Caring for someone with depression:  
Attitudes and clinical practices of  
Australian mental health clinicians

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Declaration

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4. The work in this thesis was carried out under the supervision of Ms Katie McGill, Clinical Psychologist and Program Manager at the Hunter Institute of Mental Health; Associate Professor Jenny Bowman within the School of Psychology, The University of Newcastle; and Dr Peter Kelly, University of Wollongong.

3. The conduct of this research was approved by the Hunter New England Human Research Ethics Committee and the University of Newcastle Human Research Ethics Committee (approval number 10/11/17/5.08).

Signed:............................................ Date:.........................
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Structured Abstract

**Background:** Family members and carers who support a person with depression are faced with specific challenges and are often significantly burdened as a result of the role. They report being dissatisfied with the inclusivity of, and support provided by, clinicians. There has been limited Australian research in this area and this is the first study to look at clinicians’ perspectives on providing support to family members and carers of people with depression in Australia. **Method:** One hundred and nineteen Australian mental health clinicians were surveyed regarding their attitudes towards and current clinical practices with family members and carers of people with depression. Participants comprised mental health clinicians who identified their primary client group as mental health consumers or family members and carers. Recruitment occurred via invitation to clinicians who attended training specific to providing support to family members and carers of people with depression (*Partners in Depression* (PID) program training) and clinicians who had not attended this training. Recruitment of these groups enabled comparisons to be made between groups to identify whether primary client group or training was related to differences in attitudes, perception of barriers or reported clinical practice. **Results:** Results indicated that the attitudes of clinicians towards family members and carers were generally positive, while the level of inclusive practice reported was variable. Providing family members and carers with an orientation to services and information on how to respond in crisis situations were two of the most frequently reported interventions. The sample identified a number of barriers to inclusive practice. Barriers were predominantly organisational in nature rather than clinician specific. Those who perceived more barriers also reported providing more clinical interventions to family members and carers of people with depression. In contrast, there was no relationship between reported attitudes and perceived barriers. While attitudes and barriers did not predict the inclusive clinical practice of those who worked directly with carers, there
was a significant relationship between perceived barriers and inclusive clinical practice for those who worked directly with family members and carers. **Conclusions:** It appears that in order for inclusive practice to occur more consistently there is a need for major organisational and systematic reform. Further research is necessary to explore the reasons why family members and carers are not routinely included in the care and treatment process for people with depression.
THESIS OVERVIEW

This thesis explores the attitudes of, perceived barriers to and actual clinical practices of Australian mental health clinicians supporting those who care for a person with depression. The first section provides an overview of the literature and evidence available about this topic. It also outlines the significance and aims of the study that was conducted to further investigate this topic. The second section of the thesis comprises a manuscript that describes the study and its findings. This manuscript was submitted to the Australian Journal of Psychology in June, 2012. It was accepted pending revisions, however due to external factors the requested changes were not able to be completed within the timeframe. The authors are now in the process of submitting the manuscript to other journals for publication consideration. The third section of the manuscript comprises an extended discussion which allows for further exploration and consideration of the results.
1. CRITICAL LITERATURE REVIEW

Depression affects many Australians and has far reaching consequences on family members and carers of those with the illness. It is important to look at the degree to which those caring for someone with depression are supported and whether clinicians are aware of the impact of the caring role. The study described in this thesis investigates the attitudes and clinical practices of Australian mental health clinicians towards supporting family members and carers of people with depression. It also considers the barriers that may hinder collaboration and inclusive practice. This critical review summarises the current relevant literature and limitations of the available evidence base. A brief overview of depression is provided, followed by a consideration of the issues relevant to caring for a person with a mental illness, and depression specifically. The role of inclusive practice and how it pertains to government practice is summarised and the evidence regarding current practices of clinicians in supporting carers of people with mental illness, as well as attitudes and barriers to inclusive practice are considered. Finally, a summary of the literature and the aims and broad approach of the current study are outlined.

1.1 Depression

1.1.1. A common mental illness

Depression is a prevalent mental health disorder in Australia and is one of the leading contributors to the total burden of disease (Begg, Vos, Barker, Stevenson, Stanley, Lopez, 2007; Slade, Johnston, Oakley Browne, Andrews, Whiteford, 2009). It tends to be recurrent in nature and affects people of all ages and socioeconomic backgrounds. In 2007, the National Mental Health and Well Being Survey identified that six percent of people aged between 16 and 85 years in Australia had experienced an Affective Disorder in the previous
twelve months with depression being the most common disorder (4% of those with an affective disorder). Women experience a higher rate of depression than men (5.1% compared with 3.1%) (ABS, 2007). While there is not one single cause for depression, there are factors that can increase an individual’s vulnerability. These include biological factors (family history), personality, social and environmental factors. Chronic stress and physical illness are also known to precipitate depression, and depression is a significant risk factor for suicide (ABS, 2007; RANZCP, 2009). The Australian Bureau of Statistics (ABS, 2007) indicates that almost three quarters (72%) of those who had reported suicidal ideation in the 12 months prior to their survey interview had a mental health disorder that lasted for at least a 12 month period. The ongoing and recurring nature of depression means it is important to identify the factors that help people stay well.

1.1.2. Lack of community awareness/understanding of depression

Despite depression being prevalent in Australia, it is not well recognised or understood by the public (Hight, Hickie & Davenport, 2002; McNair, Hight, Hickie & Davenport, 2002). Using public meetings to raise awareness about depression, McNair et al., (2002) recruited over 1500 Australians and found that depression was often still perceived as a personal inadequacy and rarely identified as an illness. Similarly, in another large scale Australian study, Hight et al., (2002) found that depression was not recognised as a general health issue and that participants had limited specific knowledge about depression and its associated treatment options. This corroborated McNair et al.’s (2002) findings that when a loved one has depression, their family may not have a good understanding of the course or prognosis of the illness and may interpret them as being “lazy” or “a whinger”. Further, using focus groups, Hight, Thompson & McNair (2005) found that family members and carers of
people with depression had often found it difficult to recognise depression in the person they were supporting.

This lack of community understanding can result in depression being minimised, and people not seeking appropriate treatment (McNair et al., 2002). It is estimated that up to half of those experiencing depression are reluctant to seek help from clinicians (Jorm, Medway, Horten, Jacomb, Rodgers, 2000). Further, in a national Australian survey conducted by beyondblue (n=881), when individuals were asked who they would consult in the event that they thought they were depressed they responded as follows: 45% indicated they would consult family, 28% indicated they would consult a GP and 15% indicated they would consult friends (Highet et al., 2002). With a number of individuals not being appropriately treated and the shift to community support for people with a mental illness, it seems inevitable that families provide the vast majority of the care and support for these individuals. This has resulted in family and friends facing a range of challenging and complex situations which they may not have experienced before and which have the potential to significantly impact on their own mental health and wellbeing.

1.2. Carers and Family Members

1.2.1. Definition of carers, consumers and clinicians

There is a lack of consensus regarding the definition of what constitutes “a carer”. Carers Australia (the peak national organisation representing carers in Australia) define carers as those who “provide unpaid care and support to family members and friends who have either a disability, mental illness, chronic condition, terminal illness or who are frail” (Carers Australia, n.d). One of the core components to being identified as a “carer” is the act of providing support to a person who is experiencing a condition that negatively affects their
functioning in some way. For the purposes of this study, carers will be defined as those providing unpaid care and support to a person with depression. They will be referred to as “family members or carers”. The person diagnosed with depression will be referred to as the “consumer” or “loved one”. The term clinician refers to all health professionals and includes those working with carers and consumers.

1.2.2. Identifying as a carer

It should be acknowledged that the issue of defining and recognising carers is further complicated by a lack of self-identification. Many people do not identify themselves as carers even when they meet the criteria provided by the above definition (Gray, Robinson, Seddon, Roberts, 2009). This may be because they feel they do not do “enough” to be identified as a carer or because they may be concerned about judgements made about the role. Many also indicate that they often find it difficult to know when or how the role of spouse, parent or sibling ends and where the “carer” role starts (Muscroft & Bowl, 2000). Thus, it is important to acknowledge that there may be many people who are ‘carers’ but who do not realise it. This lack of self identification may prevent clinicians from identifying carers and providing appropriate support.

1.2.3. The caregiving role

Carers perform an integral role in supporting those with mental illness in the community (Kim & Salyers, 2008; Heru, 2004). However, caregiving can take a toll and many carers report feeling isolated and experience challenges in adjusting to the role (Gray, Robinson, Seddon, Roberts, 2010; Heru, 2004; Stjernsward & Ostman, 2008; van Wijngaarden, Schene, Koeter, 2004). Carers often provide daily support, including transportation, financial management, attending medical appointments and emotional support.
Carers of people with a mental illness also face specific challenges. Stigma and social attitudes towards mental illness can further isolate carers and prevent them from accessing support for themselves (Gray et al., 2010; McNair et al., 2002; Stjernsward & Ostman, 2008).

Improving a consumer’s current mental state is usually the primary concern of clinicians, however, family members and carers may have additional concerns. The emotional investment and relationship with their loved one can mean that they are concerned about broader life issues, such as their loved one’s future, how long they can continue in a caregiver role, the future and relationships within the family (van de Bovenkamp & Trappenburg, 2010). They may also grieve the loss of their loved one as they adjust to what the meaning of depression has for them and their family (Gray et al., 2010; Highet et al., 2004, van de Bovenkamp & Trappenburg, 2010).

In addition to the day to day support provided, it can be difficult for a carer to understand the diagnosis, symptomatology and prognosis of a loved one’s mental illness (Gray et al., 2009). They can be left feeling confused and ill equipped (Gray et al., 2008, Gray et al., 2010). Lack of information for carers can also lead to a lost opportunity for carers to learn how they can best support their loved one (Wynaden & Orb, 2005).

Thus, those supporting a person with mental illness (including depression) provide a variety of important supports, but also face many challenges. The impact of this role on their wellbeing is reviewed below.
1.2.4. Caregiving burden

The existence of carer burden has been well established (Coyne, 1987; Doormbos 2002, Heru, 2004; Jones, 1996; Ostman & Hannson, 2001; Stjernsward & Ostman 2008). Caregiving burden refers to the physical and emotional difficulty that is experienced by those who care for a person with an ongoing illness or condition (Martens & Addington 2001). It has been established that the level of caregiving burden can be predictive of carers’ own mental health (Coyne et al., 1987; Steele, Maruvama & Galynker, 2010). It is also established that caregiver burden increases with severity of symptoms and acuity of illness (Friedman 1987). The specific nature of the caregiving burden as relevant to providing support to a person with depression is reviewed below.

1.3. Depression and Carers’ Burden

Thus far, a short overview has been provided of the challenges faced by carers of people with mental illness. To date, the challenges faced specifically by carers of people with depression have been less well investigated. This may be due to depression not being viewed as being as severe as other mental health disorders (Highet et al., 2005; McNair et al., 2002). However, current evidence suggests that the burden of caring for a person with depression is comparative to caring for a person with another psychiatric illness (Heru, 2004; van Wijngaarden et al., 2004). As depression is also a prevalent disorder, it is important to investigate this further.

Research shows that depression affects the individual who is diagnosed as well as their wider support network (Benazon & Coyne, 2000; Coyne 1987; Jeglic et al., 2005). Coyne et al., (1987) was one of the first people to investigate the impact of living with a loved one with depression. A sample of 42 carers were accessed through the Psychiatry
Department from the University of Michigan. They found that participants rated a number of items as contributing to the experience of burden when their loved one was unwell. These included, their loved one’s lack of energy, the emotional strain on the carer, the possibility that their loved one would become depressed again and their loved one’s feelings of worthlessness, lack of interest in doing things and worry. They found that 40% of their sample were sufficiently distressed enough to meet the criteria for psychological intervention. However, even when a person with depression was not experiencing a current episode of depression, reported burden was still associated with emotional strain, worry that they may become depressed again and the consumer’s feelings of worthlessness.

In Australia, Highet, McNair, Davenport and Hickie, (2004) conducted twelve focus groups (n=37) with people caring for a person with depression. These focus groups occurred nationally and took place over five months. Participants spoke about how caring for a loved one with depression had an intense and persistent impact on their life. They reported feeling ill prepared, unsupported by the healthcare system and left to grieve the ‘loss’ of their loved one in isolation. One participant was quoted as saying “This was not the person I married 4 years ago…. He is just a shadow of who he was, and that is sad” (Highet et al., 2004 p.s8). They also reported experiencing, as a result of the depression, reductions in earning capacity and income, restricted leisure activities, difficulties maintaining employment and marital and intimacy problems.

Jeglic et al., (2005) explored whether depression was “contagious” and tested a caregiving model of depression in spouses. They interviewed 31 married couples recruited from primary care settings in America where one spouse had a clinical diagnosis of depression. They used the Structured Clinical Interview of Diagnoses and the Caregiving
Burden Scale to determine whether spouses caring for a loved one with depression met clinical criteria for depression, as well as assessing the level of caregiver burden. They found that the consumer’s depression level was significantly correlated with the spouse’s depression level and the reported subjective carer burden. When looking at the association between depressive symptoms and the spouse’s depressive symptoms, the relationship was completely mediated by the spouses’ perceived level of caregiving stress; such that those who reported higher subjective stress and burden also reported experiencing more depressive symptoms themselves.

When looking specifically at carers’ burden for those supporting a loved one with depression, Stjernsward and Ostman’s (2008) results were also consistent with previous research. They recruited carers in Sweden and used focus groups and individual interviews to explore carers’ experience of the impact of the depression on their lives. Their sample of carers did not feel they were taken seriously by professionals. They spoke of not living their “own lives” and feeling that they had had difficulty adapting to the role and had been required to re-evaluate their current circumstances as a result of their loved one’s illness.

This body of research highlights the caregiving burden experienced by those who support a person with depression and suggests that they are vulnerable to developing mental health problems themselves (Baronet, 1999; Benazon & Coyne, 2000; Doornbos, 2002; Highect et al., 2005; Jeglic et al., 2005; van de Bovenkamp & Trappenburg, 2010; Wijngaarden et al., 2004). Thus, it is important for the health of carers that they are well supported by services and clinicians (Thomas, Guy, Ogilvie, 1999). By better supporting carers of people with depression, not only would carers’ quality of life improve, but it is likely that their resilience would also increase, possibly reducing carer burnout (Dixon,
Carer burnout is important to consider because if families and carers are unable to provide support to their loved ones, more pressure is placed on the mental health system, both in looking after those with depression and in addressing any associated health problems experienced by the carers themselves.

