binding documents to be truly effective, while others expressed concerns that the legally binding nature could deter consumers from developing an AdA. The current project piloted AdAs in MHACT without the formal establishment of legal guidelines, agreeing with Anthony and Crawford (2000) who noted that enforcing policies on consumer involvement strategies, prior to fully understanding the implications, may be equally as oppressive to consumers as adopting paternalistic methods of healthcare. Furthermore, enforcing a legal status for AdAs, and incorporating them into policy, requires the acceptance of AdAs as functional tools for service users and providers (Beever, 2002). The current study offers support for the value of AdAs to be implemented in MHACT, and considers the clarification of the legal status of AdAs as an appropriate future direction.

A second cluster of issues commonly raised by participants in Study One and Two refer to the challenges with integrating AdAs into the current model for treatment and care. In particular, participants expressed frustrations that the current model of treatment and care in MHACT is crisis driven, consists of limited choices for service provision, and that decisions continue to be largely determined by clinicians. All these aspects of treatment
and care have multiple implications. One implication of a "crisis driven" service is the pressure to discharge consumers from the clinical management. Thus consumers in partial or full remission, who are considered most suitable for developing an AdA, are less likely to receive clinical management. One implication of limited service provision is that consumers are limited in the preferences they can document, potentially resulting in an AdA that may not truly reflect their wishes for treatment and care. Similar to the current findings, recent literature on psychiatric advance directives (PADs) has highlighted the difficulty of embedding a consumer’s decision-making via PADs in the apparatus of clinical decision-making and involuntary treatments (Swanson, Van McCrory, et al. 2006).

Overall, the project results highlighted complex issues concerning the integration of a tool, which promotes consumer involvement, autonomy, and choice, into a system that may not be wholly prepared. Collecting further advice and opinions from relevant stakeholders, looking towards national and international guidelines (e.g. Geller, 2000; Scottish Executive, 2005), and incorporating recent research findings (e.g. Swanson, Swartz, et al., 2006) could facilitate the development of specific legal guidelines for MHACT.

6.2 Limitations of the project

The methodology chosen to investigate AdAs was considered appropriate, given that qualitative methods are particularly suitable when "the topic under investigation is complex, dilemmatic, novel or under-researched and when there is concern with
understanding processes, not measuring outcomes" (Smith, 1996, p. 418). Specific limitations associated with each study have been discussed in the relevant chapters. This section will attend to the general validity and reliability issues associated with qualitative research designs, and address the challenges of research in mental health settings.

Qualitative research is commonly cited to be prone to interpretation bias, lack reproducibility, and lack generalisability (Mays & Pope, 1995). To counter these limitations, and strengthen the current study, a range of tactics were applied to check for objectivity, researcher effects, reliability, and validity (Elliott, Fischer, & Rennie, 1999; Mays & Pope, 1995; Miles & Huberman, 1994). The chief tactics consisted of explicitly describing the research methods, developing clear research questions, maintaining an investigative stance, corroborating findings through triangulation (e.g. through interviews, questionnaires, focus groups), reporting atypical results, providing a coherent and plausible account of the results, and being transparent regarding the limits of the findings. While the project methodology could be criticized, the quality and richness of the information collected, structured method of content analysis, and techniques to employed to ensure validity and reliability, are considered to be consistent with current expectations of qualitative research.

Conducting research in a mental health setting provides some unique challenges. The systemic shift towards consumer involvement is an evolutionary and contentious issue that cannot be simplified. Residual symptoms from the historical adoption of a strict medical model and the fostering of consumer dependence may be continuing to impact
factors that potentially influence the uptake and success of consumer involvement initiatives. At a minimum, implementing a system-wide program requires genuine cooperation from relevant stakeholders and widespread promotion. Thus, it is critical that "organizational commitment to user involvement is reflected in adequate staffing levels and resource provision" (Anthony & Crawford, 2000, p. 432). The potential that the project could implement AdAs within MHACT was considerably restricted by time constraints, along with the limited financial and practical resources provided.

A further challenge of researching in a mental health setting was that the primary subjects under investigation consisted of consumers, who are a highly diverse population connected by the experience of mental illness. By nature, mental illness can make involvement in treatment and care planning, and participation in research projects, challenging. Moreover, relapses of mental illness, and the need for involuntary treatment methods, are often inevitable features of episodic and chronic mental illness. Therefore, designing and evaluating sound and realistic research within a mental health setting must take into consideration the unique characteristics of the population. Researching strategies where treatment adherence and prevention are outcomes should firstly, acknowledge that not all consumers will desire to engage or have the same experiences, and secondly, rely on several measures for appraising the strategy, rather than relying solely on overall outcomes such as relapse rates.

In summary, there are several limitations associated with investigating a new initiative through qualitative methods and working within a mental health population. These
limitations impact on all levels of the research including recruitment, sample size, interpreting data, and generalizing the results. Nevertheless, the AdA project succeeded in collecting a rich sample of quality information that can be employed to guide the integration of AdAs into TCP in a manner that appreciates, and is sensitive to, the limitations inherent in a clinical setting.

6.3 Recommendations

The provision of an AdA service is harmonious with a consumer focused philosophy and collaborative style of treatment and care planning. To reiterate, it is clear that the provision of AdA serves a variety of functions and is a sought after service. Given that the principal function of AdAs is to ensure consumer rights and autonomy, and that the utilisation of AdAs requires cooperation from service providers, an AdA program would benefit by adopting a shared responsibility framework. Thus, AdAs would most effectively be implemented as a consumer and staff driven initiative. The project identified organisational commitment, and support from relevant stakeholders, as crucial for AdAs to reach their potential and be implemented effectively and successfully. Sharing the responsibility within MHACT, along with extending the service to community and non-government organisations, may also ease the burden of maintaining and monitoring AdAs.

Clear policies for the provision of AdAs (e.g. requirements for education/training, legal status) and guidelines for developing and utilising AdAs are strong recommendations for the continued implementation of AdAs. Specific guidelines and policies could be
integrated into existing documents, such as policies on clinical management, record keeping etc. Throughout the project, participant and project recommendations have been offered in relation to a range of features entailed in developing and utilising an AdA. With respect to developing an AdA, protocols and guidelines could be created for the stages (offering; contemplating mental illness; decision-making; documenting), processes (psychoeducation, collaboration, role of CM), and resulting document (ensuring validity, judging competency and insight). With respect to activating and utilising an AdA, protocols and guidelines could be developed for generating awareness of an individual AdA, consulting an AdA, clinical decision-making, and adherence or refutation of an AdA. Lastly, protocols and guidelines could be created for reviewing individual AdAs and ensuring the AdA is a current and valid documentation of a consumer’s preferences.

In conclusion, AdAs are considered to function as a tool that can increase consumers’ autonomy during a time when they have an impaired ability to contribute towards decisions relating to their treatment and care. The current project provides support for the potential benefits associated with the individualised and collaborative process of developing an AdA. While AdAs may not be appropriate or desirable for all consumers, the project findings lend support to the value of AdAs for those who are suitable. Given the complex array of issues involved in implementing strategies that facilitate consumer involvement, it would not be unreasonable to assume that AdAs may require resources, time, practice and persistence before they are confidently, effectively, and successfully implemented into MHACT. Regardless, the project findings bestow further support to
the current literature on anticipatory planning and offer an initial indication of the
promising prospects and future directions for AdAs tailored for MHACT.
REFERENCE LIST


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http://www.mhca.org.au/Publications/SubmissionsReports/SubmissionsandReports.html


## APPENDICES

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Appendix A

An example PowerPoint presentation tailored to CMs
An Evaluation of Advanced Agreements created by Mental Health ACT Consumers.

A Presentation to:
Mental Health ACT Clinical Managers
2005

What Are Advanced Agreements?

- Formal documentation of a consumer's preferences for future treatment and care (anticipatory planning/advanced)

- Preferences are decided and shared with clinical managers and other MH professionals involved (Agreement)

- Referred to in the event they become unwell and have a decreased competency to make treatment decisions

- Preferences include:
  - Medical treatment
  - Treatment facility
  - Emergency intervention
  - Mental Health professionals
  - Significant others
While Advanced Agreements are a means of expressing preferences they are also one method of:

- Providing a forum for discussing past experiences
- Developing decision making skills
- Enhancing the likelihood that consumer’s preferences are referred to and implemented
- Developing your mutual working alliance with the consumer
- Treatment is a mutually agreed and reviewable method of dealing with illness

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**Content of Advanced Agreement Workbook**

- Introduction
- Treating Team
- Statement of agreement
- Relapse prevention plan
- Preferences - level of unwellness
- COPMI Kit option
- Template & MHAGIC
How are AdA’s Created?

- See checklist sheet
- Collaborative
  - Good routine practice
  - Opportunity for improving/maintaining the therapeutic relationship
  - One advantage of future planning = the opportunity to discuss issues with MH professionals and to secure their agreement and cooperation (and vice versa)

Informed Consent

- Preferences are based on idea of Informed consent to treatment
- For valid consent to treatment:
  - Provide information
  - Make decisions in the absence of coercion
  - Consumers must be competent to make decisions
- The manner information is disclosed can influence the consumers understanding and memory of the information:
  - Disclose information more than once
  - Teach the information in sections rather than all at the same time
  - Provide written information

Decision Making
REFUSING TREATMENT

- If an individual has insight into their mental unwellness, then they will agree they require medical treatment
- Alternative explanations for an individual to refuse treatment, should be explored with the consumer. Some reasons:
  - Distressing previous experience with those treatments or services
  - Misunderstanding of how the treatment may help
  - Feelings of depersonalisation or loss of control in the treatment process
  - Treatment side effects
- Along with exploring the reason for refusing treatment, it may also prove useful to discuss:
  - The implications of refusing treatment on the consumer
  - Whether the consumer has ideas about alternative routes of management during their period of relapse.

When is an Advanced Agreement referred to?

- Mentally unwell and reduced competence to make/consent to treatment decisions
- Refer to MHAGIC: 'Clinical Information' and then 'Forms'
- Principle of best care – if preferences can not honoured then the consumer has the right to know the rationale behind decisions made
- Different professions may refer to different aspects of the Advanced Agreement
- Revoking preferences - must be considered competent to make modifications or revoke
- If they have an Advanced Agreement let them know you have consulted it and remind them of their preferences
Pilot Project

- **Aim:** Investigate the effectiveness of Advanced Agreements as an anticipatory planning tool for both consumers and the service
- **Participation**
  - Collaboration between CM and Consumer to work through the Advanced Agreement workbook
  - 40 pairs
  - Recruit during any stage of CM (e.g. offer following discharge from hospital or relapse prevention)
- **Measurements**
  - Brief Questionnaire before creating Advanced Agreement
  - One to two Feedback interviews (30-40 min)
  - Demographic details, age, gender, diagnosis, frequency of hospitalisations
- **Coming up:** Survey on consumer involvement

---

Outcomes

- In align with National Mental Health Strategy & Mental Health (treatment and care) Act
- **Benefits for consumers # quote?**
  - Control & empowerment
- **Benefits for nurses, clinical managers, rehabilitation coordinators, GP’s, psychiatrists**
  - Rapport building
  - Increase positive daily contact & communication
  - Involvement of significant others – Will know who to involve, how, when and why.
  - Satisfaction
- **Benefits for Mental Health system**
  - More efficient treatment
  - Advanced Agreement procedures implemented in MHACT
"[A] PAD* conceivably might be effective even if the consumer never loses capacity and the PAD is never formally implemented during a mental health crisis. And even if a PAD does not materially change someone's course of treatment, it may be worthwhile insofar as it provides an enhanced sense of autonomy and empowerment in managing one's own illness and progress toward recovery" Swanson et al, 2000

PAD = Psychiatric Advance Directive

Useful References


Appendix B

Example of AdA promotional materials

- AdA flier for consumer participation in the project
- A consumer pamphlet
WE NEED YOUR HELP with our Advanced Agreement Project

We are recruiting consumers to join our Advanced Agreement Project. Your feedback will help to shape programs that aim to increase consumer involvement in their mental health treatment and care.