1.4. What Are The Benefits of Inclusive Practice?

Inclusive practice refers to collaboration between service providers and family members and carers in the assessment, care planning and treatment of people with a mental illness (National Mental Health Strategy, 2010). It has benefits for consumers and carers (Barrouclough, Tarrier, Lewis, Sellwood, Mainwaring, Quinn, & Hamlin, 1999; Dixon et al., 2001; McFarlane Dixon, Lukens, Luckstead, 2003). Inclusive practice has been associated with reduced rates of relapse and hospitalisation, while family involvement in treatment has also been associated with consumers more reliably using their medication, having improved social functioning, increased employment, improved community involvement and relationships within the family (Dixon et al., 2001; Parker et al., 2010; van de Bovenkamp & Trappenburg, 2010). Inclusive practice would also appear to be likely to have benefits for carers by creating opportunities where carers can be provided with more direct support, which may help to reduce carer burn out (van de Bovenkamp & Trappenburg, 2010).

Carer inclusive practice can be argued to represent best practice. It also now emphasised in government mental health policy.
1.5. Government Policy regarding the Involvement of Family Members and Carers

The National Enquiry into the Human Rights of People with Mental Illness (1993) aimed to report on the incidence of mental illness and the laws and provision that guide this sector in Australia. The report was based on extensive research in the field, public hearings in states and territories in Australia and written and oral information provided by over 1300 witnesses. It reported on the stigma associated with mental illness, for both consumers and carers. It also reported on the shift in care of those with a mental illness from inpatient settings to community treatment. It spoke of the necessary role of carers, the ongoing stress associated with this role and the common exclusion of them in the treatment of mental health consumers.

Both Federal and State Governments have reviewed relevant government policies regarding carers, their needs and involvement with mental health services. The key aspects of these policies as relevant to family members and carers are outlined in Table 1. In summary, these policies and legislation create an obligation for services to increase their responsiveness and the support provided to carers.

While government is mandating the involvement of carers through public mental health care services, there is also a small system of non-government organisations that aim to directly support family members and carers. Some of the relevant organisations include Carers Australia and the Association for Relatives and Friends of those with a Mental Illness (ARAFMI). Other organisations have engaged in carer specific initiatives. For example, both the Royal Australian and New Zealand College of Psychiatrists (RANZCP, 2009) and beyondblue (2010) have developed guidelines for family members, carers and consumers to
assist with navigation of the health system and in understanding depression and associated treatments. *Carers NSW* have developed the Carer Life Course Framework to assist both carers and clinicians in ensuring that carers receive appropriate information and support over their caring journey (Carers Australia: Carers Lifecourse n.d.; Pagnini, 2005). More recently, the *Partners in Depression (PID)* program was developed. It is a group education program for those who care for a person with depression. With funding from the *nib foundation*, Hunter Institute of Mental Health have engaged in a national dissemination of the program. This initiative has involved providing free training in the program to 400 clinicians across Australia with the agreement that they would then deliver the program in their local community.

Thus, there is increasing interest in providing support to carers of people with mental illness and the policy changes create a mandate for services to consider how to involve and address the needs of carers of people with mental illness.

**Table 1:** Government policy pertaining to the inclusion of carers and family members when working with mental health consumers

<table>
<thead>
<tr>
<th>Policy</th>
<th>Directive</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Consumer and Carer Participation Policy (National Consumer and Carer Forum 2004)</td>
<td>Outlines the core principles of involving family members, carers and consumers in the assessment and treatment of those with a mental illness. It states “consumer and carer participation is essential if improvements in service delivery are to be activated” (p. 6).</td>
</tr>
<tr>
<td>NSW Mental Health Act (2007)</td>
<td>Consumers to identify a primary carer. This has been done in an attempt to minimise the confusion as to how much information can be shared with family members and carers.</td>
</tr>
<tr>
<td>National Mental Health Policy (2008)</td>
<td>Acknowledged the crucial role of carers in prevention, early intervention, treatment and recovery” for those with mental illness (p.21).</td>
</tr>
<tr>
<td>National Standards for Mental Health Policy (2010) – Standard 3</td>
<td>Outlined the importance of consumer and carer participation It specified that carers should be acknowledged and respected and provided with appropriate support to enable them to fulfil their role.</td>
</tr>
</tbody>
</table>
1.6. What Do Carers Want From Service Providers?

While carer inclusive practice is recognised as representing best practice, there is only limited evidence available about the degree to which it is occurring “on the ground”. Family members and carers’ experience of the support provided by mental health services is one way of understanding the degree to which inclusive practice is routine. What they want from service providers is also a way of understanding how carer needs could be met within the framework of inclusive practice.

1.6.1. International studies

Family members and carers of people with a mental illness consistently report being dissatisfied with the support provided by mental health services (Doornbos, 2002; Lammers & Happell, 2004; Marshall & Solomon, 2000; Thomas et al., 1999; van de Bovenkamp & Trappenburg 2010). Qualitative studies in America, the United Kingdom and the Netherlands, highlight that carers want to feel heard and understood, be shown respect, have their difficulties understood, be validated and taken seriously (Doornbos, 2002; National Mental Health Consumer and Carer Forum, 2004, van de Bovenkamp & Trappenburg, 2010; Walker & Dewar 2001). Carers have also indicated that they would benefit from reassurance that they are not the cause of their loved one’s illness, and, further to this, encouragement to continue in their role (Doornbos, 2002). In particular it has been identified that they are not satisfied with the amount of communication and input they have with clinicians (Marshall & Solomon, 2000; Thomas et al., 1999; van de Bovenkamp & Trappenburg, 2010).

With regard to providing support to a person with depression, family members and carers have indicated the need for information on the course and prognosis of depression,
training in the skills and language to use, and advice on the ways in which to manage symptoms of the depression (Hight et al., 2005).

1.6.2. Australian studies

These issues are also apparent in Australia, although specific research investigating this issue is limited. Lammers and Happell (2004) investigated consumers’ and carers’ perceived level of their participation in the mental health system. They used focus groups to determine the level of collaboration between consumers, carers and clinicians. The carers unanimously stated that their involvement with mental health services had been minimal. They continued to feel excluded and isolated. They indicated that clinicians would respond in times of crisis, but not without significant prompting from carers. Confidentiality and communication issues were also identified, with the carers feeling that they routinely shared information with professionals but that this information exchange was rarely reciprocated. It did not appear that policy changes had assisted to facilitate change to clinical practice. More specifically, family members and carers of those with depression have also identified the importance of support groups and being referred on to agencies that assist in addressing their own needs (Hight et al., 2004).

1.7. Attitudes, Barriers and Engagement in Carer Inclusive Practice

1.7.1. What are the current inclusive practices of clinicians?

These studies suggest that carers and family members of people with mental illness are generally not included in the assessment and treatment process for the person they are supporting and their own individual needs are largely unmet. It is, however, useful to review the evidence regarding clinicians’ reports about their practice and involvement of carers or family members of people with mental illness.
In general, it appears that there is a wide variation in the degree to which clinicians engage in carer inclusive practice (Goodwin & Happell, 2007a; Marshall & Solomon 2000, 2004). Studies have found that some mental health providers work collaboratively with carers and family members (Beecher, 2009; Kim & Salyers, 2008; Wright, 1997). This may involve sharing of non-confidential information about mental illness, medication side effects, explanations of treatment approaches, discussion of coping strategies and referral on to other more specific services for carers’ needs (Gray et al., 2008). In contrast, other studies have found that service providers have more limited contact and may provide only one of the above mentioned services (Kim & Salyers 2008, Marshall & Solomon 2004). Other research has found a complete absence of providing support or inclusion to families of people with mental illness (Kaas, Lee & Peitzman, 2003). Thus, while legislation and policy has directed clinicians to work collaboratively with families and carers, it would appear that there may be a gap between the theory and practice (Kaas et al., 2003; Kim & Salyers, 2008; Marshall & Solomon, 2000, 2004). Details of the most relevant studies investigating carer inclusive practice are reviewed below.

Marshall and Solomon (2004) examined the nature and frequency of contact provided by mental health professionals for families of those with a mental illness in America. They recruited clinicians from six community mental health agencies that primarily offered outpatient services. Their participants completed a self-administered survey. Of their sample, 85% (n= 92) of professionals indicated that they had never had contact with families or carers of their clients. For those that did have contact with families and carers, it was reported as being infrequent. Contact with families was viewed as being the role of the case manager and case managers indicated that contact was primarily in response to a crisis.
Kim and Salyers (2008) were interested in mental health clinicians’ attitudes and clinical practices towards carers of people with severe psychiatric illness. They recruited a large sample of 453 participants from community mental health settings in America. Data from participants was collected through a questionnaire. A third of the sample reported that they had had contact with family members and carers, but this contact was reported to be infrequent. The most frequently provided services to families included providing emotional support, practical advice on how to support their loved ones in specific situations and providing information on mental illness generally. Activities engaged in less often included family therapy, teaching identification of early warning signs, inclusion of families in treatment planning, teaching methods for monitoring medication and referral of families on to support groups. Despite the low frequency of carer inclusive practice, they found that 31% of staff surveyed believed that carers were very satisfied and 53% believed that they were somewhat satisfied. The authors proposed that the perception of satisfaction with the service may have accounted for the low frequency with which the clinicians were engaging in inclusive practice.

Kim and Salyers (2008) also found that their sample of clinicians agreed that inclusive practice could have a positive impact on the prognosis of the client, that education for families on mental illness was needed and that sharing of general information was not a breach of confidentiality. This is a particularly interesting finding in light of carers consistently reporting that they are infrequently given information about the progress of their loved one (Doornbos, 2002; Marshall & Solomon, 2000; Ostman & Hansson, 2001; Thomas et al., 1999; van de Bovenkamp & Trappenburg 2010). While Kim and Salyers recruited a large number of clinicians and looked at attitudes, perceived barriers and clinical practices of clinicians, it is not known the degree to which their findings may be generalizable to the
Australian context. Further, like most studies done in this area, there was a focus on the support provided to carers and family members of people with mental illness and it is not known the degree to which this is similar or different to the support provided to carers and family members of people with depression. Finally, whilst recruitment of participants from the same health service is helpful in increasing power, it is possible that there may have been greater diversity of practice across the health service system occurring than was captured from focusing on one service or sector.

In short, the clinical practices of clinicians with carers in Australia are yet to be determined. To date there has only been a small amount of research investigating the attitudes and barriers of clinicians when working with carers. In the research that has been conducted overseas participants have generally been asked to consider their usual clinical practice and respond broadly with what they have usually done. Participants have not been asked to consider specific clients and report on actual practice. Further, studies to date have looked at support provided to family members and carers of people with mental illness generally, rather than depression specifically. In light of the prevalence of depression, it is important to have a better understanding about the support provided to carers and family members of people with depression. Finally, previous studies have also generally not considered what factors may determine whether inclusive practice is engaged in or not.

1.7.2. What are the attitudes of clinicians towards carers?

Attitudes of clinicians towards family members and carers may influence whether they engage in carer inclusive practice (Goodwin & Happell, 2007a, 2007b). Clinicians have been described as being patronising and unwilling to include carers (Lammers & Happell, 2004). However, it would appear that mental health professionals’ attitudes towards carers
vary from quite negative to positive. Some agree that inclusive practice can have a positive outcome on client outcomes, while others believe inclusive practice can either be unnecessary or negative (Goodwin & Happell, 2007a, 2007b Gray et al., 2008, 2010; Kaas et al., 2003, Kim & Salyers, 2008). Some professionals believe that there is not enough evidence to support the benefits of inclusive practice or do not see it as being part of their clinical role when working with clients (Kaas et al., 2003; Marshall & Solomon 2004).

Kim and Salyers (2008) found that their sample’s attitudes towards working with carers of people with mental illness were largely positive. The sample did not report seeing family involvement as harmful and generally saw families as being cooperative. However, they also believed that carers and, at times, families had unrealistic expectations about the client’s progress. In contrast, Thomas et al. (1999) and Wright (1997) suggested that carers were purely viewed as an information gathering source and when this was complete, the carers’ needs were largely ignored. In summary, this research tends to support the current feelings of carers, that services will use carers when they are helpful but do not take into consideration their needs or provide support accordingly (Goowdin & Happell, 2006; Marshall & Solomon, 2000; van de Bovenkamp & Trappenburg, 2010).

In another study, Gray et al., (2009) interviewed 65 clinicians who were working in the United Kingdom in both paid and voluntary roles. The authors were interested in finding out more about clinicians’ opinions about those caring for a loved one with a mental illness. Overall, they found that clinicians regarded the carer experience as being challenging and difficult. Clinicians appeared to have a good understanding of what carers experienced (e.g. feelings of guilt, psychosocial isolation and stigma) and recognised the need for a period of adjustment in taking on the role and the worry associated with not being able to continue on
in the caring role. However, they also found that 14 out of the 65 clinicians interviewed had not heard of carer assessments and were unaware that inclusion of carers was a directive from their health policy. Even though these participants were aware of the needs of family members and carers, they were not aware of relevant policy. Further, while this research investigated the attitudes and opinions of clinicians about carers of people with mental illness, it did not consider what the barriers were to engaging in inclusive practice with carers and how this may influence practice.

In Australia, Goodwin & Happell (2007a) found that nurses’ attitudes towards carers were generally favourable, despite there being some individuals who had had negative experiences with carers. They also found that nurses were aware of policy informing them to be inclusive of carers; however this did not always translate into practice. They speculated that implementation of policy tended to rely on the willingness of the individual clinician. While this study provided a good insight into the attitudes and barriers faced by nurses in engaging in carer inclusive practice, it did not investigate actual clinical practice. Further, because the research was conducted only in Victoria with a small sample size, the generalizability of their results to the wider Australian context may be limited.

Only one study has considered the relationship between attitudes towards working with carers of people with mental illness and actual clinical practices. Wright (1997) surveyed 231 clinicians working in psychiatric inpatient settings in America. Participants completed a self report questionnaire covering both attitudes and frequency of contact with families and carers. Overall, the sample’s attitudes towards families and carers were found to be positive. They generally viewed families as being cooperative with staff. They also acknowledged that carers and family members often had their own mental health problems.
However, despite the positive attitudes, there was little evidence that this influenced practice. Nurses were the only occupation where there was a positive relationship between attitudes and frequency of contact with families. Overall, there was also no statistically significant relationship between attitudes and the amount of family contact.

In summary, the overall attitudes of clinicians towards carers appear to be positive, however there is limited research investigating how attitudes relate to the actual clinical practices of clinicians. Further to this, the research has been largely focused on those caring for someone with a mental illness generally and there has been very little done on depression specifically.