ADVANCED AGREEMENTS ARE:

- Your preferences regarding your treatment and care for the future
- Agreements between yourself, your clinical manager, and others you might like to include
- Referred to in the event of a mental health crisis or period of reduced ability to participate in decisions

BENEFITS OF ADVANCED AGREEMENTS:

- More involvement in your treatment planning and care
- Empowerment
- Independence

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E: linette.bone@act.gov.au

or your Clinical Manager
INVITATION TO PARTICIPATE

ARE YOU A CONSUMER OF THE MENTAL HEALTH ACT?

You are invited to participate in a project on Advanced Agreements!

ADVANCED AGREEMENTS ARE:
- Your preferences regarding your treatment and care for the future
- Agreements between yourself, your clinical manager and others you might like to include
- Referred to in the event of a mental health crisis or period of reduced ability to participate in decisions

BENEFITS OF YOUR INVOLVEMENT
- More involvement in your treatment planning and care
- Empowerment
- Independence

Your feedback will be used to shape programs that aim to increase consumer involvement in their mental health treatment and care.

FURTHER INFORMATION

Bronwyn Wauchope, Principal Researcher  T: 0417 417 632  E: bronwyn.wauchope@anu.edu.au
Linette Bone, Consumer Consultant  T: 6205 1756  E: linette.bone@act.gov.au

or your Clinical Manager
Appendix C

Information sheets and consent forms

- Pilot Project Information Sheet
- Consent form for Consumers
- Consent form for Clinical Managers
ADVANCED AGREEMENT INFORMATION SHEET

What is an Advanced Agreement?
Advanced Agreements allow individuals to communicate and document their considered preferences for their future mental health treatment and care. They are created while an individual is feeling mentally well and motivated to do so. These considered preferences are referred to when the individual is experiencing a period of mental unwellness, or difficulty in making decisions regarding their mental health care. The Advanced agreement is individually tailored and developed in collaboration with a clinical manager and other individuals you may like involved.

What information is in an Advanced Agreement?
You are able to fill in any or all of the sections of an Advanced Agreement. The sections of an Advanced Agreement include:

➢ A relapse prevention plan
   o This entails identifying what early warning signs may indicate you are becoming unwell, and then coming up with some strategies you would like to put into place to assist an early recovery

➢ Preferences for:
   o medical treatment
   o treatment facilities
   o emergency interventions
   o health professionals
   o Who you would like contacted if you become unwell
   o What you would like these people to assist you with while you are unwell e.g. hospital visit, care of children, pets, bills etc.
What do I have to do?
The purpose of this project is to investigate the benefits related to Advanced Agreements for consumers of Mental Health ACT. Once you have decided you would like to create an Advanced Agreement you will be asked to fill out a brief questionnaire asking you general questions about the management and treatment of your mental health.

You will then develop your Advanced Agreement with your clinical manager, and a summary of this agreement will be available on a mental health database to be accessed by mental health practitioners if you become unwell.

Once you have finished your Advanced Agreement, you will be asked to attend an individual feedback session of around 40 minutes. This is to assess how the process is going for you, to gain information on how it has benefited you, along with how it could be improved.

Your participation, in addition to hopefully being a positive experience for you, will assist other consumers in the future. All information gathered will be kept confidential as much as the law permits. You will not be identified in any publication arising from the study. Participation in this study is entirely voluntary, where you are not obliged to participate and if you do participate you may withdraw at any time.

In case of any Ethical concerns, please contact the Human Research Ethics Committee:
T: (02) 6205 0846

If there are any questions or concerns about this pilot project please contact:
Bronwyn Wauchope (Principal Investigator)
T: 0417417632 E: bronwyn.wauchope@anu.edu.au

or
MHACT Consumer Consultant
T: (02) 6205 1756
CONSENT FORM

I, __________________________ (name of consumer/participant)

have been asked to consent to participate in a research project entitled:

An Evaluation of Advanced Agreements Created by ACT Mental Health Consumers.

In relation to this project I have read the Information Sheet and have been informed of the following:

1. Approval has been given by the ACT Department of Health Ethics Committee

2. The aim of the project is to investigate the practical and psychological benefits associated with Advanced Agreements in individuals with mild to serious mental illness.

3. The results obtained in the study may or may not benefit my mental health management and treatment.

4. The procedures will involve creating an Advanced Agreement with my clinical manager over a four-month period. This Advance agreement is flexible and can be modified through the course of the project. I will need to attend one semi-structured feedback interview that is approximately 30 minutes long. I will also be available for a period of 6 months, for any follow-up questions.

5. I understand that the interviews will be audio taped and that I have the right, at any time, to ask that the tape and manuscript be erased.

6. I understand that a summary of my Advanced Agreement will be stored on the ACT Mental Health database, which is accessible by authorised mental health professionals.

7. I give permission to the investigators to access my records on the ACT Mental Health database during the course of my involvement in the project. Information gathered from the database will be:
   - The amount of times I have required hospitalisation, due to mental illness, over the year prior to the project and during the project.
   - The length of time I spent in hospital, due to mental illness, over the year prior to the project and during the project.
   - My diagnosis
   - General demographics
8. I may withdraw my involvement in this project at any time with no negative consequences on my mental health care.

9. I understand that the results of the research will be made accessible and that my involvement and my identity will not be revealed.

10. All information gathered will be kept confidential as much as the law permits.

After considering the above points, I accept the invitation to participate in this project.

Name: 
(Please print name)

Signature: ________________ Date: __________
(of volunteer/participant)

Name: 
(Investigator)

Signature: ________________ Date: __________
(Investigator)

In case of any Ethical concerns, please contact the Human Research Ethics Committee:
T: (02) 6205 0846

If there are any questions or concerns about this pilot project please contact:
Bronwyn Wauchope (Principal Investigator)
T: 0417417632 E: bronwyn.wauchope@anu.edu.au
or
MHACT Consumer Consultant
T: (02) 6205 1756
CONSENT FORM

I, ________________________________
(name of clinical manager/participant)

have been asked to consent to participate in a research project entitled:

An Evaluation of Advanced Agreements Created by ACT Mental Health Consumers.

In relation to this project I have read the Information Sheet and have been informed of the following:

1. Approval has been given by the ACT Department of Health Ethics Committee

2. The aim of the project is to investigate the practical and psychological benefits associated with Advanced Agreements in individuals with mild to serious mental illness.

3. The results obtained in the study may or may not benefit my consumer’s mental health management or my work as a clinical manager.

4. The procedures will involve creating an Advanced Agreement with my consumer over a four-month period. This Advance agreement is flexible and can be modified through the 8 to 12-month course of the project. I will need to attend one semi-structured feedback interview that is approximately 30 minutes long.

5. I understand that the interviews will be audio taped and that I have the right, at any time, to ask that the tape and manuscript be erased.

6. I understand that a summary of my consumer’s Advanced Agreement will be stored on the ACT Mental Health database, which is accessible by authorised mental health professionals.

7. I may withdraw my involvement in this project at any time with no negative consequences on my mental health occupation.

8. I understand that the results of the research will be made accessible and that my involvement and my identity will not be revealed.

9. All data gathered will be kept confidential as much as the law permits
After considering the above points, I accept the invitation to participate in this project.

Name:  
(Clinical Manager)

Signature: ___________________________ Date: __________
(Clinical Manager)

Name: ____________________________  (Investigator/witness)

Signature: __________________________ Date: __________
(Investigator/witness)

In case of any Ethical concerns, please contact the Human Research Ethics Committee:
T: (02) 6205 0846

If there are any questions or concerns about this pilot project please contact:

Bronwyn Wauchope (Principal Investigator)
T: 0417 417 632  E: bronwyn.wauchope@anu.edu.au
Appendix D

AdA Preference Sheets
Advance Agreement

Preferences for:

TREATING TEAM

*NB. Please refer to page 6 of the Advanced Agreements workbook for guidance on completing this section.*

<table>
<thead>
<tr>
<th>NAME</th>
<th>POSITION</th>
<th>CONTACT NUMBER</th>
<th>PERMISSION TO CONSULT</th>
<th>SIGNATURE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes no</td>
<td>Yes no</td>
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<td>Yes no</td>
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<td>Yes no</td>
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<td></td>
<td></td>
<td></td>
<td>Yes no</td>
<td>Yes no</td>
</tr>
</tbody>
</table>


Advance Agreement

Preferences for:

RELAPSE PREVENTION PLAN

NB. Please refer to page 7 of the Advanced Agreements workbook for guidance on completing this section.

<table>
<thead>
<tr>
<th>EARLY WARNING SIGN</th>
<th>ACTION PLAN</th>
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<td>3.</td>
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<td>2.</td>
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<td>3.</td>
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<td>4.</td>
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<td>1.</td>
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<td></td>
<td>2.</td>
</tr>
<tr>
<td></td>
<td>3.</td>
</tr>
<tr>
<td></td>
<td>4.</td>
</tr>
</tbody>
</table>
Advance Agreement

Preferences for:

MEDICATION

NB. Please refer to page 14 of the Advanced Agreements workbook for guidance on completing this section.

- Preferences regarding medications for psychiatric treatment

<table>
<thead>
<tr>
<th>STAGE</th>
<th>MEDICATION</th>
<th>NOT TO EXCEED THE FOLLOWING DOSAGE</th>
<th>SPECIAL INSTRUCTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>1)</td>
<td></td>
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<tr>
<td></td>
<td>2)</td>
<td></td>
<td></td>
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</tbody>
</table>

- Specific Instructions to NOT administer particular medications or dosages

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>REASON</th>
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<tbody>
<tr>
<td></td>
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</tbody>
</table>
Advance Agreement

Preferences for:

PREFERRED TREATMENT FACILITY

NB. Please refer to page 17 of the Advanced Agreements workbook for guidance on completing this section.

- The consumer prefers to receive care at the following facilities

<table>
<thead>
<tr>
<th>STAGE</th>
<th>FACILITY</th>
<th>REASON</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>1)</td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>1)</td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2)</td>
<td></td>
</tr>
</tbody>
</table>

- The consumer prefers not to be admitted to the following facilities for psychiatric care for the reasons listed below

<table>
<thead>
<tr>
<th>FACILITY</th>
<th>REASON</th>
</tr>
</thead>
</table>
Advance Agreement

Preferences for:

CONSENT for EMERGENCY INTERVENTIONS

NB. Please refer to page 19 of the Advanced Agreements workbook for guidance on completing this section.