1.7.3. What are the barriers to inclusive practice?

Inclusive practice may not occur as frequently as it should because there are barriers that hinder collaboration. The literature suggests there are many barriers to inclusive practice with the most common being organisational in nature, including issues such as time restraints, lack of resources and funding, confidentiality, and lack of training on how to work with carers and families (Dixon et al., 2001; Goodwin & Happell, 2008; Gray et al., 2008, 2009, 2010; Kim & Salyers, 2008).

There is very limited Australian research on potential barriers to inclusive practice. In 2006, Goodwin and Happell conducted focus groups of psychiatric nurses in Australia. Nurses reported that carers often had unrealistic views of what clinicians could provide. They also identified that carers’ needs were not always in line with those of the consumers and they needed to prioritise the needs of the consumer. They reported feeling like they were “the meat in the sandwich” (p.138) with difficulties negotiating between the needs of the consumer and
carer. This would often lead to clinicians focusing on the needs of the consumer over the needs of the family member and carer, with a consequence being that carers felt excluded from the process. This study highlighted the potential for inconsistencies between consumer and carer needs, and how these conflicting agendas may hinder collaboration with carers.

Other research investigating barriers to inclusive practice has been conducted overseas. The common barriers identified in these studies are summarised below.

a. Confidentiality
Confidentiality has been suggested as a potential barrier to inclusive practice (Dixon et al., 2001; Gray et al., 2008; Lammers & Happell, 2004; Marshall & Solomon, 2004; van de Bovenkamp & Trappenburg, 2010,). Uncertainty and confusion regarding privacy and confidentiality has resulted in some clinicians having difficulty discerning what information is able to be shared. As a result, they have chosen not to share personal information with carers for fear of violating their ethical and legal obligations (Marshall & Solomon 2000, Parker et al., 2010, Gray et al., 2008).

Gray et al., (2008) found that in the United Kingdom a concern about confidentiality had resulted in information being kept from carers and families, which, in turn, limited their ability to manage and cope with their loved one’s illness. Further, they identified that this may also result in carers being left out of decisions that directly affected their life and well-being. This study also highlighted the need for training in this area to help increase knowledge and confidence for clinicians in working collaboratively with carers and families.
It is unclear if this is likely to pose as a barrier for Australian clinicians. Goodwin & Happell (2007a) found that their sample of nurses did not see confidentiality as a major barrier.

b. Limited training
It appears that a lack of training regarding how to work with families may have led to clinicians not feeling confident or effective when working in this area (Kaas et al., 2003; Kim & Salyers, 2008; Thomas et al., 1999). For example, amongst the mental health clinicians surveyed by Kim and Salyers (2008) only 38% reporting having received education and training on working with families and 18% reported that this training had been offered in the last year. This study found that those who were more educated in interacting with families did in fact provide more services for carers. In addition to this, they were more positive about involving carers and felt more comfortable with inclusive practice (Kim & Salyers, 2008). The impact of training on clinician attitudes or practices has not been addressed in the limited research that has been conducted in Australia to date.

c. Time and resources
Mental health services are often under-resourced and underfunded to meet demand. This is as true in Australia as it is overseas (Goodwin & Happell 2008). Lack of resources appears to have a direct impact on the services that are offered to carers, families and loved ones (Dixon et al., 2001, Goodwin & Happell, 2008; Gray et al., 2008, 2009, 2010; Kaas et al., 2003; Kim & Salyers, 2008; Thomas et al., 1999). Kim and Salyers (2008) found that 65% of clinicians identified themselves as having too many demands to interact with families. It would seem likely that the same issues are impact on capacity to engage in inclusive practice in Australia.
d. Flexible service delivery

Flexible delivery of service has also been proposed as a barrier, particularly for those family members and carers who work full time. Kim and Salyers (2008) found that 69% of their sample reported that they could not provide out of hours services to families in need. Goodwin & Happell (2007a, 2007c, 2008) have also found that mental health services operating standard business hours is also an issue in an Australian context.

e. Perceived lack of interest from families

Some professionals believe that families are not interested in being involved. Similarly, they have also suggested that clients may not want their family members involved. For example, Kim and Salyers (2008) found that four of the six most identified barriers were related to carer related variables. Over 60% of their participants indicated that the family members of their client group were not interested in being involved. Barraclough et al., (1999) also found a high number of family members and carers (up to 50% of 77 participants) declined to participate in family interventions (either group or individual based). Others have suggested that family members and carers are not interested in accessing services for their needs except in times of crisis (Gray et al., 2010). Goodwin and Happell (2007a) found that if nurses experienced carers as difficult to deal with or they did not demonstrate an interest in being involved in their loved one’s treatment, they would not necessarily encourage their involvement. Thus, a lack of interest from family members and carers in being involved in supporting the family members (the consumers) could be an issue or it could be that the interest in being included or support is not communicated or misunderstood by professionals.
f. Stigma

Stigma can have a negative impact on help seeking behaviour and willingness to seek treatment (McNair et al., 2002). This is true for the individual with depression as well as their family and loved ones (Gray et al., 2010; Stjernsward & Ostman, 2008). As previously discussed, in Australia there is still stigma regarding the experience of depression and it would not be surprising if stigma constituted a barrier to the occurrence of inclusive practice in Australia.

g. Geographical isolation

When services are a long distance from home or there are transport problems, this can constitute a barrier to the access of services and thus present problems for engaging in inclusive care. Goodwin and Happell (2008) found that geographical isolation was a problem for clinicians working collaborating with carers in Australia.

In summary, there are many barriers to inclusive practice. These can include organisational, practitioner, consumer and carer driven barriers. It is likely that they all have some degree of impact on the level of inclusive practice occurring with family members and carers of people with depression in Australia. However, research in this area has been minimal. It has focused on mental health nurses in particular and has not been depression specific (Goodwin & Happell, 2008).

1.7.4. The need to consider attitudes, barriers and actual inclusive practice

There are a number of factors that influence actual clinical practice. Attitudes may determine whether a clinical approach is deemed valuable or not (Goodwin & Happell, 2007b). They may also contribute to whether an approach is persisted with when barriers
emerge. It is likely that the number or nature of barriers may inhibit or hinder the degree to which inclusive practice occurs as it may appear to be too difficult or time consuming for clinicians to work collaboratively with family members and carers. Kim and Salyers (2008) is the only study that has investigated the relationship between attitudes, barriers and clinical practices. They found that while attitudes were not related to the amount of service provided to carers, they were related to perception of barriers and whether individuals had been previously trained in working with families. Thus to fully understand and identify how to promote inclusive practice, there is a need to know the degree to which inclusive practice is actually occurring and the factors that either help to promote or hinder it from occurring. It is important to determine what is happening in Australia.

1.8. Summary

In an ideal situation, clinicians and family members of people with mental illness would have consistent contact and communication. Family members and carers would feel as though they were partners in care and would also feel that their needs and the needs of the consumer were being addressed concurrently (van de Bovenkamp & Trappenburg, 2010). This would have benefits for both the consumer and the carer. However, it would appear that collaboration between clinicians and carers and family members of people with mental illness does not take place routinely. There has been limited research specifically looking at clinicians’ perspective on working with family members and carers of people with mental illness, in particular with regard to the support provided to those who care for a person with depression. What research has been done has largely been conducted in America, the United Kingdom or Europe and only a small amount has been conducted in Australia. Further, the role of attitudes and barriers in predicting clinical practice has only been very investigated in a very limited way. In contrast, there are numerous benefits to being able to promote
inclusive practice. Gaining a better understanding of the current frequency and factors impacting on inclusive practice in Australia will provide a first step towards helping to ensure that both carers and people experiencing with depression are provided with the best possible support.

1.9. The Current Study

This study seeks to address the evidence gap by surveying clinicians in Australia about their attitudes towards carers of people with depression, the barriers they see as impacting their capacity to support this population group, and their actual inclusive clinical practice of family members and carers of people with depression. A snapshot of actual practice was obtained by asking participants to respond based on the activities they completed with their last relevant client. While previous research has only recruited participants who work directly with mental health consumers, this study recruited participants who worked primarily with mental health consumers as well as those who worked directly and primarily with carers. In addition, the study recruited both clinicians who had a specific interest in working with family members or carers of people with depression (as indicated by their attendance at Partners in Depression (PID) program training) and those who had not attended this training, which provided capacity to extend the investigation of whether attitudes, practices were influenced by carer relevant training (as found by Kim & Salyers, 2008).

In summary, this study extends previous research in seven specific ways:

i. It focuses on clinicians’ perspectives on carers of people with depression specifically (versus providing support to carers of people with mental illness generally).
ii. It includes participants who work primarily with mental health consumers and participants who work primarily with carers.

iii. It includes participants who have a specific interest in working with family members and carers of people with depression i.e. those who have attended *Partners in Depression* program training, as well as those who have not demonstrated such interest.

iv. It includes participants who come from a broad range of locations and services (i.e. participants were not all from the same health service).

v. It asks participants to report actual clinical practice with their last relevant client, rather than asking for broad frequency ratings.

vi. It was conducted in Australia.

vii. It investigates attitudes towards working with carers, barriers to working with this population group and clinical practice; and looks at the relationship between these variables.

In short, this study provides valuable information about how policy mandates are being translated into actual clinical practice and what issues are hindering inclusive practice with carers of people with depression within Australia. It is the first time this sort of study has been conducted in Australia.

The specific aims of this study were to:

1. Describe the attitudes of clinicians towards family members, carers and support persons of people with depression and explore whether they differed based on primary
client group (families and carers or mental health consumers) or exposure to family focused training.

2. Describe the barriers that clinicians perceived in regard to including family members, carers and support persons of people with depression in their clinical practice and explore whether they differed based on primary client group (families and carers or mental health consumers) or exposure to family focused training.

3. Determine if there was a relationship between attitudes of clinicians and the barriers that they perceived.

4. Describe the clinical practices of those working directly with family members, carers and support persons and explore whether their practices were related to attitudes or barriers.

5. Describe the clinical practices of those working directly with mental health consumers and explore whether their practices were related to attitudes or barriers.

It was hypothesised that:

1. The attitudes of those working in family member and carer specific roles would be more positive than those working in consumer focused roles; and that the attitudes of those who had completed the family focused training would be more positive than those who had not completed the training.

2. There would be multiple barriers identified by participants as impacting on capacity to engage in inclusive practice, and that barriers would be at both clinician and organisational levels.

3. Higher frequency of reported inclusive clinical practice would be predicted by positive attitudes and fewer barriers, regardless of participant group.
2. RESEARCH MANUSCRIPT

Caring for someone with depression:
Attitudes and clinical practices of Australian mental health clinicians

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2.1. Abstract

**Background:** Family members and carers who support a person with depression are faced with specific challenges and are often significantly burdened as a result of the role. Those caring for someone with depression report being dissatisfied with the level of inclusivity and support provided by clinicians. However, little is known about what influences the support provided to Australian carers of people in depression. **Method:** To investigate this, 119 Australian mental health clinicians were surveyed with a self-report questionnaire to gather information on their attitudes towards, and current clinical practices when, working with family members and carers of a person with depression. Participants comprised mental health clinicians who identified their primary client group as mental health consumers or family members and carers. Recruitment occurred via invitation to clinicians who had attended a *Partners in Depression* facilitator training course and recruitment of clinicians who had not attended this training. **Results:** Results indicated that the attitudes of clinicians towards family members and carers were generally positive, while inclusive clinical practices varied. Providing family members and carers with an orientation to services and information on how to respond in crisis situations were two of the most frequently reported interventions. There were a number of barriers to inclusive practice identified, which were predominantly organisational in nature. In addition, those who perceived more barriers reported providing more clinical interventions to family members and carers of people with depression. In contrast, there was no relationship between reported attitudes and perceived barriers. Additionally, attitudes and barriers did not predict the inclusive clinical practice of those working directly with carers, while there was a significant relationship between perceived barriers and the inclusive clinical practice for those working directly with family members and carers. **Conclusions:** It appears that in order for inclusive practice to occur more consistently there is a need for major organisational and systematic reform. Further research
is necessary to explore the reasons why family members and carers are not routinely included in the care and treatment process for people with depression.

2.2. Introduction

Depression is one of the most common illnesses and leading contributors to illness in Australia (ABS 2007). It tends to be a recurrent in nature and affects people of all ages and socioeconomic backgrounds. Despite depression being common, it is not well recognised or understood (Highet, Hickie & Davenport, 2002; McNair, Highet, Hickie & Davenport, 2002). People still view the development of depression as being due to personal inadequacy, rather than seeing it as a health issue (Highet et al., 2002; McNair et al., 2002). These types of attitudes can mean that depression as an illness is minimised and people do not access treatment when it could be helpful (Jorm, Medway, Christensen, Horten, Jacomb & Rodgers, 2000).

2.2.1. Caregiving Role and Burden

Family and friends provide the majority of practical day to day care and support to those experiencing depression in the community. This support can include completing practical tasks as well as providing emotional and moral support (Muscroft & Bowl, 2000). While many people who provide this type of support do not identify themselves as carers, they would meet the criteria used by the Australian federal government to identify carers (Gray, Robinson, Seddon, Roberts, 2009).

Caring for someone with mental illness can significantly impact a carer’s daily life and their own mental health (Coyne, Kessler, Tal, Turnbull, Wortman & Greden, 1987; Highet, Thompson & McNair, 2005). Through interviews with family members of psychiatric
inpatients, Ostman and Hansson (2001) found that those caring for a loved one with a psychiatric illness experienced considerable burden. Nearly half of their sample (47%) reported that they had experienced mental health problems of their own, while 42% had had to give up personal leisure time due to their caregiving role. Of those who identified they needed support, over three quarters felt they did not receive it.

It would appear that the experiences of those caring for a person with depression are similar. In a qualitative study conducted in Australia by beyondblue, Highet, McNair, Davenport and Hickie, (2004) found that family members and carers of people with depression consistently reported that the depression had had an intense and persistent impact on their life. Family members and carers reported feeling unprepared and isolated in their role and had limited confidence in the healthcare system.

**Caring for a person with depression**

Caring for a person with depression also appears to impact on a carers’ own mental health and wellbeing. Coyne et al., (1987) investigated the impact of living with a loved one with depression. They found that the issues that contributed to caring burden included their loved one’s lack of energy, the emotional strain from the carer role, the possibility that their loved one would become depressed again and their loved one’s feelings of worthlessness. They also found that 40% of their sample were sufficiently distressed enough to meet the criteria for psychological intervention.

Family members and carers want to feel heard and understood, be shown respect, have their difficulties understood, to be validated and taken seriously (Doornbos, 2002). For those supporting a person with depression, they want information on the course and
prognosis of depression, training in the skills and language to use and ways in which to manage their loved ones without upsetting them further (Hidget et al., 2005). Literature in the area has consistently reported that family members and carers are dissatisfied with the support and inclusiveness of mental health services (Doornbos, 2002).