<table>
<thead>
<tr>
<th>TRANSPORT</th>
<th>REASON</th>
</tr>
</thead>
<tbody>
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<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>IN HOSPITAL INTERVENTIONS</th>
<th>REASON/INSTRUCTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>1)</td>
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<td>3)</td>
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</table>
Advance Agreement

Preferences for:

TREATING DOCTOR/MENTAL HEALTH PROFESSIONAL

NB. Please refer to page 21 of the Advanced Agreements workbook for guidance on completing this section.

(A) PREFERENCE TO NOT BE TREATED BY A PARTICULAR MH PROFESSIONAL

NB: Prior to documenting a particular MH Professionals name, you must ensure you have informed them and received their permission to place their name on this Advanced Agreement

<table>
<thead>
<tr>
<th>DOCTOR/MH PROFESSIONAL</th>
<th>PROBLEM OR ISSUE</th>
</tr>
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<tbody>
<tr>
<td></td>
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</tbody>
</table>

OR

(B) EXPRESSION OF PROBLEM/REASON IDENTIFIED REGARDING A PARTICULAR MH PROFESSIONAL

NB: Through using the workbook and trying to resolve an issue/problem the clinical manager-consumer team may have discussed the issue with a particular MH professional.
As this issue/problem has been addressed with discretion, no MH Professionals name should be given here. Please state only the specific issue/problem, along with the ‘profession’ if necessary.

<table>
<thead>
<tr>
<th>PROBLEM/REASON</th>
<th>PROFESSION (Eg. CATT, Psychiatrist, Nursing staff, MH staff, social workers etc)</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>
**Advance Agreement**

*Preferences for:*

**SIGNIFICANT OTHERS to be NOTIFIED**

NB. Please refer to page 22 of the Advanced Agreements workbook for guidance on completing this section.

<table>
<thead>
<tr>
<th>NAME</th>
<th>PHONE</th>
<th>RELATION (Friend/family)</th>
<th>NOTIFY (Immediately/few days)</th>
<th>SPECIAL TASKS (pay bills; feed pet etc)</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

- WHO the consumer prefers to NOT be contacted or visit

<table>
<thead>
<tr>
<th>NAME</th>
<th>RELATION (Friend/family)</th>
</tr>
</thead>
<tbody>
<tr>
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Appendix E

AdA Supplementary Workbook
Advanced Agreements Pilot Project 2004
An
ADVANCED AGREEMENT
WORKBOOK for CONSUMERS
and CLINICAL MANAGERS
PREFACE

This workbook has been developed to help in the process of making an Advanced Agreement. Deciding on preferences for mental health treatment and care can be complex and difficult. We believe that this workbook will help the consumer and clinical manager work through decisions to arise at the most beneficial outcomes.

This project has been designed to be a positive experience for consumers and clinical managers. We would like to thank you for your participation and look forward to hearing about your feedback. We understand that this workbook is reasonably lengthy and will take some time and effort to complete. It is important that you persevere with the workbook as we hope the process and finished Advanced Agreement will be beneficial for you. Your experience will be used as feedback for developing the Advanced Agreement process into the best possible practice for consumers and clinical managers.

We would like to thank all the individuals, especially the consumer focus group, who provided constructive feedback. This feedback gave valuable input into shaping this workbook. We would also like to acknowledge David L. Judge who is the author of the website for the Bazelon Centre for Mental Health Law. This website was extremely useful in the initial stages of creating this workbook.

Bronwyn Wauchope  
Principal Researcher

Linette Bone  
Consumer Consultant & Associate Researcher
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
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<td>1</td>
</tr>
<tr>
<td>Treating Team</td>
<td>6</td>
</tr>
<tr>
<td>Relapse Prevention Plan</td>
<td>7</td>
</tr>
</tbody>
</table>

**Preferences for:**

<table>
<thead>
<tr>
<th>Preference</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Treatment</td>
<td>14</td>
</tr>
<tr>
<td>Treatment Facility</td>
<td>17</td>
</tr>
<tr>
<td>Emergency Interventions</td>
<td>19</td>
</tr>
<tr>
<td>Treating Doctor/Mental Health Professional</td>
<td>21</td>
</tr>
<tr>
<td>Significant Others to be Notified</td>
<td>22</td>
</tr>
</tbody>
</table>
Introduction

1.1 GENERAL PHILOSOPHY

The term Advanced Agreement (AA) signifies a written document containing a Mental Health Consumer’s preferences regarding future treatment. They are written in anticipation of a mental health crisis or period of reduced ability to participate in decisions regarding their mental health.

While Advanced Agreements are a means of expressing preferences they are also one method of:

- Presenting the consumer with choices
- Providing the skills and opportunities for the consumer to develop self direction
- Enhancing the likelihood that consumer’s preferences are respected and implemented
- Developing the mutual working alliance between consumers and clinical managers
- Allowing for treatment to be understood as a mutually agreed and reviewable method of dealing with illness
- Providing the consumer with opportunities to develop expertise in their own recovery
1.2 THE MENTAL HEALTH CONTINUUM

Advance Agreements are based on the idea that there are differing degrees of mental wellness. Therefore Advanced Agreements are individually designed to address the different stages you may go through when you become unwell.

Mental health is considered as a continuum from mental wellness to mental unwellness (illness), where mental health entails how well you are functioning.

Judging where you are along the mental wellness-unwellness continuum can be different for each individual. For the purpose of developing an Advanced Agreement, three main stages of mental unwellness are identified: mild, moderate and severe. These stages represent different levels of functioning. Table 1.2 gives a general outline of how these stages may be experienced.

Table 1.2 Levels of functioning

<table>
<thead>
<tr>
<th>STAGE</th>
<th>HOW IS THIS STAGE EXPERIENCED?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>Few symptoms</td>
</tr>
<tr>
<td></td>
<td>Minor disturbance in daily functioning</td>
</tr>
<tr>
<td>Moderate</td>
<td>The symptoms of unwellness are between mild and severe</td>
</tr>
<tr>
<td></td>
<td>Some disturbance in daily functioning</td>
</tr>
<tr>
<td>Severe</td>
<td>Many symptoms</td>
</tr>
<tr>
<td></td>
<td>Severe disturbance in daily functioning</td>
</tr>
</tbody>
</table>
1.3 MAKING DECISIONS
When making decisions for your mental health treatment and care, such as deciding on your preferences for medical treatment, there are three standards that should be met, so that yourself and significant others can feel more confident about the decisions.

These standards are:

i. Your decisions are based on accurate information. For instance, your clinical manager can give you information on treatment options.

ii. Your decisions are made free from coercion

iii. Your decisions are not unduly influenced by current symptoms

1.4 STRUCTURED PROBLEM SOLVING
Making decisions about preferences for your future mental health treatment and care can be difficult. Therefore it can be helpful to have a technique that helps you confidently make the best decision. A technique that is useful for this workbook is based on a ‘Structured Problem Solving’ approach.

Structured problem solving consists of the following steps:

- Thinking about all the options and choices (brainstorming)
- Listing the advantages (pros) and disadvantages (cons) for each option and choice
- Weighing up the advantages and disadvantages and choosing which option is the best or has the most beneficial outcome
1.5 INFORMATION PLACED ON THE DATABASE

Once the workbook has been completed, the summary Advanced Agreement is filled out and the clinical manager will place the information on the ACT Mental Health database (See Appendix A for summary template).

To increase the likelihood that Mental Health professionals consult, consider, and remember the preferences documented in an Advanced Agreement, it is important to state the essential preferences. Therefore some sections of the workbook are not placed on the database.

All sections are important and therefore included in the workbook for the benefit of the consumer and clinical manager. The actual Advanced Agreement information that will be placed on the database MHAGIC is a summary of the workbook information.

1.6 COLLABORATION

Co-operation and communication between the consumer and Mental Health professionals is already part of good routine practice.

One important aspect of Advanced Agreements is that the preferences stated are Agreements between yourself, as a consumer, and significant others, especially your clinical manager.

For some individuals one advantage of future planning (such as Advanced Agreements) is the opportunity to discuss issues with Mental Health professionals and to secure their agreement and co-operation. Therefore Advanced Agreements offer the opportunity for improving and/or maintaining the relationship between yourself and others.
1.7 SCHEDULING APPOINTMENTS
The amount of time spent working on the Advanced Agreement may differ for each individual. Before beginning, the Clinical Manager and consumer should briefly look over the workbook together and estimate the amount of time they would like to spend on each section. Keep in mind that the Advanced Agreement should be finished in approximately four months.

1.8 STORING INFORMATION
At all times the Clinical Manager should store a hard copy of the Advanced Agreement summary information and workbook in a locked file. You also have the right to keep a copy of the workbook and summary Advanced Agreement.

1.9 REVISIONS & MODIFICATIONS
Any changes to the original document must be recorded on MHAGiC and also changed on the database MHAGiC.

1.10 LEGAL LIMITATIONS
During a Mental Health admission it is intended that Mental Health professionals will refer to a consumer's Advanced Agreement. The consumer's preferences should be considered and implemented as long as their preferences are in their best interest at the time.

For the purpose of this project the Advanced Agreement will only be valid in the Australian Capital Territory.

1.11 EXPIRATION DATE
For the purpose of this project, each AA will have an expiration date. At the very latest this will be at the conclusion of the study (approximately mid 2006) unless stated otherwise at the discretion of the consumer.
**Treating Team**

List the main individuals involved in the management of your mental health treatment and care. The treating team should include yourself, your clinical manager, your psychiatrist, and your general practitioner, along with other individuals whom play a major role in the management of your mental health. Once you have completed the advanced agreement it is recommended that you give each member of the team a copy of your advanced agreement summary. Then they can sign their name to demonstrate they have received a copy and agree with the summary.

<table>
<thead>
<tr>
<th>NAME</th>
<th>POSITION</th>
<th>CONTACT NUMBER</th>
<th>PERMISSION TO CONSULT</th>
<th>SIGNATURE &amp; DATE</th>
</tr>
</thead>
<tbody>
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</table>
Relapse Prevention Plan

INTRODUCTION TO CREATING A RELAPSE PREVENTION PLAN

Main Tasks:

- One task in this section is to identify ways you can change your thinking, behaviour and situation before you experience a serious period of mental unwellness.

- This is achieved by listing the ways you change before a period of mental unwellness (early warning signs), and intervening these changes (action plan) before they develop into a full period of unwellness.

- You will also be educated on ways to assess your early warning signs.

- You may have already formulated a relapse prevention plan, therefore you can use this section as a way to review and update your existing relapse plan.

- To develop your relapse prevention plan, follow through this section and fill out the table: Individual Relapse Prevention Plan.
**Individual Relapse Prevention Plan**  
(This information will be entered in the summary AA)

<table>
<thead>
<tr>
<th>DESCRIPTION of EARLY WARNING SIGNS</th>
<th>ACTION PLAN</th>
</tr>
</thead>
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</table>
CREATING A RELAPSE PLAN

1. Early Warning Signs

- The first step in creating a relapse plan is identifying ‘Early Warning Signs’ that may signal a relapse into mental illness and that you need extra support.

- To identify early warning signs, ask yourself, what kinds of situations, physical feelings or emotions signal, trigger, or intensify my mental illness?

- Here are some tips if you are having trouble thinking of your early warning signs:
  - Think back to the recent times you have been ill. What kinds of emotions, events, or sensations were you feeling just prior to your relapse?
  - Ask your family, friends, or health professionals what kinds of changes they notice in you before you relapse
  - Ask other individuals who also experience mental illness similar to you

- Sometimes thinking about early warning signs can bring up many distressing memories. However keep in mind that a clear memory of a warning sign may help you to be more aware of what helps you cope and recover for the future

- List all the early warning signs you can think of in the table 4.0.

2. Action Plan

- The second step in creating a relapse plan is to identify things you can do to prevent early warning signs from getting worse

- For your action plan, try to think of around four interventions for each warning sign. List them in order from what you may do initially to what you can do if the initial intervention does not relieve the symptoms. By listing at least four interventions, you now have a ‘back up’ plan.
• For instance, consider Tom. One of Tom’s early warning signs is difficulty sleeping three days in a row. Tom identified that, for him, difficulty sleeping is related to stress. His first step of intervention is relaxation exercises. If that does not help, then he will reduce his workload. If that does not help, or is only helping a little, he will go to his general practitioner, and lastly he will seek counselling.

• This section may take a little more time to complete. Just remember that there is no rush to finish this in one day! An action plan may become more clear after you have experienced a warning sign, as you begin to be more aware of what helps you cope and recover.

3. ASSESSING EARLY WARNING SIGNS

• Once you recognise an early warning sign, it is important to assess that sign before intervening, so that you are aware firstly of which stage you should begin in your action plan; secondly, so that you become aware of other possible warning signs.

• When you recognise an early warning sign, whether you intervene using your first intervention or fourth intervention, or whether you do all is really an individual decision. However sometimes it may not be necessary to do all four interventions, so here are some ways that you can assess the early warning signs and decide where to intervene.
3.1 Intensity

- You may be in tune with how intense or strong a symptom is for a relapse to occur. Intensity can be measured using 'subjective units of distress' (SUDS). This is a scale ranging from zero to 100 and it is up to you where you decide you feel on that scale and where you need to be when you intervene. Here is an example of a scale, however feel free to create your own.

<table>
<thead>
<tr>
<th>SUDS</th>
<th>0</th>
<th>30</th>
<th>50</th>
<th>80</th>
<th>100</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Worst ever</td>
<td></td>
</tr>
</tbody>
</table>

- Ask yourself:
  - How intense is the early warning sign? I.e. rate from 0 to 100
  - What intervention is most appropriate? I.e. Intervention 1, 2, 3, and/or 4

- For instance, one early warning sign may be work stress. When work stress is mild, your intervention may be relaxation exercises. When work stress is high, your intervention may involve having some time off, or seeking counselling.

3.2 Duration

- The duration, or how long your early warning sign has been present, can also be a good indication of when and what intervention is appropriate. In your relapse plan you may also like to specify how long the symptom or early warning sign is present before it may signal a relapse.

- For instance, one bad nights sleep may not necessarily be considered an early warning sign, whereas five consecutive bad nights sleep may be considered an early warning sign, and indicate an increased likelihood of relapse.

3.3 Clusters

- It is also important to be aware that an early warning sign may occur with other early warning signs. It is important to be able to recognise that when one symptom occurs, this may trigger or be associated with other symptoms. For instance stress at work may be associated with lack of sleep.
EXAMPLE

Consider Mandy, one of Mandy's warning signs is family stress—especially when she has arguments with her sister. Once she recognises she feels stress due to arguments, she begins to assess whether she needs to intervene. When she was developing her plan, she decided that she only needed to rate the strength of her stress as a 50 in order to begin intervening. Today she rates it as 50, so knows she begins to intervene. Before she does, she also assesses how long it has been going for and whether any of her other warning signs are there. She notices that she has also been losing some sleep. This strengthens her confidence that she should intervene. So she begins with relaxation, as sometimes tension contributes towards the conflict between herself and family members. She completes her relaxation exercises for several days and feels more relaxed however there is still some conflict. Therefore goes to her next step—communication. She decides to confront her family in an assertive way and tell them how she is feeling. This works, and her stress levels decline.

'Mandy's' Individual Relapse plan for one early warning sign.

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>ASSESS</th>
<th>ACTION PLAN</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.g. create a list of things/situations that you feel may cause you to have a relapse</td>
<td>SUDs needs to be around 50 for me to intervene. Are there any other warning signs? How long have I been arguing with them for?</td>
<td>1. Relaxation- I usually feel less irritable when I'm relaxed 2. Communication- Can I sort this out by talking to them? 3. Seek support from friends 4. Counselling</td>
</tr>
<tr>
<td>Family stress- having arguments with family members</td>
<td></td>
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</tbody>
</table>
SUMMARY OF STEPS FOR USING YOUR INDIVIDUALISED RELAPSE PREVENTION PLAN

Step one: Recognise early warning sign

Step Two: Assess
- How intense or strong is it? Use your SUDs rating scale. Is this intense enough for intervention?
  - Yes...go to action plan
  - Not sure...use other assessment techniques to help you decide.
- How long has this been happening?
- Is there any other warning signs occurring?

Step Three: Action Plan
- Even if you feel unsure about intervening, it is usually safer to follow through with your action plan.
PREFERENCES for MEDICAL TREATMENT

1. Medication

STEP ONE: Identify all the medication/s that are viable options for if you relapse into mental illness and list the advantages and disadvantages of each.

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>DISADVANTAGES</th>
<th>ADVANTAGES</th>
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<tbody>
<tr>
<td></td>
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</tbody>
</table>
STEP TWO: Are there any medications you specifically would prefer not to be prescribed? If so, what are your reasons for this decision?

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>REASON</th>
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</tbody>
</table>

STEP THREE: Write your first and second preferences for medication during each stage of unwellness (mild, moderate and severe), along with special instructions. *(This information will be entered in the summary AA)*

<table>
<thead>
<tr>
<th>STAGE</th>
<th>MEDICATION</th>
<th>Special instructions e.g. dose range, method of administration such as liquid, tablets, injection.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>1)</td>
<td></td>
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<td></td>
<td>2)</td>
<td></td>
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<tr>
<td>Moderate</td>
<td>1)</td>
<td></td>
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<tr>
<td></td>
<td>2)</td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>1)</td>
<td></td>
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<tr>
<td></td>
<td>2)</td>
<td></td>
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</tbody>
</table>
2. Other Treatments

**STEP ONE:** Think about whether there are any alternative forms of treatment that may benefit you during each stage of unwellness, and write them in the table.

Here are some examples of other treatments:

- Therapy and counselling
- ECT
- Natural therapies, such as massage and acupuncture
- Spiritual therapies, such as meditation and relaxation
- Expressive therapies, such as art and music
- Exercise

**STEP TWO:** Next write how they might benefit you and where you can access them.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Other treatment</th>
<th>How will this help me?</th>
<th>Where access treatment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
PREFERENCES for TREATMENT FACILITY

STEP ONE: Identify the places you are likely to be treated when you become mentally unwell, and list the advantages and disadvantages

<table>
<thead>
<tr>
<th>PLACE OF TREATMENT</th>
<th>DISADVANTAGES</th>
<th>ADVANTAGES</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
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</tbody>
</table>
**STEP TWO:** Are there any places you would prefer not to be admitted in as a patient?

<table>
<thead>
<tr>
<th>FACILITY</th>
<th>REASON</th>
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<tbody>
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</table>

**STEP THREE:** List your two most preferred treatment facilities for each stage of unwellness (mild, moderate and severe)

<table>
<thead>
<tr>
<th>STAGE</th>
<th>FACILITY</th>
<th>REASON</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2)</td>
<td></td>
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<tr>
<td>Moderate</td>
<td>1)</td>
<td></td>
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<td></td>
<td>2)</td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2)</td>
<td></td>
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</tbody>
</table>
PREFERENCES for EMERGENCY INTERVENTIONS

Transport to Hospital

STEP ONE: Identify ways you can travel to hospital if you become unwell and list the advantages and disadvantages

<table>
<thead>
<tr>
<th>TRANSPORT TO HOSPITAL</th>
<th>DISADVANTAGES</th>
<th>ADVANTAGES</th>
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</thead>
<tbody>
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STEP TWO: List your most preferred options for travelling to hospital, along with a brief reason.

For example, if you are severely unwell you may prefer that CATT assist you. If you fall unwell and pose danger to yourself or others, you may agree to be taken with a police escort.

<table>
<thead>
<tr>
<th>TRANSPORT</th>
<th>REASON</th>
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- Please Note: If you own a car you may prefer to have a significant other with whom you would like to drive or accompany you, or drive your car to the hospital, please specify who they are and what you would like them to do. Please place this information in the section called ‘Significant others to be Notified’ on page 35.
Emergency Interventions within Hospital

STEP ONE: Read the list of emergency interventions given. Identify the interventions you think are helpful or more appropriate for yourself, and list the advantages and disadvantages.

- Quiet time e.g. in room or chapel
- Talking time
- Medication in pill form
- Medication by injection
- Sleep
- Liquid medication
- Seclusion
- ECT

<table>
<thead>
<tr>
<th>EMERGENCY INTERVENTION &amp; SPECIFIC DETAILS</th>
<th>DISADVANTAGE</th>
<th>ADVANTAGE</th>
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STEP TWO: Decide on your most preferred form of emergency intervention. Next to the interventions you have chosen you may place special instructions for your choice E.g. how long would you like quite time for? Where would you like quite time? For talk time, what can people say to help?

(This information will be entered in the summary AA)

<table>
<thead>
<tr>
<th>INTERVENTION</th>
<th>Special Instructions</th>
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<tbody>
<tr>
<td>1)</td>
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<td>2)</td>
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</table>
PREFERENCES for TREATING DOCTOR/ MENTAL HEALTH PROFESSIONAL

Please Note:

- We acknowledge that individuals can recover best when they are in tune with their doctors and vice versa. In order to facilitate the MHACT system working as best as possible doctors are allocated to consumers and continue working with the same consumers to allow some continuity of care.
- This section is really about trying to identify aspects of a relationship you're not happy with and using problem solving skills and assertiveness to solve these problems in a positive fashion!

STEP ONE: List any doctor-consumer (or other) relationships where you feel there is an issue or problem, and think about how the problem/s could be resolved.

<table>
<thead>
<tr>
<th>RELATIONSHIP</th>
<th>ISSUE or PROBLEM</th>
<th>SOLUTION/S</th>
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STEP TWO: Choose the most workable solution and follow it through

STEP THREE: If there is a particular issue relating to the doctor-consumer relationship that you feel has not been resolved, with their permission, you may state your preference not to be treated by them along with the problem or issue. ALTERNATIVELY, if you would prefer not to state names or you have not received permission from the particular MH professional to document their name, then you may state the specific problem, reason and profession in the template.