2.2.2. Government policy and current clinical practices

Both Federal and State Governments in Australia have reviewed relevant government policies regarding carers, their needs and involvement with mental health services. These policies and legislation create an obligation for services to increase their responsiveness and the support provided to carers.

However, the degree to which clinicians engage family members and carers in the assessment and treatment process for a person with mental illness (including depression) is varied (Kim & Salyers, 2008). Some clinicians work collaboratively with family members and carers (Kim & Salyers, 2008), while others have limited contact and do not see it as being part of their role (Gray, Robinson, Seddon & Roberts, 2008; Kim & Salyers, 2008; Marshall & Solomon, 2004). While Australian legislation and policy has directed clinicians to work collaboratively with family members and carers, it remains unclear as to the degree to which Australian mental health clinicians engage family members and carers in inclusive practice. When looking at the limited research in the area, it appears that there may be a gap between policy and practice (Goodwin & Happell, 2006; Lammers & Happell, 2004).

2.2.3. What influences the clinical practice of clinicians?

There are many factors that influence the degree to which clinicians engage in carer inclusive practice. Attitudes can have a strong influence on behaviour (Goodwin & Happell,
Carers have reported that the attitudes of clinicians can prevent collaboration, and that they experience clinicians to be patronising and unwilling to include carers (Lammers & Happell, 2004). While some clinicians agree that inclusive practice can have a positive outcome on client outcomes, others see it as being unnecessary, unhelpful or not part of their clinical role (Gray et al., 2008; Kim & Salyers, 2008; Marshall & Solomon, 2004). In addition, there is some suggestion that attitudes may be more positive when clinicians have participated in carer focused education activities (Kim and Salyers).

Research in this area in Australia is limited, although that which is available suggests that these issues are also apparent in Australia (Goodwin & Happell 2007a; Lammers & Happell, 2004). Using focus groups, Lammers and Happell (2004) investigated how consumers and carers perceived their level of participation in the mental health system. The carer participants unanimously stated that, despite policy change, their involvement with mental health services had remained minimal and they continued to feel excluded and isolated. They indicated that clinicians would respond in times of crisis, but not without significant prompting from carers. Confidentiality and communication issues were also identified, with the carers feeling that they routinely shared information with professionals but that this information exchange was rarely reciprocated. This study suggests that policy changes have not assisted in facilitating change to clinical practice.

Other specific issues may also constitute barriers to inclusive practice. The literature suggests common barriers for clinicians are often the result of organisational factors including lack of resources and funding to provide a carer focused service, confidentiality pressures, not being able to offer flexible hours or service delivery and lack of training on how to work with carers and families (Goodwin & Happell, 2007a; Gray et al., 2008; Kim &
Salyers, 2008). Beecher (2009) found that clinicians felt they received mixed messages from management, such that whilst there was a directive to engage in inclusive practice, caseload numbers made it difficult to do so. In contrast, some barriers may be driven by consumer or carer preferences or capacity. For example, family members may not want to be involved in the treatment process, financial burden pressures may not allow carers to be involved, consumers may refuse to have their loved ones involved, or family members and carers’ lack of knowledge about mental illness may result in a lack of interest or support for being involved in the treatment process (Kim & Salyers, 2008). Stigma may also inhibit help seeking behaviour on the part of carers and willingness to be supportive or involved in the treatment process (McNair et al., 2002).

**2.2.4. Summary**

While inclusive practice has been clearly recommended in Australian government policy, it is unclear what is occurring in day-to-day practice. The majority of research conducted to date has focused on clinicians outside of Australia and the support provided to family members and carers of people with mental illness. Previous research has also not specifically explored whether there are differences in attitudes, perceived barriers or the relationship between these factors for clinicians who work specifically with family members and carers rather than mental health consumers. Developing a better understanding of what influences Australian health professionals’ inclusive practice for depression will provide a step forward in ensuring that people with depression receive the best possible care. It will also help to inform practices to ensure that the needs of family members and carers of people with depression are addressed.
2.2.5. The current study

The aim of the current study was to provide a snapshot of the attitudes, barriers experienced and current clinical practices of Australian clinicians who support those who care for a person with depression. Attitudes, perceived barriers and clinical practices were systematically compared based on primary client group (family members and carers or mental health consumers) and exposure to specific training in working with family members and carers of people with depression. This study also investigated the relationships between attitudes, perceived barriers and clinical practices and compared the relationships between different groups within the sample.

It was hypothesised that those working in carer focused roles and those who had completed the family focused training would have report more positive attitudes towards working with family members and carers of people with depression, than those working in consumer focused roles and those who had not completed the family focused training. It was predicted that participants would identify numerous barriers to engaging in inclusive clinical practice, at both the clinician and organisational level. It was hypothesised that reported clinical practice would be predicted by more positive attitudes and lower barriers, regardless of participant group.

2.3. Method

2.3.1. Study Design and Setting

This study used a cross sectional design. Data was collected on one occasion using a self-administered questionnaire. It was undertaken in the context of the national dissemination training initiative of the Partners in Depression (PID) program and sampling involved recruitment of clinicians who had and had not attended the training. The PID program is a group education course for those who love or support a person with depression. Free facilitator program training was available to clinicians across Australia if they met
eligibility criteria and could deliver the PID program at least three times in twelve months to family members and carers in their local community. Recruitment of participants who had not attended the training were drawn from the same sectors who were offered the training.

2.3.2. Participants

Demographics of the participants can be viewed in Table 2. Clinicians from public health, mental health services and non-government organisations from across Australia were contacted to participate in the current study. Participants came from a range of disciplines (see Table 2) and worked across sectors (see Figure 1). Participants worked directly with consumers (n=70) or family members and carers (n=37).

Participants who had attended the Partners in Depression (PID) facilitator training comprised 46% of the sample (n= 55). This represented a response rate of 13.55% of the 406 clinicians who had been invited to participate in the study and who had attended the PID facilitator training. PID facilitator training was provided free to health and community professionals who met eligibility criteria and registered interest. The training was advertised through information disseminated by managers in health agencies and non-government services, after approval from state level policy managers. To be accepted as a facilitator, participants had to have mental health knowledge and experience, group work experience and the capacity to deliver the program three times in the twelve months following their training. There were no significant differences in demographic characteristics between PID and non PID trained facilitators, except for age (t(119)= 3.30, p=.05), where PID participants were significantly older than non PID facilitators.
Table 2: Demographics of participants

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<th>PID trained</th>
<th>Non-PID trained</th>
<th>Whole sample</th>
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<tr>
<td>Number of participants</td>
<td>55</td>
<td>64</td>
<td>119</td>
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<tr>
<td>Gender- % female</td>
<td>89%</td>
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<td>89%</td>
</tr>
<tr>
<td>Average Age- years</td>
<td>46.81 (SD 11.8)</td>
<td>39.87 (SD 10.63)</td>
<td>43.04 (SD 11.66)</td>
</tr>
<tr>
<td>Average years of experience</td>
<td>12.02 (SD 9.35)</td>
<td>9.88 (SD 8.09)</td>
<td>10.87 (SD 8.72)</td>
</tr>
<tr>
<td>Primary client group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work with consumers</td>
<td>46.3%</td>
<td>70.3%</td>
<td>_</td>
</tr>
<tr>
<td>Work with carers</td>
<td>46.3%</td>
<td>18.8%</td>
<td>_</td>
</tr>
<tr>
<td>Discipline</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologists</td>
<td>22%</td>
<td>55%</td>
<td>40%</td>
</tr>
<tr>
<td>Social Workers</td>
<td>19%</td>
<td>13%</td>
<td>14%</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>4%</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Nurses</td>
<td>13%</td>
<td>9%</td>
<td>11%</td>
</tr>
<tr>
<td>Counsellors</td>
<td>19%</td>
<td>9%</td>
<td>14%</td>
</tr>
<tr>
<td>Other</td>
<td>24%</td>
<td>11%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Figure 1: Sectors of employment
2.3.3. Procedure

The first group of participants were recruited from a pool of health and community professionals who had registered for the *PID* facilitator training. These training courses were delivered nationally across two days and attendance was voluntary. Each participant that attended this training was invited to participate in the study. Participation was voluntary and it did not have any bearing on their *PID* training if they chose not to take part. Each participant was provided with an information sheet and consent form (Appendix A), the questionnaire and an unmarked envelope. Participants completed the questionnaire following the training course. The questionnaire could be returned on the day, posted back to the researchers in a reply paid envelope or completed online. Those who did not want to participate either did not take a questionnaire or were asked to place the blank survey into an envelope in the collection box provided.

Multiple recruitment strategies were used to recruit participants who had not attended the *PID* training. This included advertising the study on the Hunter Institute of Mental Health website and through word of mouth distributed by Hunter New England Health local heads of disciplines and professional associations. *PID* facilitators were also invited to provide information about the study to their service. Non-*PID* participants completed the questionnaire on-line. Response rates of non-*PID* participants were unable to be calculated as it is unknown as to how many people information about the study was disseminated to.

2.3.4. Measures

A self-administered questionnaire was adapted for the purposes of this study. The questionnaire covered clinicians’ attitudes, barriers, beliefs and perceived confidence in working with those who care for a person with depression (see Appendices A & B). The
questionnaire was based on a questionnaire developed by Kim & Salyers (2008), which has been shown to have good internal reliability and validity. For this study, the questions were modified to refer to individuals diagnosed with depression rather than severe mental health problems.

Participants provided background information including their discipline/profession, years of working, main area of work, and caseload numbers. The second part of the questionnaire comprised the adapted Kim and Salyers (2008) questionnaire. Firstly, participants answered a range of questions about their attitudes towards carers and including them in their clinical practice. All responses were multiple choice and measured on a Likert scale from 1 (strongly disagree) to 5 (strongly agree). An overall attitudes score was calculated using the total sum of scores for the 17 items in the scale, with relevant items reverse coded. Higher total scores indicate more positive attitudes towards family members and carers. The scale had acceptable reliability (Cronbach’s alpha = .63). Secondly, participants answered questions about perception of barriers to including carers of people with depression in their clinical practice. Answers were multiple choice and rated on a Likert scale from 1 (Not at all) to 4 (Great Impact). An overall barriers score was calculated using the total sum of scores for the 16 items in the scale. Higher total scores indicated greater perceived impact of barriers. The scale had excellent reliability (Cronbach’s alpha = .86).

The third part of the questionnaire focused on clinical practices. As participants in the current study were either employed to work directly with the person affected by mental illness (including depression) or carers of people affected by illness (including depression), there were two variations of questions included to accommodate this. Participants were asked to consider the last consumer with depression/carer of someone with depression who they had
supported and answer whether they had completed any of the listed interventions. The list of activities were drawn from Kim & Salyers (2008) original questionnaire. The scale had good reliability (Cronbach’s alpha = 0.76).

### 2.3.5 Ethics

The study was approved by both the Hunter New England Human Research Ethics Committee and the University of Newcastle Ethics Committee (approval number 10/11/17/5.08).

### 2.3.6. Data Analysis

Participants identified their primary clientele as being mental health consumers, family members and carers or both. Those who worked with both groups were excluded from comparative analyses. Descriptive statistics were used to identify patterns in the data. Independent t tests, ANOVA’s, (and non-parametric equivalents) were used to look for associations. Bivariate correlations were used to investigate relationships between variables. Regressions were used to further explore these relationships. All variables were tested for normality, homogeneity and symmetry. Only the barriers scale was normally distributed. For those scales that were not normally distributed, non-parametric equivalent statistical analyses were used.

### 2.4. Results

#### 2.4.1. What were the attitudes of clinicians?

The distribution of responses to the attitudes questions can be viewed in Table 3. The mean total scores can be viewed in Table 4. Overall, attitudes of clinicians towards carers of
people with depression and inclusive practice were generally positive. There was a
significant difference between the attitudes of those working directly with families and carers
and those working directly with mental health consumers (t(97)=-2.676, p=.009, 95%
confidence interval). Those who worked with family members and carers had significantly
more positive attitudes (M=64.53, SD= 4.27) than those working with mental health
consumers (M=61.92, SD=4.87). There were no significant differences between the attitudes
of the PID trained and non-PID trained participants.

Table 3: Mean scores of attitudes, barriers and services provided to families and carers
by category

<table>
<thead>
<tr>
<th>Primary client group</th>
<th>Mean Attitude score</th>
<th>Mean Barriers score</th>
<th>Mean score of services provided to family members and carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health consumers</td>
<td>61.92 (SD 4.87)</td>
<td>45.75 (SD 7.98)</td>
<td>17.55 (SD 4.73)</td>
</tr>
<tr>
<td>Family members and carers</td>
<td>64.53 (SD 4.27)</td>
<td>51.25 (SD 5.59)</td>
<td>17.04 (SD 3.92)</td>
</tr>
<tr>
<td>Exposed to training</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PID trained</td>
<td>62.2 (SD 4.52)</td>
<td>49.96 (SD 7.65)</td>
<td>16.79 (SD 3.56)</td>
</tr>
<tr>
<td>Non- PID trained</td>
<td>63.31 (SD 5.19)</td>
<td>46.38 (SD 7.96)</td>
<td>17.26 (SD 50.4)</td>
</tr>
</tbody>
</table>
Table 4: Attitudes towards family members and carers

<table>
<thead>
<tr>
<th>n=119</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers as a resource to clinicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Carers are an important source of information for clinicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>19. Carers are co-partners with clinicians in the rehabilitation/recovery of the person with depression</td>
<td>0.9</td>
<td>1.7</td>
<td>14.8</td>
<td>43.5</td>
<td>39.1</td>
</tr>
<tr>
<td>20. Carers are an important resource for clinicians in advocating for change in the mental health system</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inclusive practice makes a difference</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Provided information and skills for carers to help reduce relapse rates for their loved ones</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Supporting someone with depression can have an impact on the carer’s own mental health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. The involvement of carers in the care planning process is often harmful to the person with depression</td>
<td>29.3</td>
<td>54.3</td>
<td>11.2</td>
<td>3.4</td>
<td>1.7</td>
</tr>
<tr>
<td>Inclusive practice and carers’ satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I work hard to involve (or support involvement of) carers in the treatment for the person diagnosed with depression</td>
<td>4.4</td>
<td>15.8</td>
<td>47.4</td>
<td>32.5</td>
<td></td>
</tr>
<tr>
<td>32. Carers are generally satisfied with the level of support they are provided with</td>
<td>13.8</td>
<td>44.8</td>
<td>32.8</td>
<td>8.6</td>
<td></td>
</tr>
<tr>
<td>Carers’ interest and capacity to be included</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Carers want to work more closely with staff</td>
<td>4.3</td>
<td>48.3</td>
<td>37.1</td>
<td>10.3</td>
<td></td>
</tr>
<tr>
<td>28. Carers are often resistant clinicians’ suggestions</td>
<td>3.5</td>
<td>25.2</td>
<td>51.3</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>30. Carers are generally cooperative in the treatment process of the person with depression</td>
<td>1.7</td>
<td>3.4</td>
<td>32.8</td>
<td>54.3</td>
<td>7.8</td>
</tr>
<tr>
<td>31. Carers are too emotional to deal with information about depression</td>
<td>23.3</td>
<td>55.2</td>
<td>15.2</td>
<td>4.3</td>
<td>1.7</td>
</tr>
<tr>
<td>Carers’ limitations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Family members of people with depression often have their own mental health issues</td>
<td>0.9</td>
<td>6.9</td>
<td>31</td>
<td>39.7</td>
<td>21.6</td>
</tr>
<tr>
<td>24. Many carers have learnt to manage the depression fairly well</td>
<td>0.9</td>
<td>20</td>
<td>56.5</td>
<td>19.1</td>
<td>3.5</td>
</tr>
<tr>
<td>25. Carers often have unrealistic expectations for the person’s (diagnosed with depression) improvement</td>
<td>1.7</td>
<td>5.2</td>
<td>49.1</td>
<td>38.8</td>
<td>5.2</td>
</tr>
<tr>
<td>26. Carers generally have little knowledge or understanding about depression</td>
<td>2.6</td>
<td>21.7</td>
<td>40</td>
<td>33.9</td>
<td>1.7</td>
</tr>
<tr>
<td>27. Carers have difficulty communicating with clinicians</td>
<td>1.7</td>
<td>22.6</td>
<td>35.7</td>
<td>28.7</td>
<td>11.3</td>
</tr>
</tbody>
</table>
## Table 5: Barriers to inclusive practice

<table>
<thead>
<tr>
<th>Rate the degree to which the following is a barrier for your inclusion of family members and carers n=119</th>
<th>Not at all %</th>
<th>Minor Impact %</th>
<th>Moderate Impact %</th>
<th>Great Impact %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family/client Barriers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Consumers refusing to allow involvement of carers</td>
<td>0.9</td>
<td>23.3</td>
<td>38.8</td>
<td>37.1</td>
</tr>
<tr>
<td>41. Lack of interest from carers in being involved in the care planning for the person with depression</td>
<td>11.3</td>
<td>27</td>
<td>38.3</td>
<td>23.5</td>
</tr>
<tr>
<td>42. Carers difficulties in communicating with clinicians</td>
<td>6.1</td>
<td>21.7</td>
<td>38.3</td>
<td>33.9</td>
</tr>
<tr>
<td><strong>Agency/staff related barriers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Not knowing how to work with a person’s culture to encourage carers</td>
<td>19.1</td>
<td>43.5</td>
<td>37.4</td>
<td></td>
</tr>
<tr>
<td>39. The lack of knowledge/understanding that carers have of depression</td>
<td>3.5</td>
<td>16.5</td>
<td>50.4</td>
<td>29.6</td>
</tr>
<tr>
<td>40. Lack of knowledge or scepticism about the benefits to be obtained by involving carers</td>
<td>6.1</td>
<td>18.3</td>
<td>37.4</td>
<td>38.3</td>
</tr>
<tr>
<td>46. Limited skills and confidence of working with carers</td>
<td>11.2</td>
<td>19.8</td>
<td>42.2</td>
<td>26.7</td>
</tr>
<tr>
<td>48. A lack of interest in wanting to work with or involve carers of people with depression.</td>
<td>17.2</td>
<td>29.3</td>
<td>31</td>
<td>22.4</td>
</tr>
<tr>
<td><strong>Work related barriers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Organisations not being able to provide services</td>
<td>13.8</td>
<td>42.2</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>34. Services not being available in certain areas</td>
<td>4.3</td>
<td>25</td>
<td>70</td>
<td></td>
</tr>
<tr>
<td>35. Carers not being able to afford services</td>
<td>4.3</td>
<td>17.4</td>
<td>32.2</td>
<td>47</td>
</tr>
<tr>
<td>43. A lack of agency support to provide services for carers</td>
<td>4.3</td>
<td>13</td>
<td>35.7</td>
<td>47</td>
</tr>
<tr>
<td>45. A lack of guidance and leadership from my organisation about how carers should be involved</td>
<td>36.2</td>
<td>22.4</td>
<td>19.8</td>
<td>21.6</td>
</tr>
<tr>
<td>47. Mental health workers have too many other demands with their workload to work with carers of those with depression</td>
<td>1.7</td>
<td>13.8</td>
<td>31</td>
<td>53.4</td>
</tr>
<tr>
<td>38. The complexity of the work required for clinicians when carers are involved</td>
<td>6.9</td>
<td>34.5</td>
<td>38.8</td>
<td>19.8</td>
</tr>
</tbody>
</table>
2.4.2. What barriers were identified by clinicians?

Distribution of responses to the barriers questions can be viewed in Table 6. The mean total barriers scores can also be viewed in Table 5. Nearly all items were identified as constituting a barrier by at least some of the sample. The most frequently identified barriers were organisational in nature.

There was a significant difference between the barriers perceived by those working directly with families and carers (n=37) compared to those working directly with mental health consumers (n=70) \((t(98)=-.3658, p=.001, 95\% \text{ confidence interval})\). The mean score for those working directly with mental health consumers \((M=45.75, SD=7.98)\) was significantly lower than for those working directly with carers \((M=51.25, SD=5.59)\). Thus, those working with families and carers perceived greater impact of barriers on capacity to engage in inclusive practice than those working with mental health consumers.

There was also statistically significant difference in barriers reported by those who were \textit{PID} trained and those that were not \textit{PID} trained \((t(107)=2.387, p=.019, 95\% \text{ confidence interval})\). The mean of the \textit{PID} trained group was significantly higher \((M=49.96, SD=7.65)\) than the non-\textit{PID} trained group \((M=46.38, SD=7.96)\), meaning the \textit{PID} trained group reported greater impact of barriers on capacity to engage in inclusive practice.
Figure 2: Percentage of participants who indicated they completed this activity with the family members of the last client they saw with depression
2.4.3. What were the reported clinical practices of clinicians?

Figure 3 shows the frequency with which professionals working with mental health consumers reported that they generally involved family members and carers in the assessment and treatment of those with depression. Figure 3 provides an overview of the proportion of participants who reported that they had completed the listed activity with their last relevant client, divided by primary client group.

![Figure 3: Percentage of clinicians working with mental health consumers who involved the family member/carer in the assessment/treatment process as part of routine care (n=70).](image)

2.4.4. Was there a relationship between attitudes, barriers and clinical practice?

A bivariate correlation indicated that there was no significant relationship between the attitudes and barriers scores for the whole sample.
a) Was there a relationship between attitudes, barriers and clinical practices for those working directly with family members and carers?

There was no significant relationship between the attitudes of clinicians working with family members and carers and their clinical practices. There was a moderate, positive relationship between the barriers perceived by those working with family members and carers and their clinical practices ($r=.378, n=28, p=.047$), with higher scoring of barriers being associated with more interventions reported as having been provided to family members and carers. Perceived barriers significantly predicted clinical practice scores for those working directly with family members and carers ($\beta=31.48, t(1)4.353, p=.030$). However, barriers only predicted a small proportion of variance (14%) in health professionals’ clinical practices, $R$ squared adjusted=$.137, F(1, 27)=5.297, p=.030$.

b) Was there a relationship between attitudes, barriers and clinical practices for those working with mental health consumers?

There was no significant relationship found between the attitudes of clinicians working with consumers and their clinical practices, their barriers or their clinical practices.

2.5. Discussion

In summary, the attitudes of participants were largely positive towards inclusive practice and working with family members and carers of people with depression. While clinicians reported that they were engaging in inclusive practice it did not appear to be necessarily routine practice and a number of barriers were identified. Participants were largely consistent in their reported attitudes, the barriers they identified and their clinical practices. The barriers identified as hinder ing inclusive practice were primarily associated with organisational factors, rather than clinician related variables. Interestingly, there were
some differences in barriers identified by those who worked directly with families and carers compared to those who worked directly with mental health consumers. In contrast, there were no apparent specific differences in the clinical practices reported by these two groups.

It should be noted that the sample was relatively homogenous, despite recruitment of participants who worked with different client groups and who had or had not attended family focused training. Over all, participants were middle aged and predominately female. A range of disciplines were represented, however psychologists comprised the majority. There were also a number of participants who identified as having more than one primary discipline or role. While participants in the PID trained group were significantly older than the non-PID trained group, there were no significant differences between the two groups in years of experience.

2.5.1. Attitudes

The sample reported positive attitudes towards including family members and carers when working with a person with depression. This is a promising result and is also consistent with previous research (Goodwin & Happell, 2007a; Kim & Salyers, 2008; Wright, 1997). However, it is possible that social desirability may have accounted for some of these findings.

Over three quarters of the sample strongly agreed that supporting someone with depression could have an impact on the family member, carer or support person and 61% strongly agreed that families, carers and support persons could be an important source of information for mental health clinicians.

In contrast, only 9% of the whole sample agreed that families, carers and support persons were satisfied with their current level of support, which suggests that these clinicians were aware of carers’ dissatisfaction with the current level of support available to them.
(Doornbos, 2002; Highet et al., 2004; Marshall & Solomon, 2000). This is different to the findings of Kim and Salyers (2008) where the majority of their sample indicated that family members and carers were satisfied with the current level of support. It is possible that while participants were not routinely including family members and carers they still recognised that this was what family members and carers wanted, such that this participant group may be more sensitive to the family member and carers needs. This could be due to professionals becoming more aware of the carer experience over the last few years. Alternatively, it may be due to cultural differences between Australia and America.

Attitudes were consistent and positive across the sample. It would seem unnecessary then to target interventions towards particular professionals, age groups or experience levels. This result also suggests that positive attitudes were not associated with exposure to carer specific training. This may be due to the fact that increasing the perception of the value of carer inclusive practice was not an aim of the PID training. However it would not have been surprising if it had been a secondary outcome.

In contrast, there was a significant difference in attitudes for those who worked with family members and carers compared to those working directly with mental health consumers. Those working with carers had more favourable attitudes towards family members and carers. Many factors may have contributed to this finding. Clinicians working with family members and carers may have chosen this field because they already held more favourable attitudes regarding the importance of supporting carers or because they have experienced the value of inclusive practice first hand. Alternatively, those working with consumers may naturally focus more on the needs of the mental health consumer and not value as highly the importance of carer inclusive practice, or they may have experienced more difficulties in integrating carer inclusive practice into routine care. This is suggested by
previous research where clinicians have referred to themselves as the “meat in the sandwich” (Goodwin & Happell, 2006). As a result, clinicians may find it challenging or awkward to attempt to support both parties. It would be beneficial for further research explore this further.

2.5.2. Barriers

The most frequently identified barriers were, for the most part, organisational in nature and, those least frequently identified were clinician-related variables. This is consistent with previous research (Dixon et al., 2001; Goodwin & Happell, 2008; Gray et al., 2008, 2009, 2010; Kim & Salyers, 2008). A lack of services available in certain geographical areas was rated by 71% of the sample as having a “great impact” on their capacity to engage in inclusive practice. In addition, 53% believed that being under-resourced and high caseload numbers also had a “great impact” on their inclusive practice. The presence of organisational barriers is consistent with previous research conducted in Australia, America and the UK (Beecher, 2009; Gray et al., 2008, 2009; Kim & Salyers, 2008). However, it highlights and reiterates the ongoing impact that the lack of capacity to provide a service has on front line clinicians’ interest in engaging in carer inclusive practice. Addressing these issues would require high level systems reorientation and support and highlights that clinicians perceive system capacity issues as being a primary inhibitor of providing support to those who care for a person with depression.

The impact of confidentiality and privacy on capacity to engage in inclusive practice has been widely discussed in previous literature (Lammers & Happell, 2004, Marshall and Solomon, 2000). In this study, over half of the sample rated confidentiality as having a moderate or great impact on service delivery. This is consistent with previous research (Gray et al., 2008), indicating that a lack of expertise or confidence in what constitutes confidential information can prevent clinicians from communicating with family members and carers.
Those working with family members and carers perceived significantly greater impact of barriers than those working with consumers. Similarly, the PID trained participants identified significantly greater impact of barriers when compared with non-PID participants. It is important to note that there were a higher proportion of those working with family members and carers in the PID trained group so these findings are consistent with each other. There may be a number of explanations for the differences in barrier perception. For those working with family members and carers, it is likely that they hear firsthand the difficulties that carers experience with other service providers. Similarly they may face more barriers as a simple consequence of providing support to carers at a higher frequency than those whose working directly with mental health consumers. However, the finding also suggests that having attended the PID training was associated with a higher perception of barriers score. This may be because attendance at the training itself raised participants’ awareness of barriers to inclusive practice; or it could be that those participants who sought out the PID training had done so in an attempt to find a way to engage in more increase inclusive practice and overcome the barriers they had noticed. To better understand this finding, future research could investigate whether perceptions of barriers increased after training. Regardless, this finding highlights that those who provide more support, or are interested in providing more support, to carers of people with depression are also more likely to identify more or a greater impact of barriers. It is possible then that previous research that has recruited only clinicians whose primary client group was the person with the mental health issue may have under-rated the impact of barriers.

2.5.3. Clinical Practices

Of this participant group, approximately 40% of clinicians reported that they did not regularly include family members or carers in their routine assessment and treatment process
for a person with depression. When asked to reflect back on what support they had provided
to the last relevant client they had seen with depression, the frequency of some completed
activities were more promising, although it highlighted that there still appears to be some way
to go to reach best practice. Having said this, it is important to acknowledge that asking
clinicians to report on what happened with their last relevant client will be influenced by a
number of factors, such as a participants’ memory, social desirability issues, and individual
case characteristics. This means that, individually, the reports cannot necessarily be taken as
indicative of general clinical practice, although taken as a group it should provide a broad
sense of what sort of support carers of people with depression are currently offered.

*Practices reported by participants who worked with family members and carers*

Of those who worked directly with family members and carers, the most frequently
reported activities were providing information about illness and treatment (86%) and
providing an orientation to services for the family member or carer (80%). This is promising
as research has shown positive benefits in providing this type of information and support to
family members and carers (Lammers & Happell, 2004; Marshall & Solomon, 2000). The
least reported activity was teaching the family member or carer methods for monitoring
medication. This may not have been required as frequently for our sample as medication is
not necessarily the first line treatment for depression.