<table>
<thead>
<tr>
<th>DOCTOR/MH PROFESSIONAL</th>
<th>PROBLEM OR ISSUE</th>
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</table>
PREFERENCES for SIGNIFICANT OTHERS TO BE NOTIFIED

STEP ONE: List all the family/friends that you would like to help out if you become unwell. Identify when you would like them notified and any special tasks they could do.

<table>
<thead>
<tr>
<th>NAME</th>
<th>Phone</th>
<th>RELATION (Friend/family)</th>
<th>NOTIFY (Immediately/few days)</th>
<th>SPECIAL TASKS (pay bills; feed pet etc)</th>
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Please Note: If you are a parent, you also have the choice of filling out a care plan for your child through COMIC (Children of Mentally Ill Consumers). This includes more specific information to give to your child such as a letter for school, and important contact phone numbers. Please ask your Clinical Manager for more information.
**STEP TWO:** Is there anyone who you would prefer not to be notified?

<table>
<thead>
<tr>
<th>NAME</th>
<th>RELATION (Friend/family)</th>
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**STEP THREE:** Tell the people who you have chosen to be contacted and ask them if they mind being on your list of people to contact and what you would like them to do.

- Through asking their permission to fulfil their role, your significant others can feel more involved and prepare themselves to make your recovery a little more bearable

- It may also be a good idea to arrange a proxy for your significant others, just in case they are unable to complete the tasks you have specified. Give them the name and phone number of another member of your significant others team whom they can contact

<table>
<thead>
<tr>
<th>NAME</th>
<th>CONTACTED</th>
<th>PROXY</th>
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AdA Manual for Clinical Managers
A Manual on Advanced Agreements for Clinical Managers
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1.0 INTRODUCTION

- The term *Advanced Agreement* predominantly signifies a written document containing a Mental Health Consumer's preferences regarding future treatment. They are written in anticipation of a mental health crisis or period of reduced ability to participate in decisions regarding their mental health.

- While Advanced Agreements are a means of expressing preferences they are also one method of:
  - Presenting the consumer with choices
  - Providing the skills and opportunities for the consumer to develop self direction
  - Enhancing the likelihood that consumer's preferences are referred to and, where possible, implemented
  - Developing your working alliance with the consumer
  - Allowing for treatment to be understood as a mutually agreed and reviewable method of dealing with illness
  - Providing the consumer with opportunities to develop expertise in their own recovery
• The manner information is disclosed can influence the consumers understanding and memory of the information that will be employed to make treatment decisions. Understanding and retainment of information may be enhanced through:
  o Disclosing the information more than once
  o Teaching the information in sections rather than all at the same time
  o Providing written information

• For further information on informed consent see Forrester & Griffiths (2001) or the website www.austlii.edu.au; or for more information about consent for specific procedures, such as ECT, see Part 7, Division 7.1 in the Mental Health (Treatment and Care) Act 1994.

3.3 Decision Making

• In some cases the consumer may be capable of making decisions but lack the techniques to make the decision with confidence.

• For the purpose of creating an Advanced Agreement, the most useful approach for making decisions is a structured problem solving approach (See Appendix B)

• As making decisions regarding MH treatment and care may require remembering periods of unwellness, going over some of these details may include painful history experiences.

• Supportive counselling along with specific techniques, such as reframing past periods of unwellness as experiences that can be used positively for the Advanced Agreement, may be useful.

SUMMARY

➢ There are three important processes involved in creating an Advanced Agreement.
   1) Collaboration
   2) Informed consent
   3) Decision making
4.0 RELAPSE PREVENTION PLANS

4.1 Individualised Plans

- As every situation and individual is unique, relapse prevention plans are individually tailored. Creating, developing and working with this plan is a joint activity between the consumer, clinical manager, family and friends.

- If family members or friends do become involved in the project, it is then helpful to the consumer if the clinical manager is present when discussing the plan.

4.2 Successful Plans

- Factors that influence the success of Early recognition and intervention planning include (Van Meijel et al, 2002- See Appendix C for more detail on these factors):
  - The provision of information and education
  - Attitudes towards healthcare professionals
  - Insight
  - Acceptance
  - Motivation
  - Individual Characteristics
  - Continuity of care
4.3 Methodology

- The following is one method of creating a early recognition and intervention plan as outlined by Van Meijel et al, 2002

1. Preparatory work

Inform and educate consumer and others
Analyse their situation and their social network concentrating on:
- Consumers insight
- Consumers acceptance
- Consumers motivation
- Characteristics

Decide on strategy for early detection and intervention concentrating on:
- Contributions by the individuals involved to the plan; and
- Timing: Is this an appropriate time to be preparing a plan? I.e. is the consumer ready?

2. Listing early warning signs

Listed from the perspectives of the consumer, family/friends, and healthcare professionals

3. Monitoring early signs

Instruct people involved how to monitor early warning signs, and guide this process. For example symptom intensity, duration and cluster.

4. Preparing a plan of action

Main features:
- Addresses of relevant contacts
- Details of most prominent early warning signs
- Relevant sources of stress
- Existing coping skills
Action to be taken by person and relevant others

SUMMARY

➢ If the consumer already has a relapse prevention plan in place, review their current plan and place the information in the Advanced Agreement workbook.

➢ In cases where a relapse prevention plan is not currently in place, follow through the four main steps as outlined by Van Meijel et al (2002)
5.0 ADMINISTRATION

5.1 Scheduling Appointments

- The amount of time spent working on the Advanced Agreement may differ for each individual.

- Prior to beginning the document, the Clinical Manager and consumer should briefly look over the workbook together and estimate the amount of time they would like to spend on each section.

- Keep in mind that the Advanced Agreement should be finished in approximately four months.

5.2 Recording Appointments

- Once the Advanced Agreement process has begun, please place the consumer on MHAGIC in the Advanced Agreement (AA) Team

- Maintain a record of hours and sessions spent on creating the Advanced Agreement with your consumer on MHAGIC under ‘occasions of service’

5.3 The Advanced Agreement Summary and MHAGIC

- Once the workbook has been completed, the consumer or clinical manager will fill out a hard copy of the Advanced Agreement template

- It is then the responsibility of the Clinical Manager to enter the summary template on the Mental Health database MHAGIC,

- Place an ‘Alert’ on MHAGIC stating ‘Please refer to Advanced Agreement’
5.4 Storage of an Advanced Agreement

- At all times the Clinical Manager should store a copy of the Advanced Agreement Summary, where any revisions should be documented in 'occasions of service' on MHAGIC, and changed on the Advanced Agreement in MHAGIC.

- The consumer has the right to keep their workbook, however this decision can be agreed upon with the Clinical Manager, whom may also store a copy of the workbook in a locked file.

5.5 Utilisation of Advanced Agreements

5.5.1 Areas an Advanced Agreement can apply

- For the purpose of this project the consumers AA will only be valid in the Australian Capital Territory. This will be stated in the consumer's workbook and summary template

5.5.2 Referring to Advanced Agreement on MHAGIC

- During a period of crisis, where the consumer is judged to display a reduced ability to participate in treatment and care decisions, the consumer's Advanced Agreement should be referred to by Mental Health professionals

5.5.3 The Common Law

- When a consumer displays a reduced ability to make decisions for themselves, mental health professionals i.e. individuals' responsible for making those decisions, have to apply the common law

- "The common law respects and preserves the autonomy of adult persons of sound mind with respect to their bodies" (Bayliss, 2002)
• The Mental Health (Treatment and Care) Act 1994 objectives emphasise the importance of the common law. For instance, the first objective is to: “provide treatment, care, rehabilitation and protection for mentally dysfunctional, or mentally ill persons in a manner that is least restrictive of their human rights”

• Advanced Agreements are a tool for consumers to document their preferences for treatment and care and these preferences are an important factor in determining what care and treatment is in the consumer’s best interest.

• “The agreement itself should have an express reservation that in the future if the patient, whilst incompetent, requires medical treatment that the Agreement may not be able to be complied with by the Territory although the Territory will provide its best endeavours to honour the Advanced Agreement” (Bayliss, 2002)

5.5.4 Following a Period of Crisis

• Following a period of crisis, it is suggested that part of the next session be dedicated to discussing the consumer’s experience. This provides an opportunity to discuss:
  o Issues and feelings they may have towards how their Advanced Agreement was used
  o The success of their treatment
  o Whether they would like to modify their preferences
  o What they would like to stay the same and what they would like to happen differently
5.6 Revoking and Revisions

- In the same way that the consumer must be competent to create and make modifications on their AA, so must they be in a state of competency to revoke any of their preferences.

- Any changes to the original document must be recorded in hard copy and also changed on the database MHAGIC.

5.7 Expiration Date of an Advanced Agreement

- Each AA will have an expiration date. At the very latest this will be at the conclusion of the study (approximately early 2006) unless stated otherwise at the discretion of the consumer.

SUMMARY

➢ There are several issues particular to the clinical manager with respect to the process of creating an Advanced Agreement. These include:
  - Scheduling appointments
  - Recording appointments
  - The AA summary and MHAGIC
  - Storage of an AA
  - The utilisation of AAs
  - Revoking and Revisions
  - Expiration date of an AA

➢ Advanced Agreements are limited to the extent that they are not legal documents or a means of refusing treatment.

➢ The time period they may be used and also the area they can be applied also limit them.
6.0 COMPETENCE

6.1 Definition

- Competence is the state or quality of being adequately or well qualified to performs a particular ability

6.2 Competence and Mental Health

- For the purpose of creating and developing an Advanced Agreement:
  - The consumer is presumed competent to make decisions regarding their future treatment, where a diagnosis of mental illness is not a sufficient reason for deeming an individual incompetent to make treatment
  - Competency should be determined on an individual basis
  - An individual is deemed competent or incompetent with respect to particular tasks or roles (cf. general competence/incompetence). For instance, to decide on hospitalisation, to consent to treatment.
  - The level of Competency an individual displays is not static. Rather, it is a condition that reflects the individuals present functional state. This can alter in relation to changing clinical or environmental conditions

6.3 Assessing Competence

- There is no standard method for measuring competence. Four main domains of competence have evolved through examining standards commonly applied in legal courts when determining competence. These include:
  - The ability to communicate and express a choice
  - The understanding of treatment options
  - Ability to appreciate the nature of the situation and likely consequences
  - The ability to think rationally about treatment
Please Note:
For the purpose of creating and developing an Advanced Agreement, these domains are outlined to increase awareness and knowledge regarding the issue of competency assessment. Actual measurement instruments within each domain exist however they will not be covered. The measurements are not recommended for regular clinical use, as they require considerable time and effort for administration and scoring. The information provided should be applied only as guidelines to aid the clinician in making clinical judgments regarding competency during sessions with the consumer.