*Practices reported by participants who worked with mental health consumers*

The most frequently reported activities for those working directly with mental health
consumers were including the family member and carer in the treatment planning for the
person with depression (82%) and how to respond in a crisis situation (80%). Inclusion in
treatment planning was higher than expected based on previous findings, as Kim and Salyers,
(2008) found that only 11% of their participants reported having included family members
and carers in treatment planning for the consumer. This is also an interesting result as it contradicts the information that has been provided to us by carers throughout the literature (Goodwin & Happell, 2006; Marshall & Solomon, 2000). This difference may be explained by the fact that the current study asked about a specific case rather than usual practice. Information regarding crisis intervention is more consistent with previous research, as carers have reported that professionals are more willing to assist during a crisis period (Doornbos, 2002). While crisis support is useful and appropriate at times it is reasonable to suggest that earlier support for families and loved ones may reduce the need for crisis support. Overall, the findings suggest that the actual practice of clinicians has some way to go to be in line with best practice for those with depression and their families and carers.

### 2.5.4. Do attitudes and barriers predict inclusive practice of family members and carers of people with depression?

There were no significant associations between attitudes and barriers scores. This suggests that positive attitudes (or otherwise) towards family members and carers were not related to perception of barriers. This is interesting as it indicates that those perceiving greater barriers to inclusive practice did not necessarily mean that participants had more negative attitudes towards family members and carers. With the attitudes of the sample being primarily positive it suggests that professionals may be willing to make changes to incorporate inclusive practice into their routine if they feel supported to do this.

There were also no significant relationships between the attitudes and clinical practices of those working with family members and carers or for those working with mental health consumers. This suggests that the clinical interventions offered to family members and carers are independent of attitudes. This is somewhat contrary to previous research that has
indicated some negative attitudes towards the benefits on inclusive practice with family members and carers (Goodwin & Happell 2007a, 2007b, Gray et al 2008, 2010). If attitudes had been related to clinical practices then future interventions could have focused on improving attitudes by informing clinicians about the family members and carers’ perspective and the benefits of inclusive practice. However, the lack of a relationship found in this study may be because attitudes were relatively homogeneously positive and at a ceiling level, meaning it was difficult to identify differences with a small sample size. Alternatively, the lack of a relationship between attitudes and clinical practices in this study may simply suggest that it is not the value of the activities that determined whether inclusive practice occurred but other factors.

There was a significant relationship found between barriers and clinical practice for those working with family members; with the more barriers identified by clinicians who worked with family members and carers, the more interventions they reported providing. This is interesting as it was reasonable to speculate that the more barriers perceived the fewer interventions would be provided, with the number of barriers representing the deterrent. However, the current finding suggests that if professionals are providing more interventions they are more aware of the issues faced by family members and carers. In contrast, this relationship was not seen for those working with consumers. Perhaps this can be explained by the fact that those working directly with mental health consumers may be less familiar with the issues experienced by family members and carers due to their reduced contact. However, it also implies that it is not necessarily barriers that hinder inclusive practice, rather it may be that those who work with family members and carers (and are more aware of the barriers) are also enabled in some way to support this target group. Perhaps, simply having delivering support to carers and family members identified as ‘core business’ creates a capacity to deliver a service that would otherwise be overwhelmed by the difficulties. In summary,
however, this finding highlights that it is not just barriers that impact on frequency of clinical practice, it may also be useful to consider what enables family inclusive practice to occur.

2.5.5. Implications for the ‘real world’

Our findings suggest that it is not necessarily the attitudes of clinicians or the perceived barriers that determine whether inclusive practice is engaged in or not. In this study, attitudes, and to a lesser degree barriers, were not significantly related to the support clinicians reported they had provided to the last relevant client. Therefore it seems necessary to investigate other potential contributing factors. For example, Goodwin and Happell (2008) suggested that desensitisation of staff to the impact of mental illness may be a barrier to inclusive practice, in that they can forget what it is like to not have information and expertise in mental illness. They also suggest that in certain treatment environments such as inpatient settings, staff are pressured to move consumers through quickly, reducing the opportunity to work collaboratively with carers. Thus, there is a need to look at other factors that may impact on capacity to provide family inclusive services.

The findings from this study also reiterate the need for systematic and structural changes within the government and non-government mental health service system to increase capacity for services. It would appear that frontline clinicians feel organisational pressures create limited opportunities to support family members and carers, such that workload pressures and competing priorities mean that carer collaborative support is seen as an add on rather than core business. These findings suggest that reform needs to occur at an organisational level to help promote inclusive practice.
That major organisational or systemic changes are required for health services to be more carer inclusive is reiterated by other major, recent reports. The *2012 Report Card on Mental Health and Suicide Prevention* indicated that there was a need for a “new way of thinking” and a “new way of working” for mental health services to ensure they were carer inclusive (p.39). This report recommended specific investment to ensure families had access to appropriate supports and that investigation was needed to identify why only a minority of mental health services had specific carer consultant roles. They also highlighted the need for specific research into models of inclusive practice, in order that effective models could be identified and then implemented in a broad fashion. Thus, carer inclusive practice may not just be about implementing models of care that specifically identify or recruit family members and carers participate in a specific way with the service.

Current national guidelines and reforms have highlighted the importance of carer inclusion when working with consumers with a mental illness. The *National Mental Health Strategy* (2008) has clearly indicated that carers have unique needs and clinicians need to be responsive to these. This includes carers having access to information, resources and support programs to assist them in their support role. The *Roadmap for National Mental Health Reform (2012–2022)* has also made recommendations for inclusive practice with carers. Again it highlights the necessary funding to individualise support for consumers and their carers. It also specifies the need to empower family members and carers to understand and plan for times when their loved one may become unwell. All of these strategies would assist and promote carer inclusive practice.

Despite this sample identifying less frequently individual barriers as impacting on capacity to engage in carer inclusive practice, the findings from this study highlight the importance of improving the frequency and quality of contact between family members,
carers and clinicians within the existing service structure. There are various ways to do this, including providing education on current policies in place to guide practice. Developing clinical guidelines for clinicians, equivalent to the guidelines available for family members, carers and consumers of people with depression could also be beneficial. This is a practice that is already evident in other areas. The *Australian Clinical Guidelines for Early Psychosis* (2011) clearly outline the importance of including and providing support to family members and carers of those with a psychosis, and similar guidelines could be developed for depression.

### 2.5.6. Strengths, limitations and future research

It is important to acknowledge the limitations of the current study. The sample size was relatively small and there was a small response rate of participants, meaning that caution must be used when generalising results to clinicians across Australia. Notwithstanding, we did manage to recruit from a national pool of clinicians which enabled the study to get a snapshot of what is happening nationwide across sectors and diverse roles. Previous research has predominately been conducted overseas and usually recruited from participants from the same health services. Whilst in some ways serving as a strength, the diversity of the sample has also meant that results may have been weakened because of the different experiences of participants.

While the recruitment strategy enabled capture of a diversity of inclusive practice, it also represents a limitation of the study. It is likely that self-selection bias existed for the *PID* trained and non-*PID* trained as only those with the most interest may have chosen to participate in the study. Consequently, the attitudes of this sample may have been more positive than those that would be found in the general health professional population. This
could also explain why few significant differences were found between the two groups on attitudes, perceived barriers and clinical practices. Thus, it is likely that the results from this study represent the attitudes, perceived barriers and clinical practices of only the most interested family and carer inclusive clinicians; this would suggest that it is possible that attitudes may have been poorer and barriers greater, if a broader sample had been recruited. It is also possible that the frequency with which carer inclusive clinical practice was reported may have been lower if participants had not been self selecting.

It may also be useful for future research to investigate the inclusive practice of Australian clinicians with family members and carers of people with other types of mental illness to help better understand the degree to which these findings are specific to carers of people with depression or representative of carers of people with mental illness more generally. This could be strengthened by further development of the scale used, including specific comparison of responses of Australian clinicians compared to clinicians from other countries (e.g. USA) and comparisons of confirmatory factor analyses based on different target population groups (e.g. supporting cares of people with depression versus schizophrenia). Further psychometric exploration of the scale used with regard to it’s construct validity would also be useful in better understanding the degree to which the current scale captured Australian barriers and attitudes and may indicate the need for use of different instruments. For example, a more sensitive attitudes scale, a scale with a greater scope of barriers incorporating barriers specific to the Australian context or clinical practice captured through audit processes rather than self report. Measures asking clinicians to rate their level of inclusive practice in a retrospective way could also be used to improve understanding of the factors influencing inclusive practice. Further, it is unclear as to what impact the different ways of completing the questionnaire (hard copy or online) may have had on responses.
2.5.7. Summary

The sample was largely consistent in their attitudes towards family members and carers of a person with depression, their perceived barriers and their reported clinical practices. This was irrespective of the clientele they worked with, their age or years of working. They expressed an interest in incorporating family members and carers into their practice but identified a number of obstacles to being able to do it. Similar barriers were identified by participants; however those working with family members and carers, and the PID trained group, identified more perceived barriers than those working with consumers or the non-PID trained group. Generally, attitudes and barriers did not predict the clinical practice reported as being engaged in with the last relevant client. In only one instance was this not the case, for those working with family members and carers, those who perceived more barriers in fact provided more interventions. This pattern was not observed with those working with consumers. Further work needs to be done to either replicate these results in order for the results to be more generalisable. This may also involve using different measures, recruiting a different sample or recruiting a larger sample size.

Overall, our findings are consistent with previous research and build on the existing body of research, while providing a specific look at mental health professionals’ perspective on supporting family members and carers of people with depression in the Australian context. It is interesting to see that our findings regarding attitudes and barriers of clinicians towards this population group were comparative to those reported in studies conducted overseas and specifically with mental health consumers with a range of psychiatric diagnoses.

In short, this study provides a snapshot of clinicians’ attitudes towards and actual clinical practices with those who care for a loved one with depression. It is promising that clinicians have positive attitudes towards family members and carers of people with
depression and this suggests that clinicians would be willing to address current issues that are preventing them from working more collaboratively with family.

2.6. Manuscript References


3. EXTENDED DISCUSSION

The purpose of the extended discussion is to further explore and discuss the findings described in the manuscript. A summary of the results are presented and specific findings are discussed in more detail. This is followed by consideration of the study’s implications for clinical practice and a review of the limitations of the study.

3.1 Summary of findings

This study provided a snapshot of the attitudes, clinical practices of and barriers perceived by clinicians when working with family members and carers of people with depression. Attitudes towards supporting family members and carers of people with depression were largely positive. The clinical practices of those working with family members and carers and those working with consumers were also largely similar. Clinicians reported engaging in inclusive practice, however not so much for it to be described as ‘routine’ practice. This study suggests there is likely to be room for improvement in the frequency and nature of carer inclusive practice that is occurring in Australia. A number of barriers impacting on inclusive practice were identified and the most frequently identified were primarily organisational in nature.

Despite the recruitment of different participant groups, the sample was fairly homogenous with regard to demographics and their reported attitudes, perceived barriers and reported inclusive practice. Overall, the sample was middle aged and predominately female. A range of disciplines were represented, with psychologists comprising the majority and participants from across public and non-government sectors were recruited.
3.2 What were the attitudes of clinicians?

The sample reported generally positive attitudes towards including family members and carers when working with a person with depression. The results were positively skewed indicating very few participants had negative views. This is a promising result and is also consistent with previous research (Goodwin & Happell, 2007a; Kim & Salyers, 2008; Wright 1997). Goodwin and Happell (2007a), Kim and Salyers (2008) and Wright (1997) also found that their participants had generally positive views of carers and families with regard to working collaboratively with them. While this finding is encouraging, it is important to acknowledge that social desirability may have had an effect on participants’ responses, such that participants may have been aware of the “right” or “socially acceptable” response and answered accordingly. The PID trained participants may have felt pressured to have extremely positive attitudes toward family members and carers and answered accordingly. However, participants reported many barriers and less than ideal clinical practice and thus it would seem reasonable to assume that the responses to the attitudes’ questions were relatively authentic. Specific interesting item responses are discussed below. However, it is important to note when reflecting on these results, that they are considering responses to individual items rather than the full scale. Thus, while the percentages provide us with valuable information they should be considered in context of the other questions asked.

Participants largely believed that inclusive practice for carers could make a difference for the family members or carers of people with depression. Over three quarters of the sample (77%) strongly agreed that supporting someone with depression could have an impact on the family member, carer or support person. This is consistent with previous research (Wright, 1997). Approximately 84% of the sample indicated that they disagreed and only 2% agreed that the involvement of family members and carers in the care and planning process was often harmful to the person with depression. This result is also consistent with previous
research (Kim & Salyers, 2008; Beecher 2009). Given that research has consistently reported on the benefits of inclusive practice for both carers and consumers it is reassuring to know that professionals appear to be aware of this. Further, the ratings suggest that the exclusion of family members and carers from the assessment and treatment process of the person with depression has not been because professionals believe their involvement would be harmful.

The sample identified that families and carers can be an important source of information for clinicians, with 62% strongly agreeing with this statement. Previous research has also indicated that clinicians are willing to receive information from carers (Beecher et al., 2009). However, it also suggests that clinicians are less willing to share information with carers and loved ones (Lammers & Happell, 2004). In future research it would be interesting to ask more specifically about how important clinicians view the exchange of information, and, further to this, what barriers may prevent them from engaging in a more full exchange of information.

Participants appeared to be aware that the current rate and nature of carer inclusive practice may not be meeting carer needs or expectations. Only 9% of the sample agreed that families, carers and support persons were satisfied with their current level of support. Thus, while these clinicians had positive attitudes towards families and carers, they were also aware that carers and loved ones may not have positive attitudes about clinicians and services. The lack of satisfaction some carers have reported about the support offered by the mental health system has been described in previous research (Doornbos, 2002; Goodwin & Happell, 2006; Lammers & Happell, 2004; Marshall & Solomon, 2000; van de Bovenkamp & Trappenburg, 2010). For example, Doornbos (2002) found that approximately 30% of carers surveyed could not find anything positive to report on their involvement with mental health services. Hight et al., (2004) also found that those caring for a loved one with depression felt they
were not respected or supported by health professionals. Thus, it is promising that in this study there appears to be a consistency between clinicians’ perceptions of and carer’s experience of their inclusion in the system.

When examining the responses on the attitudes scale, the patterns of “neutral” responses, where participants did not either agree or disagree, also provided valuable information. A number of high neutral responses were related to carers’ variables. Nearly half of the sample (49%) was neutral when asked if family members and carers had unrealistic expectations for their loved one’s improvement and 39% agreed with the statement. It is possible that clinicians are less likely to include families and carers if they do not believe that they can meet expectations placed on them. They may feel that family members’ and carers’ expectations are above what they can provide or that their clinical skills are being critiqued based on how much the client’s depression is improving. This is consistent with Kim & Salyers (2008) who found that clinicians believed families often had unrealistic expectations on their loved one’s progress. This may be a factor in explaining why inclusive care may not occur as frequently as expected.

3.2.1 Were there differences in attitudes between those working with consumers and those working with family members and carers?

A significant difference was found between the total attitudes scores of those working directly with mental health consumers and those working with family members and carers of those with depression. The former group had more positive attitudes than the latter group. This is not surprising as those working with family members and carers have demonstrated an interest in working with this clientele. Many factors may have contributed to this finding. Clinicians working with family members and carers may have chosen this field because they already held more favourable attitudes regarding the
importance of supporting carers. Alternatively, participants working directly with family members and carers may see the value of inclusive practice first hand. Similarly those working with consumers may naturally be more focused on the needs of the mental health consumer and consequently not value as highly the importance of carer inclusive practice. It is possible that these clinicians may have experienced more difficulties in integrating carer inclusive practice into routine care. This is suggested by previous research where clinicians have referred to themselves as the “meat in the sandwich” (Goodwin & Happell, 2006).

Clinicians may feel that their priority is with the consumers that they work with and not their family members or carers and it may be challenging or awkward to attempt to support both parties. It would be beneficial for further research explore this further.

3.2.2 Were there differences in attitudes between PID trained and non-PID trained participants?

There were no significant differences between the PID trained and non-PID trained samples regarding attitudes. While we were aware there may have been self-selecting bias, particularly with the PID trained group (as they had shown an interest in attending training about supporting families and carers of people with depression), the PID trained group did not report more positive attitudes than those who not taken part in the training. This is inconsistent with Kim & Salyers (2008) finding that those who had been trained in working with carers had more positive attitudes towards them. This result also suggests that positive attitudes were not associated with exposure to carer specific training. This may be due to the fact that increasing the perception of the value of carer inclusive practice was not an aim of the PID training. However it would not have been surprising if it had been a secondary outcome. The current results are encouraging and suggest that it is not only those
professionals that demonstrate an interest in training that show a positive attitude toward carer involvement.

### 3.2.3 Attitudes summary

Previous research has yielded mixed attitudes of clinicians towards the value of working with family members and carers (Goodwin & Happell, 2007a, 2007b; Gray et al., 2008, 2010). Overall, the results from this study are largely consistent with the small amount of existing research that has indicated positive attitudes towards family members and carers (Goodwin & Happell 2007a; 2007b; Kim & Salyers 2008). Our findings support the suggestion that it is not negative attitudes that are inhibiting collaboration between clinicians and carers. It is therefore necessary to continue to consider what else may hinder inclusive practice for family members and carers of people with depression.

### 3.3. What barriers were identified by clinicians?

The most frequently identified barriers identified by the sample were, for the most part, organisational in nature, which was consistent with previous research (Kim & Salyers, 2008). 71% indicated that services not being available in certain geographical areas was a barrier that greatly impacted capacity to engage in inclusive practice. In addition, 84% believed that being under-resourced and high caseload numbers had a moderate or great impact on not being able to include family members and carers in the treatment of those with depression. This was consistent with previous research, where clinicians are time poor and under resourced to include families and carers (Dixon et al., 2001; Goodwin & Happell, 2008; Gray et al., 2008, 2009, 2010; Kaas et al., 2003; Thomas et al., 1999). Financial difficulties (with regard to paying for services) was also seen to have a moderate or great impact by 78% of the sample. Lack of agency support to provide services to carers was rated
by 47% as also having great impact. Financial difficulties for family members and carers and high case load numbers were consistent with the barriers reported in previous research (Kim & Salyers, 2008; Beecher 2009).

Consistent with Kim and Salyers’ (2008) and Goodwin & Happell’s (2007a, 20007c, 2008) findings, over 85% of the sample believed that organisations not being able to provide services outside of business hours had a moderate or great impact on capacity to support family members and carers of people with depression. This highlights that lack of flexibility in service delivery may be affecting capacity to support carers of people with depression in Australia. Allowing service provision to occur outside of traditional business hours may provide the opportunity for involvement of carers who are working and find it difficult to attend appointments during working hours.

The impact of confidentiality and privacy on inclusive practice has been widely discussed in previous literature (Dixon et al., 2001; Gray et al., 2008; Lammers & Happell, 2004; Marshall & Solomon, 2004; van de Bovenkamp & Trappenburg, 2010; Kim & Salyers, 2008). Certainly from the family and carer perspective it has been put forward as one of the “excuses” that clinicians hide behind in order to have less meaningful communication with families (Lammers & Happell, 2004; Marshall & Solomon, 2000). Gray et al., (2008) found that there was a lack of understanding and training for professionals in the area of confidentiality and as a result professionals would often err on the side of caution and not disclose information for fear of breaching confidentiality. However, interestingly, our sample did not rate confidentiality as one of the most prevalent barriers. This was consistent with Goodwin & Happell’s (2007a) finding that confidentiality was not one of the primary barriers. This finding suggests that clinicians do not feel that confidentiality is one of the most significant barriers to inclusive practice. There was no significant difference in ratings
of this item by those working directly with mental health consumers and those working with family members and carers.

Thus, the most frequently identified barriers were primarily organisational in nature and the perception of these barriers by clinicians is consistent with other studies that have involved family and carers, or barriers which are widely recognised as impacting on the capacity of the mental health service system to respond to the needs of consumers. Addressing these issues would require high level systems reorientation and support. This may include restructuring services to ensure that carer inclusive practice is part of the consumer support system. It may also mean providing more flexible working hours as well as allocating an increase in funds to ensure that family members and carers are able to access appropriate services.

In contrast, the ratings of barriers related to clinicians’ skills or personal attributes or opinions were under-represented. This suggests that targeting interventions to address barriers at an individual staff level may not be worthwhile and reinforces that clinicians feel that a broader organisational level would be more effective in promoting inclusive practice. However it is worth noting that attributional bias may have accounted for an under representation of clinician variables bring noted as barriers. For instance clinicians may have been less likely to identify personal variables as the reasons why inclusive practice was not occurring. It may be easier or less confronting to attribute this to organisational and systemic problems.

3.3.1. Were there differences in barriers between those working with consumers and those working with family members and carers?

Significant differences were found between the perceived barriers by those who worked directly with mental health consumers and those that worked with family members
and carers. Those who were working with families and carers reported a higher mean score for perceived barriers. This is interesting as they are presumably a group who work with carers every single day. Thus, the higher barrier rating may reflect the fact that they are more aware of the barriers faced because of greater exposure to them in their day to day work. It is likely that those working with family members and carers hear firsthand the difficulties that carers experience with other service providers as their core business is to support carers. Similarly they may face more barriers as a simple consequence of providing support to carers at a higher frequency than those whose primary client group is the person with the mental health issue. Alternatively it could reflect that those working with family members and carers actually face more barriers in their work than those working with mental health consumers (rather than being more aware of the barriers).

3.3.2 Were there differences in barriers between PID trained and non-PID trained participants?

There were also significant differences between the barriers perceived by those who were PID trained and those that were not. There may be a number of explanations for this. It is possible that PID trained participants may have attempted to be more inclusive of family members and carers and, as a result, were more aware of existing barriers or perceived barriers to have a more profound impact. Alternatively, it could be that attendance at the PID training raised PID participants’ awareness of barriers; or that those participants who sought out the PID training had done so in an attempt to find a way to engage in more inclusive practice and overcome the barriers they had noticed. To better understand this finding, further research could identify the specific impact of training on perception of barriers (before-after design).
3.4. What were the reported clinical practices of clinicians?

Clinical practices were captured by asking participants to reflect back on the last client that they had worked with and indicate whether they had completed the activity or not. For those working directly with family members and carers they were asked to think of the last client they had worked with that had been caring for a loved one with depression. For those working directly with consumers they were asked to reflect back on the last client that they had worked with who had a diagnosis of depression. This was done in an attempt to get an accurate understanding of actual clinical practices, rather than an overview of what they do ‘most’ of the time. However, it is important to acknowledge that asking clinicians to report on what happened with their last relevant client will be influenced by a number of factors, such as a participants’ memory, social desirability issues, and individual case characteristics, such that, individually, the reports cannot necessarily be taken as indicative of general clinical practice, although taken as a group it should provide a broad sense of what sort of support carers of people with depression are currently offered.

3.4.1 For those working directly with families and carers

Of those working directly with family members and carers, 86% indicated that they had provided information about the illness and treatment (including medications) to the family member or carer. Previous research has suggested that consumers have improved prognosis and the carer is better equipped if this particular type of information is provided to them (Marshall & Solomon, 2000; Lammers & Happell, 2004). This result is promising and suggests that clinicians are aware of the benefits in offering this type of support. 80% of the sample reported that they had provided an orientation to services available to support the family member and carer. This is consistent with the suggestion that if participants felt they were not the most appropriate support option for family members and carers they were willing to refer on to services that were better equipped to support them. It is interesting to
note that both of these activities are of a general or generic nature and do not necessarily require the clinician to disclose personal information about the consumer, which may indicate that clinicians feel more comfortable with providing generic support rather than potentially breaching their client’s confidentiality or betraying their trust by sharing personal information. Of those working with families and carers, only 30% taught the family member or carer methods for monitoring medication. Unlike other psychiatric illnesses, medication is quite often not the first line treatment for depression and as a result this type of intervention may not have been necessary. It is also possible that given the sample was largely allied health professionals, they may not have seen this as being part of their role. It is also possible that the professionals in our sample had experiences of working with individuals who did not require monitoring with their medication due to responsible medication compliance.

The items that were seen as being not relevant also provided valuable information. Over one third (38%) of the sample indicated that it had not been relevant to mediate conflicts between the family member or carer and the consumer. There may not have been the opportunity or need to mediate conflicts between loved ones or clinicians may have felt that it was not their place to be involved in the intricacies of the relationship between the carer and consumer.

One of the more surprising trends in responses was that 23% of those working with family members and carers indicated that it was not relevant to assist loved ones to identify early warning signs of relapse. Relapse prevention is one of the most important and helpful aspects of treatment for depression and family members and carers are often well placed to provide valuable information regarding observable changes in a person with depression. This is particularly so when a consumer does not realise they are becoming unwell but the carer has noticed a deteriorating in their mental state. It is difficult to think of a clinical instance
where having a carer or family member able to identify early warning signs would not be relevant. Depression is recurrent, it is possible and, in fact, likely that those who have experienced an episode of depression will experience a further episode. Even in the event that they don’t, it is still useful for all parties to be aware of the possibility of relapse. The role of the carer in relapse prevention becomes even more important if the person with depression is not regularly seeing their GP or is not linked in with services at the time. Early identification of relapse can prevent the episode from becoming worse and ensure a smoother recovery process. Thus, it is surprising that such a basic activity was not completed more frequently. This is a clear area for improvement in order to be consistent with best practice.

When those working with family members and carers were asked if they provided support during crisis periods with the last client they worked with, only 7% indicated that they did this frequently, while 24% indicated that they did this “a lot” and 40% indicated that they did this “a little” or “none” of the time. This was somewhat inconsistent with previous research by Marshall & Solomon (2004). They found that the support offered to carers and family members was largely in response to crisis. These findings indicate that there is definite room for improvement. Crisis periods are certainly very stressful for families and a time during which they frequently need support. Without support at these times carers and family members are more likely to burn out and be less able to continue with supporting their loved ones.

3.4.2. For those working directly with mental health consumers

One of the questions asked of participants working with mental health consumers was whether they routinely included family members or carers when working with those with depression. Only 23% replied that they ‘always’ did, while 22% indicated doing this ‘often’ and 43% indicated they ‘sometimes’ did. This suggests that including family members or
carers in the assessment and treatment process for people with depression is not yet routine clinical practice and is as likely to not be happening as often as it is happening. Participants were also asked to reflect back on the last client that they had worked with and indicate whether they had included the family member or carer in the assessment, treatment and care planning for that person. 60% indicated that they had while 40% indicated they had not. While it is positive that nearly two thirds of the sample reported having been carer inclusive with their last relevant client, it is still a high proportion for whom inclusive practice had not occurred. This pattern is somewhat consistent with Kim and Salyers’ (2008) findings, where they found that approximately one third of their sample reported they had at least one contact with the family member or carer of a client.

Of those working directly with mental health consumers, 82% of the sample reported that they included the family member or carer in the treatment planning for the person with depression. This is inconsistent with Kim and Salyers’ (2008) finding with 85% of their sample reporting that they had never had contact with family members and carers. They also found that families and carers were rarely involved in treatment planning for clients (54%). It is also an interesting result as it contradicts some of the previous findings from research conducted directly with carers (Marshall & Solomon, 2000; van de Bovenkamp & Trappenburg, 2010; Goodwin & Happell, 2006) or depression (Highet et al., 2002) The carers surveyed by Marshall and Solomon (2000) indicated that they had to work hard to gain relevant information from clinicians and they did not see it as a collaborative partnership. The authors also found that even when families and carers had a good relationship with professionals only 36% of consumers were encouraged to involve a family member in their mental health treatment. Van de Bovenkamp and Trappenburg (2010) also found that carers consistently reported a lack of information being received by health professionals.
The vast majority of the sample (80%) indicated that they discussed with the last family member or carer they saw how to respond to a crisis situation. This is probably more consistent with what carers have reported, as they have indicated that professionals are more willing to assist during a crisis period. Doornbos (2002) reported that carers felt they needed to be in crisis to gain support from professionals. However, carers have also indicated that even crisis support does not happen without their assertive follow up. In an Australian study, Lammers and Happell (2004) found carers were frustrated with the lack of support at crisis times when the client themselves was reaching out for help. This is somewhat different to what was found in this study and it is encouraging to find that the clinicians surveyed indicated they had provided crisis support. While crisis support is useful and appropriate, at times it is reasonable to suggest that earlier support for families and loved ones may reduce the need for crisis support. Early intervention for families, in particular teaching relapse prevention, may circumvent the need for crisis management.

About one fifth (21%) of those working directly with mental health consumers reported providing family therapy to the last client with depression they saw. This is also consistent with previous research which has indicated that family therapy is not routinely provided (Kim & Salyers, 2008; Wright, 1997). These findings were consistent with those working directly with family members and carers, as participants working in this area did not indicate that they routinely provided family therapy. Again, it may be due to the fact that mental health clinicians do not see any fundamental flaws in the family unit and deem family therapy unnecessary. Family therapy may also not be the most appropriate approach to treat the depression or clinicians may not be trained in this area.