6.3.1 Expressing a Choice

- If an individual is unable to reach a decision, or unable to indicate what course of treatment they would prefer, then it may be considered inappropriate for the consumer and clinical manager to make a treatment preference at that particular point in time. For example, the consumer or clinical manager may like time to consult others

6.3.2 Understanding the Treatment Options

- Understanding treatment options forms part of the informed consent process that should accompany any treatment decision (See section 3.2)

- Understanding one’s options for treatment is operationalised as the ability to demonstrate comprehension of information related to one’s own mental disorder after they are presented in an informed consent disclosure. Comprehension of information can be obtained through asking the individual to paraphrase or ask them to recognise items of information that may or may not have been presented.

- Techniques to increase the understanding and comprehension of information:
  - Use simple language
  - Disclose more than once
  - Disclose part by part as opposed to all information at once
  - Explain and teach the information
6.3.3 Appreciate Nature and Consequences

- Appreciation refers to the consumers' recognition that information presented to them on their disorder, such as potential treatments, are applicable to their own circumstances.

- Appreciation focuses on patients' acknowledgment of the potential value of treatment; whether they actually accept the treatment is not relevant and there may be various reasons for not accepting the treatment. Both situations, appreciating the value of treatment and accepting the treatment, should be handled carefully and with genuine respect of the consumer's beliefs. Reasons surrounding the consumer's inability to appreciate the nature and consequences of their illness should be explored prior to a determination of incompetency.

6.3.4 Thinking Rationally

- The ability to think rationally leads to the formulation of judgement based on a logical process of comparing benefits and risks of particular treatment preferences.

- This criterion does not refer to the quality, rationality, or reasonableness of that individuals' actual choice.

- Caution should be made with respect to the amount of emphasis placed on this aspect of competency as many authors have disputed the rationality criterion. This controversy is best captured by Strachan and Spaulding (2003) whom point out that 'Whether or not rational decision-making is a norm toward which we should strive as a species... it is demonstrably the case that human being do not (as a class) make decisions based on rational principles in most situations'
6.4 How Frequently Should Competency be Determined?

- During each session a determination of competency with respect to making treatment decisions should be made.

- Competency levels may fluctuate during session; therefore it remains at the discretion of the Clinical Manager to decide whether the agreements made during that session are valid, or whether they should be reconsidered.

- If the assessment of competency during a session is questionable, it is advised that the content covered during that time is revised in the following sessions.

6.5 Documenting the Competency of the Consumer

- After each session of working on the consumer’s Advanced Agreement, a general judgment should be documented regarding their competency to work on their Advanced Agreement during that session (Appendix D contains a table that can be utilised to document competency).

- Obtain a copy of the consumer’s rationales for important decisions, such as preferences for medication, treatment facility, or treating physician.

<table>
<thead>
<tr>
<th>SUMMARY</th>
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<tbody>
<tr>
<td>➢ The consumer is presumed competent to make decisions regarding their future treatment</td>
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<tr>
<td>➢ Competency should be assessed based on process (the way a decision has been reached), as opposed to focusing on the outcome (the consumer’s treatment decision)</td>
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<tr>
<td>➢ The most important variables in assessing competency include:</td>
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<tr>
<td>• Ability to express a choice</td>
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<tr>
<td>• Understanding of treatment options</td>
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<tr>
<td>• Appreciating the nature and consequences of treatment options</td>
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<tr>
<td>• Weighing between pros and cons</td>
</tr>
<tr>
<td>➢ A judgment on the consumers overall level of competency should be made and documented following each session</td>
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</tbody>
</table>
7.0 INSIGHT

7.1 Definition

- Insight is whether or not someone believes he or she is mentally unwell and is therefore in need of treatment (see Appendix E for more information on insight).

- It is not absolutely necessary that the consumer have insight into their diagnosis, only that they demonstrate insight into feeling mentally unwell and therefore require treatment.

7.2 Assessing Insight

- For the purpose of creating an Advanced Agreement, it is recommended that insight be assessed each session through clinical judgment. If there is any concern regarding deficiency or decline in insight this should be recorded on MHAGIC under 'occasions of service'.

SUMMARY

➢ Insight is whether or not someone believes he or she is, or has been, mentally unwell and is therefore in need of treatment.
➢ Symptom severity accounts for impaired insight more so than the diagnosis itself.
➢ It is likely that levels of insight fluctuate over time.
➢ It is necessary that the consumer have insight into their illness as creating an Advanced Agreement requires that the individual is aware there is a likelihood that they may experience a period of future mental illness.
8.0 LIMITATIONS

8.1 Refusing treatment

- Refusing medical treatment is not an optional preference when creating an Advanced Agreement, the rationale is as follows: It is necessary that the consumer have insight into their mental illness when creating or developing their Advanced Agreement. If an individual has insight into their mental illness, then they will agree they require medical treatment, most likely in the form of medication.

- It is important to be aware of alternative explanations for an individual to refuse treatment, and these should be explored with the consumer. Some alternative reasons include:
  - Distressing previous experience with those treatments or services
  - Misunderstanding of how the treatment may help
  - Feelings of depersonalisation in the treatment process
  - Feeling a loss of control in the treatment process
  - Treatment side effects

- Along with exploring the reason for refusing treatment, it may also prove useful to discuss:
  - The implications of refusing treatment on the consumer
  - Whether the consumer has ideas about alternative routes of management during their period of relapse.
8.2 Legal Limitations

- Advanced Agreements are not legally binding documents.

- Mental Health professionals will not be held responsible for making decisions that were not congruent with a consumer’s Advanced Agreement.

- During a period of crisis it is intended that a consumer’s Advanced Agreement is consulted and considered. The consumer’s preferences should be honoured and implemented as long as their preferences are in their best interest at the time.

9.0 SUPPORT

9.1 Consumer support

- Encouraging consumers to include family members and friends

- Encourage consumers to discuss their AA with other ACT MH consumers

9.2 Clinician support

- It is advised that the Clinical Managers involved in this project communicate to each other and share strategies/information/advice.

- If there are any questions regarding any aspect of the Advanced Agreement, the researchers can be contacted

  Bronwyn Wauchope  Ph: (02) 6125 0509
  Email: bronwyn.wauchope@anu.edu.au

  OR

  Linette Bone  Ph: (02) 6205 1756
  Email: linette.bone@act.gov.au
REFERENCES & BIBLIOGRAPHY


Lysaker, P. H., Bryson, G. J., & Bell, M. D. (2002). Insight and work performance in schizophrenia. The Journal of Nervous and Mental Disease, 190(3), 142-146.


APPENDICES

APPENDIX A

Theoretical definitions of the ‘therapeutic relationship’ or ‘working alliance’ generally have three themes in common:

1) The collaborative nature of the relationship
2) The affective bond between patient and therapist, and
3) The patient’s and therapist’s ability to agree on treatment goals and tasks

APPENDIX B

For the purpose of this project, structured problem solving consists of the following steps:

- Define the problem. Gather relevant information, clarify the nature of the problem and set realistic goals
- Generate alternative options and solutions
- Listing the advantages and disadvantages of each solution
- Evaluate the options by weighing the advantages and disadvantages for each option to source out the preference that has the most beneficial outcome
- Choose and implement the favored solution
APPENDIX C
Van Meijal and colleagues (2002) outlined factors associated with successful relapse prevention plan:

1) The provision of information and education

Information can be given on several levels:
- General information - common early warning sign and the associated intervention
- Specific information - Early warning signs the individual has shown in the past and intervention tailored to them
- Daily information - applying instances that occur through the day and integrating them into the plan
- Sharing information - to increase the efficacy of relapse prevention plans include family and friends, giving them written information as well as discussing the plan with them.

Caution must be taken when disclosing information, as it may not always generate a positive response. If a consumer is not ready to absorb information about future episodes of a mental illness informing them of early warning signs and recognition may trigger tension and resistance. Information may also cause confusion, for instance it is important to emphasise that although there are many common early warning signs, not every individual experiences them. Emphasising this point may decrease any unnecessary fears or confusions of oncoming episodes.

2) Attitude of healthcare professionals

The attitudes a consumer holds towards Mental Health professionals can also influence the success of a relapse prevention plan. Relapse prevention plans work best when Mental Health professionals work collaboratively with the consumers. While working collaboratively it is important to remain aware of your own and the consumer’s limitations and time required generating the plan.
3) Insight

A certain degree of insight is necessary for early recognition and intervention. As a general statement, consumers are not likely to see the importance of discussing preventative strategies if insight is low- in other words if they do not believe anything is wrong.

As insight can fluctuate over time, there is no reason to believe that an individual demonstrating a high level of insight during remission will continue having insight during the prodromal stages of an episode. Therefore it is important to identify and anticipate a drop in insight and develop the plan accordingly.

4) Acceptance

A relapse prevention plan may be compromised if the consumer is dealing with acceptance or denial issues. For the purpose of this project, focus on these issues prior to continuing on the preference agreements. The processes of acceptance should be given adequate attention and time, where only when the consumer feels ready should the relapse prevention plan be created.

Acceptance issues may be difficult to discern, especially passive resistance. This occurs when the individual may create the plan but fail to take the appropriate action. One reason for this may be that the individual has not yet genuinely accepted they are experiencing an episode of mental illness.

5) Motivation

Motivation to monitor early warning signs often wanes over time. This should be made clear to the consumer so they know that it is normal to lose motivation. In order to increase the maintenance of motivation, the following strategies are suggested:

- Limit monitoring early warning signs to certain periods, such as when the consumer is confronted with stress factors or when they observe the first warning sign.
- Use the plan as a plan for the future- through preventing relapse the individual can select and target goals in their life. For example, through increasing the level of self-management the individual can achieve the goal of increasing independent living.
6) Individual characteristics

Some individual characteristics may impede the recognition and intervention on early warning signs. These include:

- The presence of psychotic symptoms
- The presence of negative symptoms
- Cognitive disturbances in the fields of memory and attention
- Drug dependency
- Personality features such as negative self image, antisocial personality disorder (it may prove difficult to set up or continue a cooperative basis for early recognition and intervention), paranoia (whom may regard their clinical managers with suspicion and therefore have insufficient trust in them)
- Different cultural backgrounds- these consumers may have different notions of disease and mental illness.

7) Continuity of care

A relapse prevention plan will have a greater likelihood of success if there is continuity of care such as:

- Continued guidance in preparing a plan
- Support to consumers and their families in making use and evaluations of the plan
- Alertness to possible adjustments on the basis of new information
- Adequate transfer of information by healthcare professionals in case of a change in staffing
**APPENDIX D**

Rate competency on a scale of 0-10:

0- The consumer demonstrates no competence to make collaborative preference decisions
3- The consumer demonstrates some competency to make collaborative preference decisions, but these preferences will be reviewed
7- The consumer demonstrates high competency to make collaborative preference decisions
10- The consumer demonstrates full competency to make collaborative preference decision

<table>
<thead>
<tr>
<th>Date</th>
<th>Subjective Competency Judgment</th>
<th>Notes</th>
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APPENDIX E

In the current literature, poor insight in psychiatric illness has been defined as ‘a multidimensional construct composed of unawareness of symptoms, denial/minimisation of illness-related consequences, and failure to recognise the need for treatment’ (Goldberg et al, 2001: 138)

A current study examining the correlates of insight in serious mental illness revealed (Goldberg et al, 2001):

- Impaired insight is more strongly associated with the presence of a psychotic versus mood disorder
- Symptom severity accounts for impaired insight more so than the diagnosis itself
- It is likely that levels of insight fluctuate over time
- Current impairment in insight was related to less favourable attitudes about medication, poorer ratings of overall social skill, and increased rates of substance involvement.
- Insight was found not to correlate with quality of life variables or social network variables.
- Ratings of insight differed across race- Individuals of an African-American background were rated showing less insight compared to white-American participants. This could indicate bias among raters (all of whom were white-American, or it could provide evidence for the possibility that in minority communities mental illness is highly stigmatised resulting in a greater denial of mental illness.

A distinction should be made regarding insight into one’s mental illness and acceptance of one’s mental illness. For the purpose of creating and utilising an Advanced Agreement, insight refers only to the individual acknowledging something about them (mentally) is not functioning as well as it should be, by comparison to a normal and culturally appropriate population. Acceptance refers to a deeper level of one’s views about their mental illness where they genuinely accept they have a mental illness and accept they require treatment, as opposed to denial or resignation to the state.
If the consumer is judged to lack acceptance of their diagnosis then it may prove useful to discuss this issue. An assessment of how much it may interfere with treatment management should be conducted. It is also plausible for treatment options to be presented without reference to the diagnosis. For example, rather than disclosing that 'individuals with schizophrenia can benefit from...' this can be rephrased into 'individuals with symptoms similar to yours can benefit from...'

Acceptance issues may also become important if the consumer does not want and/or accept that treatment is required. Consumers may not want the medical treatment offered for a variety of reasons and these reasons should be explored prior to making any preferences.
Appendix G

Pre-AdA Questionnaire for Consumers
THANK YOU for participating in this exciting research project!

This questionnaire has been developed in collaboration with a focus group of Mental Health Consumers.

NAME: ________________________________
PART A

Question 1.

Thinking over the past year, how many times did you become either moderately and/or severely unwell? (You may or may not have been hospitalized)

Please tick the box that best describe your experiences of mental unwellness over the past year.

☐ None

☐ 1 to 3 times

☐ More than 3 times

Question 2.

When you have become moderately or severely unwell, how often have you been able to recognize ‘early warning signs’ that you were becoming unwell?

DEFINITION
‘early warning signs’ are symptoms or situations that indicate you are becoming unwell, such as lack of sleep, stress, feeling down etc.

Please tick the box next to the choice that best represents your answer.

☐ All of the time → go to Question 3

☐ Over half of the time → go to Question 3

☐ Less than half of the time → go to Question 3

☐ None of the time → go to PART B on page 4
Question 3.

When you recognized an early warning sign indicating you were becoming mentally unwell, have you been able to intervene? i.e. were you able to help yourself and/or access help to reduce the early warning sign?

Please tick the box next to the choice that best represents your answer.

☐ Yes → go to question 4

☐ No → go to PART B on page 4

Question 4.

In the past, how often do you think were you able to intervene (even if the intervention did not help)?

☐ Not often → go to question 5

☐ Most of the time→ go to question 5

☐ All of the time→ go to question 5

Question 5.

How effective do you feel the intervention was?

☐ Not effective at all i.e. every time I intervened the early warning signs I would experience a full relapse

☐ Occasionally effective i.e. some of the time when I intervened the early warning signs I would become well again

☐ Commonly effective i.e. most of the time when I intervened the early warning signs I would become well again

☐ Always effective i.e. every time I intervened the early warning signs I would experience a full remission/recovery
PART B

Question 1.

Remembering the last time you became ill and were hospitalised (voluntary or involuntary), were you given a choice about what kind of medication you were prescribed?

Please follow through the diagram and tick the boxes that best represent your answer

During your last hospitalisation were you...

- Involved in the decision regarding your medication
  - Given the medication you would have preferred [ ]
  - Not given the medication you would have preferred [ ]
- Not involved in the decision regarding medication
  - Given the medication you would have preferred [ ]
  - Not given the medication you would have preferred [ ]

Question 2.

From your perspective, how helpful have the following aspects of treating/managing your mental illness been in the past year?

If the aspect relates to you, please place a tick in the box that best describes how helpful that particular aspect has been. If the aspect is not applicable, tick NA box.

- Medication
  - Not Helpful [ ]
  - Somewhat Helpful [ ]
  - Very Helpful [ ]
  - Extremely Helpful [ ]
  - N/A [ ]

- Support from family about my mental illness
  - Not Helpful [ ]
  - Somewhat Helpful [ ]
  - Very Helpful [ ]
  - Extremely Helpful [ ]
  - N/A [ ]
- Support from friends about my mental illness

  ![Rating Scale]

- Education about my mental illness

  ![Rating Scale]

- Making a relapse prevention plan

  ![Rating Scale]

- Staff assistance in the PSU or Calvary or Hyssen Green

  ![Rating Scale]

- Support from my clinical manager

  ![Rating Scale]

- Support from the community

  ![Rating Scale]

- Are there any other aspects that may have contributed towards your recovery over the past year? *Please specify*

  _______________________________________________________
  _______________________________________________________
  _______________________________________________________
Question 3.

On a Scale of 0-100, place a tick in the box that you think best represents how you feel at this current stage of your life:

(a) How **independent** do you feel towards managing your mental illness?

- [ ] Not at all  - [ ] Somewhat  - [ ] Moderately  - [ ] Extremely  - [ ] Completely

(b) How often do you feel in **control** of managing your mental illness?

- [ ] None of the time  - [ ] A little of the time  - [ ] Half of the time  - [ ] Most of the time  - [ ] All of the time

(c) How **motivated** do you feel towards managing your mental illness?

- [ ] Not at all  - [ ] Somewhat  - [ ] Moderately  - [ ] Extremely  - [ ] Completely

(d) How **confident** do you feel with managing your mental illness?

- [ ] Not at all  - [ ] Somewhat  - [ ] Moderately  - [ ] Extremely  - [ ] Completely

(e) How **empowered** do you feel when managing your mental illness?

- [ ] Not at all  - [ ] Somewhat  - [ ] Moderately  - [ ] Extremely  - [ ] Completely

Question 4.

Lastly, could you please briefly describe how you think participating in this Advanced Agreement project may affect your life e.g. daily activities, managing life, relationships, work etc.

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
Appendix H

Pre-AdA Questionnaire for Clinical Managers
ADVANCED AGREEMENT PILOT PROJECT

Questionnaire for clinical managers/rehabilitation coordinators

Name of Clinical Manager: ____________________________

Name of consumer: ________________________________

NB. Please complete a separate form for each consumer you are collaborating with.

PART A

1.0 Have you had any previous experience with helping clients to create Advanced Agreements or similar documents? ]

☐ Yes

Please Specify:

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

☐ No

2.0 How do you think the Advanced Agreement will benefit, or not benefit, your client?

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

3.0 How do you think Advanced Agreement will benefit, or not benefit, yourself?

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________
PART B

On a Scale of 0-100, place a cross along the line where you think best represents where the consumer you are collaborating with fits at this current stage of their life:

(a) How independent do you feel they are towards managing their mental illness?

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<th>75</th>
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(b) How in control of managing their mental illness do you feel they are?

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(c) How motivated do you feel they are towards managing their mental illness?

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(d) How confident do you feel they are with managing their mental illness?

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(e) How empowered do you feel they are with managing their mental illness?

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Appendix I

AdA Semi-structured Interview
ADVANCED AGREEMENT (AdA) SEMI-STRUCTURED INTERVIEW QUESTIONS

Answer as honestly as possible

Feedback for the future use of AdA – so any kind of constructive criticism will be valued
I, the researcher, will not be offended if you have any negative comments as I am more
interested in what are the good things about AdA along with what we can improve

1. Can you briefly describe the reason you decided to create an Advanced Agreement (AdA)?

2. The next few questions ask you about the AdA workbook:
   a) How could the workbook be improved?
   b) What did you like about the workbook?
   c) Were the steps for deciding preferences useful i.e. listing options, weighing
      pros/cons?

3. The next few questions ask about the collaboration between yourself and your clinical/case
   manager:
   a) Did you have more/less/equal input into the AdA compared to your clinical manager?
   b) How satisfied are you with the amount of involvement your CM put in?
      *i.e. Extremely dissatisfied / somewhat dissatisfied / somewhat satisfied / extremely satisfied*
   c) How satisfied are you with the amount of involvement you had?
      *i.e. Extremely dissatisfied / somewhat dissatisfied / somewhat satisfied / extremely satisfied*
   d) Did you and your clinical manager disagree on any issue/s? If so, how where the
      issue/s resolved?

4. Was there enough time given for you to complete your AdA?

5. Did you feel you had adequate information and knowledge to create your AdA? If not, what
   would you have liked to know and/or found helpful?

6. a) What was the most difficult aspect of creating your AdA?
   b) What was the easiest aspect of creating your AdA??
7. Do you feel your AdA adequately represents your treatment preferences? Refer to answer a) OR b)
   a) *If NO* - what are you unhappy with? Can you give me an example?
   b) *If YES* - In what way? How does it make you feel?

8. The next few questions ask whether creating an AdA changed the way you felt towards the management (treatment and care) of your mental illness:
   a) Did your level of independence in managing your mental illness change?
      i.e. More independent / less independent / no change
   b) Did your sense of control in managing your mental illness change?
      i.e. More control / less control / no change
   c) Did you level of motivation to manage your mental illness change?
      i.e. More motivated / less motivated / no change
   d) Did your sense of confidence in managing your mental illness change?
      i.e. More confident / less confident / no change

9. Did you involve any family/friends in developing your AA? If so, how has this helped or not helped?

10. Have you used your AdA yet? i.e. used the relapse plan or preferences. If yes, please briefly describe what you used and how it was useful, or not useful.

11. How do you expect your AdA to benefit, or not benefit, you in the event you become unwell?

12. Would you recommend creating an AdA to other consumers of Mental Health? i.e. No / Yes / Perhaps. Please provide a brief reason for your answer

13. Are there any other comments you would like to make about the general Advanced Agreement process or your individual Advanced Agreement?
Appendix J

CIQ-CM
SURVEY INFORMATION SHEET

Thankyou for taking the time to complete this brief survey!

The survey should take approximately 15 minutes to complete. The aim of the survey is to investigate the concept of consumer involvement, and to help in the understanding of Mental Health (MH) professionals' opinions towards involving consumers and the reality of consumer involvement. This survey is intended to complement the Advanced Agreement pilot project currently being conducted in MHACT.

Consumer involvement refers to service users of Mental Health ACT. Consumer involvement has also been labelled negotiated care, user involvement, collaborative care, and patient participation. The type of involvement ranges along a continuum from passive forms of participation to consumers being active agents within the system.

Active consumer involvement in TCP will be defined as participation that involves the following elements:

- Participating in decision making processes
- Holding a significant amount of control over decisions made e.g. having the final say
- Providing/sharing information
- Expressing views and having them integrated into TCP

This survey will predominantly explore consumer involvement within the treatment and care planning (TCP) aspect of case management. Aspects of a TCP include medication, therapies, counselling, relapse prevention and anticipatory planning.

Your participation is greatly appreciated and will contribute to a greater understanding of the culture, prospect and challenges of involving consumers of MHACT in the services provided.

Should I have any problems or queries about the way in which the study was conducted and I do not feel comfortable contacting the research staff, I am aware that I may contact the ACT Health and Community Care Human Research Ethics Committee Secretary, on (02) 6205 0846

AND/OR

In case of any ethical concerns, please contact the Human Ethics Officer, Research Office, The Australian National University, ACT, 0200 Telephone: 6125-7945. Fax: 6125-4807.
Email: Human.Ethics Officer@anu.edu.au

In case of any questions or concerns regarding this survey, please contact Bronwyn Wauchope T: 0417 417 632
Demographic Details

1. Profession

<table>
<thead>
<tr>
<th>Please Tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologist</td>
</tr>
<tr>
<td>Rehabilitation Coordinator</td>
</tr>
<tr>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Registered Nurse</td>
</tr>
<tr>
<td>Psychiatrist</td>
</tr>
<tr>
<td>GP</td>
</tr>
<tr>
<td>Social Worker</td>
</tr>
<tr>
<td>Student</td>
</tr>
</tbody>
</table>

Other (please Specify)

2a) Are you a case/clinical manager or rehabilitation co-ordinator? Yes  No

2b) Number of consumers you are currently case managing: ________

2c) Average/usual caseload (If different to current caseload): ________

2d) Approximately how many consumers/clients do you have in the following categories?

<table>
<thead>
<tr>
<th>Extremely Unwell</th>
<th>Moderately unwell</th>
<th>Slightly unwell</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.g. Chronic and/or Currently in hospital</td>
<td></td>
<td>E.g. managed well in community</td>
</tr>
</tbody>
</table>

3a) approximately how long have you worked in your profession? ________

3b) approximately how long have you been working for MHACT? ________

Please Note: Each page is DOUBLE SIDED and there are 6 sections to complete

Thank You!
Section 1
Please complete this section by placing a tick under the appropriate answer

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does your service routinely conduct consumer satisfaction surveys on the services it offers?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. (a) Does your service have a complaints procedure for consumers?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. (b) Is it simple to use – i.e. is it in plain language, and are the steps or procedures user-friendly?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Does your service ask for consumer input for the planning of mental health services?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Do consumers participate in the provision of mental health services?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Are consumers involved in the hiring decisions of your agency’s staff?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Are consumers invited to participate in staff training meetings at your service?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Has your service ever asked clients to act as teachers at staff training events?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Additional Comments:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Section 2 – Please read the front page information sheet for a definition of active involvement

Thinking about your service generally,

(a) How often are consumers actively involved in the diagnosis of their presenting problem/s?

All of the time  most of the time  some of the time  none of the time
☐    ☐    ☐    ☐

(b) How often are consumers actively involved in the planning and/or administering of treatment/s?

All of the time  most of the time  some of the time  none of the time
☐    ☐    ☐    ☐
(c) How important do you believe it is to actively involve consumers in the decision-making processes and planning for following aspects of treatment and care planning?

<table>
<thead>
<tr>
<th></th>
<th>Not important</th>
<th>Somewhat Important</th>
<th>Extremely important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapse prevention</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anticipatory planning, such as Advanced Agreements</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(e) Under your current caseload, please state approximately how many consumers are actively involved in the following aspects of treatment and care planning. Where an aspect is not applicable to any of your clients please tick N/A

<table>
<thead>
<tr>
<th>My Current case load</th>
<th>N/A</th>
<th>None</th>
<th>Some</th>
<th>Most</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
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<td></td>
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<tr>
<td>Medication</td>
<td></td>
<td></td>
<td></td>
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<td>Relapse prevention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anticipatory planning, such as Advanced Agreements</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Additional Comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
### Section 3
Read each statement carefully and state how much you agree/disagree with the following statements by placing a tick under the appropriate answer.

<table>
<thead>
<tr>
<th></th>
<th>SD</th>
<th>D</th>
<th>N</th>
<th>A</th>
<th>SA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

1. Individuals with mental illness are experts with invaluable experience to contribute to Treatment and Care Planning (TCP)

2. Consumer involvement is a priority in my line of work

3. Mental illness can be successfully diagnosed and treated by mental health professionals without consumer involvement

4. Consumers have the skills to actively participate in TCP

5. Mental illness decreases consumers’ motivation levels to participate in TCP

6. Consumers make realistic and useful contributions to TCP

7. Professional judgment and competence is being questioned by involving consumers in TCP

8. Mental illness distorts consumers’ opinions regarding treatment

9. Facilitating patient choice is the primary objective in TCP

10. If a consumer does not agree with a professional suggestion for treatment, then they are most likely in denial, lacking insight, and/or irrational

11. Consumers who are mature and broadminded are more suitable to participate than consumers who are more difficult to work with

12. Individuals with mental illness do not have the knowledge to participate in TCP

13. Involving consumers is a form of ‘tokenism’

14. Consumers who can easily articulate their views are more suitable for involvement than consumers who find their views difficult to articulate.

15. It is too difficult and/or time consuming to actively involve consumers in decisions for their TCP

16. Consumers are capable of being involved in decision-making for TCP

17. Mental health professionals are not criticized by their colleagues for
This section lists possible outcomes that could be influenced by involving consumers in treatment and care planning (TCP). Rate each one according to how you believe it will be influenced.

<table>
<thead>
<tr>
<th>Strongly Decrease</th>
<th>Decrease</th>
<th>No Change</th>
<th>Increase</th>
<th>Strongly Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Do you believe actively involving consumers in treatment and care planning will increase or decrease:

1. A consumer’s level of dependence on MH professionals
2. Staffs work efficiency
3. Staff responsiveness to clients needs
4. Stress levels with Staff
5. A consumer’s sense of empowerment
6. Adherence to treatment and care plans
7. Frequency of disagreements between consumer and staff
8. A consumer’s perception of treatment choices
9. A consumer’s motivation levels
10. The quality of the therapeutic relationship
11. A consumer’s sense of control
12. Service efficiency
13. Frequency of hospitalizations
14. Staff tolerance of consumers opinions/views
15. A Consumers perceptions of coercive treatment

Scoring for sub-scales:
Intrapersonal (Item # 5, 6, 8, 9, 11; Reverse # 1, 15)
Interpersonal (Item # 3, 1, 14; Reverse # 7)
Section 5
The following is a list of factors considered important for consumer involvement (CI) to work effectively in the MH system.
Please indicate whether your workplace provides the factors listed, and if so, whether you believe they are adequate or need to be improved.

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
<th>Don’t Know</th>
<th>Adequate</th>
<th>Improve</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff Support for CI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial resources for CI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specific strategies for CI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clear outcomes for CI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education on CI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section 6
Advanced Agreements are a document that allow consumers to formally record their preferences for future treatment and care in the event they become unwell and display a reduced competence to be actively involved in treatment and care planning.

(a) How much do you know about Advanced Agreements?

Nothing  | A little  | A moderate amount | A lot
☐        | ☐         | ☐                  | ☐

(b) In your line of work, what level of priority would you give Advanced Agreements?

Low  | Medium  | High  | Don’t Know
☐   | ☐       | ☐     | ☐

(c) How beneficial do you think Advanced Agreements are, or would be in MH practice?

Not at all  | Somewhat  | Moderately  | Extremely
☐         | ☐         | ☐           | ☐

(d) To what degree do you think Advanced Agreements are currently being utilized in the service?

Not at all  | A little  | A moderate amount | A lot
☐         | ☐         | ☐              | ☐

Comments and suggestions:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
Appendix K

Letters of ethics approval
Ms Bronwyn Wauchope  
Postgraduate Student,  
School of Psychology  
Faculty of Science  
The Australian National University  ACT 0200

Dear Ms Wauchope,

Protocol 2003/247  
An evaluation of Advanced Agreements Created by ACT Mental Health Consumers

On behalf of the Human Research Ethics Committee I am pleased to advise that the above protocol has been approved as per the attached Outcome of Consideration of Protocol.

For your information:
1. Under the NHMRC/AVCC National Statement on Ethical Conduct in Research Involving Humans we are required to follow up research that we have approved. Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research and whether it proceeded according to the plan outlined in the above protocol.
2. Please notify the Committee of any changes to your protocol in the course of your research, and when you complete or cease working on this project.
3. The validity of this current approval is five years' maximum from the date shown on the attached Outcome of Consideration of Protocol form. For longer projects you are required to seek renewed approval from the Committee.

Yours sincerely,

Sylvia Deutsch  
Secretary, Human Research Ethics Committee
Ms Bronwyn Wauchope  
ANU School of Psychology  
Building 30, ANU  
ANU CANBERRA 0200

Dear Ms Wauchope

Thank you for your email of 20 April 2004, addressing concerns raised by the Committee about the proposed study ‘An Evaluation of Advanced Agreements Created by Mental Health ACT Consumers’. Ethics Committee Submission No ETH.10/03.433 refers.

I am pleased to advise you that the study has received out of session approval, including the Patient Information Sheet, Consent Form (Consumer/Participant), Consent Form (Manager/Participant) and Questionnaires.

I attach for your records an Outcome of Consideration of Protocol form.

You may recall that the ACT Health and Community Care Guidelines for Submission of Application require you to complete payment of the levy when approved by the Ethics Committee.

Please forward $27.50 levy fee to the Secretariat, ACT Health and Community Care Human Research Ethics Committee, GPO Box 825, Canberra ACT 2601 as soon as possible. An invoice is attached for your attention.

Yours sincerely

[Signature]

Elizabeth Grant AM  
Chair  
Ethics Committee

20 April 2004

cc: Ms Linette Bone  
Ms Amanda Urbanc  
Dr Richard O’Kearney
16 March 2005

Ms Bronwyn Wauchope  
Postgraduate Student,  
School of Psychology  
Faculty of Science  
The Australian National University  
ACT 0200

Dear Ms Wauchope,

Protocol 2003/247
An evaluation of Advanced Agreements Created by ACT Mental Health Consumers  
Variation: Adding a new survey to the protocol

I am pleased to advise that the above variation to the above protocol, as described in your letter to me of 4 March 2005, has been approved by the Chair of the Human Research Ethics Committee Prof Lawrence Cram. The approval of the variation will routinely be reported to the Committee at its next meeting.

Please do not hesitate to contact me if you have any queries.

Yours sincerely

[Signature]

Yolanda Shave  
Secretary, Human Research Ethics Committee
Ms Bronwyn Wauchope  
School of Psychology  
Building 39  
Australian National University  
ANU  0200

Dear Ms Wauchope

Thank for your letter of 6 May 2005, addressing concerns previously raised by the ACT Health and Community Care Human Research Ethics Committee about the ‘ACT Mental Health Evaluation of Advanced Agreements Created by ACT Mental Health Consumers Survey’. Ethics Committee Submission No ETH.10/03.433 refers.

The Committee considered and approved the Survey Information Sheet and Survey at the meeting held on 9 May 2005.

Yours sincerely

Elizabeth Grant AM, Hon LLD Monash  
Chair  
Ethics Committee  

20 May 2005