Similar to those working directly with families and carers, only one third of participants working with mental health consumers (33%) reported that, for their last relevant
client, they had taught family members and carers methods for monitoring medication. This was also consistent with Kim & Salyers’ (2008) findings. However, the responses across this item were evenly spread with approximately one third responding to yes, no and was not relevant. Again this may be due to the reasons previously discussed.

Also similar to those working directly with family members and carers, one third of participants working with mental health consumers (33%) indicated that it had not been relevant to advocate for access to services for the family member or carers, and 35% indicated that it had not been relevant to mediate conflicts between family members and carers. This was also consistent with previous findings (Kim & Salyers, 2008). It would seem to be clinically relevant to advocate for families and carers regarding ongoing support from services as those working directly with consumers have indicated difficulty in finding time to support families and carers. It is interesting that even though clinicians rated satisfaction by family members and carers as low, advocacy was not reported as being routinely engaged in. As for the conflict finding, as already mentioned, this may have been due to the fact that the need to mediate conflict did not arise or was not felt to be their role.

3.5 **Was there a relationships between attitudes, barriers and clinical practice?**

The attitudes and barriers total scores were not significantly related. This suggests that participants’ positive (or otherwise) attitudes towards families, carers and support people were not related to their perception of barriers. Hence, trying to change the attitudes of staff may not necessarily have a direct impact on perception of barriers to inclusive practice, whilst addressing barriers may have an impact on the attitudes held by health professionals towards working with family members and carers of people with depression.

This finding is somewhat surprising given the previous findings of Kim and Salyers’ (2008). They found that attitudes were related to the barriers that professionals perceived
when working with families of people with mental illness. It is possible that the difference in these findings was due to this research being specific to family members and carers of people with depression. Perceptions of consumers with depression may be different to those of other mental illnesses. It could also be because the study was conducted in Australia, in that practitioners in Australia may experience different sorts of barriers and the most pertinent ones may not have been captured by the questionnaire used. Other research has been conducted overseas and it is possible that barriers are more culturally specific than anticipated. If different barriers were included, it is possible that a significant relationship may have been found.

3.5.1. Those working directly with families and carers

There was no significant relationship between the attitudes and reported clinical practices of those working with family members and carers. This suggests that the clinical interventions offered by those in carer focused roles to family members and carers occurred independently of their attitudes. Wright (1997) also found little evidence that clinical practices were influenced by clinicians’ attitudes.

There was a moderate significant relationship between perceived barriers and clinical practices of those working directly with family members and carers, with higher scoring of barriers being associated with more interventions provided to family members and carers. This may be due to the fact that clinicians will attempt to provide more support when they are aware of the barriers that exist for family members and carers.
3.5.2. Those working directly with mental health consumers

There was no significant relationship between attitudes and the clinical practices of those working with mental health consumers. This suggests that the interventions offered to families by those working with mental health consumers occurred independently of their attitudes towards carers. We may have expected that those with positive attitudes towards carers would have been reported more inclusive practice with carers and that those with negative attitudes towards carers would have been less likely to include carers in the treatment process. However this was not the case. The lack of a relationship found in this study may be because attitudes were relatively homogeneously positive and at a ceiling level meaning it was difficult to identify differences with a small sample size. Alternatively, the lack of a relationship between attitudes and clinical practices in this study may simply suggest that it is not the value of the activities that determined whether inclusive practice occurred but other factors.

There was also not a significant relationship between the clinical practices of those working with mental health consumers and the barriers that they perceived. Again we may have thought that those who identified more barriers or felt they had more impact may have performed fewer interventions for families. However the barriers perceived by those working with consumers did not appear to influence their clinical practice.

It is important to acknowledge when interpreting these correlational results that the results were based on yes and no responses only and did not take into account the ‘was not relevant’ responses. It is not thought this issue would greatly affect interpretation of results as there were only a small number of was not relevant responses, however, it is important to acknowledge that there may have been valid reasons as to why specific activities were not relevant in the individual situations. It is possible that by asking about the last client has
skewed the results. This may be due to the last client not being representative of their overall case load. However the sample size would hopefully overcome these issues.

### 3.6 Clinical implications and application to real world

#### 3.6.1. Attitudes

This sample reported fairly positive attitudes towards working with family members and carers of people with depression. This would suggest a minimal need to improve the attitudes of clinicians towards working with this group. Positive attitudes may reflect the effectiveness of legislation and the carer advocacy movement or education provided regarding carer involvement over the past decade. However, given that attitudes towards family members and carers were positive, it is important to consider how to ensure that this remains the case. Possible ways to do this could be to ensure that clinicians continue to be exposed to contact with family members and carers of people with depression in a way that promotes alliance and trust. It may also be helpful to ensure information is disseminated outlining the importance and benefits of inclusive practice to reinforce the value of the activity.

#### 3.6.2. Barriers

It is important to note that ratings of barriers were not consistently associated with, or predictive of, reported clinical practice. Thus, addressing the barriers explored in this study would appear to be important with regards to enhancing capacity to support family members and carers of people with depression, but it seems that there are other factors at play that affect what clinical support is offered to carers and family members of people with depression. In terms of improving frequency of inclusive practice, this study suggests that it is not as simple as just removing or improving the barriers identified. However, differences between carer group with regard to the relationship between barriers and clinical practice
suggests that it is not only about barriers or attitudes, but may also be about enablers. There appears to be a reason why those working with family members and carers are better placed to deliver more interventions and potentially overcome barriers. This may be due to working with carers and families being their core business. In addition to this they may not experience the same conflict in duty of care.

The barriers that participants identified as having the most impact were largely organisational in nature, which was consistent with previous findings (Dixon et al., 2001; Goodwin & Happell, 2008; Gray et al., 2008, 2009, 2010; Kim & Salyers, 2008). This suggests that clinicians think that the issues that most hinder their capacity to engage in inclusive practice with family members and carers require changes at a management and funding level. Overall, this sample did not indicate that a common barrier to supporting family members and carers of people with depression was a lack of interest or ability of clinicians. Rather, they identified not having adequate funding, clinicians being under resourced and high caseload numbers as preventing them from working with carers and loved ones of people with depression. It may be that these fundamental service and funding difficulties are discouraging clinicians from encouraging the involvement of family members and carers as they know that they do not have the capacity to follow this through. An increase in funding would undoubtedly assist in this area. This would potentially enable clinicians to have the capacity to support family members and carers as part of their existing client work. Alternatively it may enable additional staff to be employed within mental health services for this sole purpose.
3.6.3 Clinical practice

Previous research has suggested that clinicians’ value inclusive practice with family members and carers when treating those with a mental illness, yet this doesn’t necessarily occur (Kim & Salyers 2008, Wright 1997). Our findings indicate that approximately 40% of participants reported not routinely including family members and carers. However, our findings also suggest that this frequency is not necessarily because of their attitudes towards working with family members or carers, or the barriers that they perceived as impacting on their capacity to work with this group. One explanation for this would be that clinicians were not aware of the specific ways that they could provide services that are more satisfying to family members and carers. As a result, they may have positive attitudes towards, and see the benefits of, inclusive practice but not be clear on how to effectively engage with them.

Increasing accessibility to training regarding the needs of family members and carers could be beneficial. This training may also involve learning more about how to interact and communicate successfully with family members and carers. For example, Hunter New England Area Health Service are attempting to do this with the current APT (Assessment and Planning Training) program. As a part of this training, a carer of a person with mental illness presents to clinicians on their experience of service delivery within local mental health services. This allows clinicians to have direct feedback from carers in a real and meaningful way.

One of the questions asked of clinicians working with consumers was whether they routinely included family members and carers when working with those with depression. Only 23% replied that they ‘always’ did, while 22% indicated doing this ‘often’ and 43% indicated they ‘sometimes’ did. This suggests that including family members or carers in the assessment and treatment process for people with depression may not yet be routine clinical
practice and seems to be as likely to not be happening as often as it is happening. The low rates of inclusive practice suggest that there is a need to improve, at a minimum, rates of contact between family members, carers and clinicians. This is important to ensure that family members and carers receive the support they require to continue in their role as well as helping to ensure that consumers are provided with the most supportive environment possible. In addition, including the family member and carer in the assessment and treatment process also ensures that the clinician has another source of information to assist in their case formulation and consequent treatment and therapy. Changes to systems and processes may assist in this area. For example, when clinicians are assessing a client it would be useful for a prompt to exist that reminds clinicians to get informed consent from the consumer to contact the family. It may also involve checking whether the client has nominated a primary carer and whether they have been contacted or included in the treatment process. Similarly, existing client review processes could provide a forum to prompt clinicians to engage in inclusive practice.

In addition to clinicians being more aware of the policy that mandates inclusive practice, they may also benefit from a short fact sheet being developed that outlines the importance and benefits of involving family members and carers of the person with depression. Dedicated family workers could also assist in promoting inclusive practice between clinicians, family members and carers. A position dedicated solely to service provision for family members and carers could also relieve the responsibility of clinicians broadening their workload to include servicing families. However, collaboration and communication would still be required and the family worker and clinician working with the consumer could ensure that the consumer and family member receive the best treatment possible.
As mentioned in the critical review, both beyondblue and RANZCP have developed guidelines for consumers and carers regarding the nature of depression and the services and treatment available. However, there does not appear to be equivalent for clinicians. Comparative guidelines for clinicians on how to work collaboratively with family members and carers of people with depression would seem likely to be useful for clinicians in this field. This is a practice that is already evident in other areas. For example the Australian Clinical Guidelines for Early Psychosis (2011) clearly outlines the importance of including and providing support to family members and carers of those with a psychosis. A similar document could be developed for people with depression.

Current national guidelines and reforms have highlighted the importance of carer inclusion when working with consumers with a mental illness. The National Mental Health Strategy (2008) has clearly indicated that carers have unique needs and clinicians need to be responsive to these. This includes carers having access to information, resources and support programs to assist them in their support role. The Roadmap for National Mental Health Reform (2012–2022) has also made recommendations for inclusive practice with carers. Again it highlights the necessary funding to individualise support for consumers and their carers. It also specifies the need to empower family members and carers to understand and plan for times when their loved one may become unwell. All of these strategies would assist and promote carer inclusive practice.

In summary, to improve the frequency and nature of inclusive practice of carers of people with depression it appears that a number of changes need to occur. For the most part changes to funding and structure of mental health services from an organisational level would appear to help in this area. Clinicians seem to be restricted by their current case loads and capacity to spend time engaging carers and family members. If they were supported to work
inclusively with carers and family members it is likely that this area would improve.
However, further research that does not rely on self-report measures is needed to validate the specific barriers to current carer inclusive practice.

3.7. Limitations of current study and possible areas for future research

It is important to acknowledge the limitations that exist within the current study. The sample size was relatively small, meaning that caution must be made when generalising results to clinicians across Australia. However, we did manage to recruit from a national pool of clinicians which enabled us to have a good representation of individuals working for a range of government departments and non-government organisations and from diverse clinical roles nationwide. Previous research has predominately been conducted overseas and usually recruited from participants from the same health services. Whilst in some ways serving as a strength, the diversity of the sample has also meant that results may have been weakened because of the different experiences of participants.

While the recruitment strategy enabled capture of a diversity of inclusive practice, it also represents a limitation of the study. It is likely that self-selection bias existed for the PID trained and non-PID trained as only those with the most interest may have chosen to participate in the study. Consequently, the attitudes of this sample may have been more positive than those that would be found in the general health professional population. This could also explain why few significant differences were found between the two groups on attitudes, perceived barriers and clinical practices. Thus, it is likely that the results from this study represent the attitudes, perceived barriers and clinical practices of only the most interested family and carer inclusive clinicians; this would suggest that it is possible that attitudes may have been poorer and barriers greater, if a broader sample had been recruited. It is also possible that the frequency with which carer inclusive clinical practice was reported
may have been lower if participants had not been self selecting. We attempted to counteract this by recruiting another group who had not elected to do the PID training. Again, these people were recruited nationally and were invited to take place in the research. However, it is reasonable to suggest that only those who were interested in this area responded and completed the questionnaire. This may also explain why we found few significant differences between the two groups. Thus, it is possible (even likely) that the results from this study represent the attitudes and barriers and clinical practices of our most interested clinicians. It is therefore possible that attitudes may be worse and barriers may be greater, particularly those that relate to individual clinicians, when looking at a broader sample. It is also possible that clinical practices may be worse from clinicians who have not demonstrated an interest in this area. This is concerning as the clinical practices of interested clinicians, although promising, were less than ideal and suggests that there is still a great deal of work that can be done to improve inclusive practices for family members and carers of people with depression.

The measures used could have been piloted with a wider sample and this may be beneficial to do in future research. It would also be useful to conduct factor analyses to further strengthen the findings.

It may also be useful for future research to consider looking at inclusive practice towards family members and carers of those with mental illness in Australia to help with making comparisons with the inclusive practice reported here of support provided to family members and carers of people with depression specifically. In addition, this study could be strengthened through the use of other measures. For example, a more sensitive attitudes scale, a scale with a greater scope of barriers incorporating barriers specific to the Australian context or clinical practice captured through audit processes rather than self report retrospective measures could be used to improve the understanding of the factors influencing
inclusive practice. Further, it is unclear as to what impact the different ways of completing the questionnaire (hard copy or online) may have had on responses.

As this is the first questionnaire of this kind to be used with an Australian population it would be useful to replicate the study but looking more broadly at the support provided to those who care for a loved one with mental illness generally. This would help to confirm the relevance of the attitudes and barriers covered in this scale to the Australian context, strengthen the construct validity of the scale and confirm the stability of the factor structure. It would also help to inform us as to the degree to which carer inclusive attitudes, barriers and clinical practices are diagnosis specific or sensitive to illness acuity. Further, while this study provides an international perspective, it would also be beneficial to have the capacity to look more closely at national differences and make comparisons between rural and urban participants. Future research could identify this by asking participants to indicate if they lived or worked in rural or urban areas. There may also be alternative ways of capturing clinical practice. As this study has been based on a self-report survey it is possible that there is a gap between what is being reported and what is occurring.

**3.8. Summary**

The clinicians who participated in this study were largely consistent in their positive attitudes, perception of barriers and reporting of the nature of their inclusive practice with family members and carers of people with depression, despite differences in previous training, primary client group, age, year of experience and professional backgrounds. In short, the sample saw the value of carer inclusive practice, however did not report engaging in it routinely. A number of barriers were identified and again these were predominately consistent across the sample, although those working with carers and the PID trained group did indicate a greater impact of perceived barriers than those who worked with consumers
and the non-PID trained group. As the attitudes and barriers explored in this research were not generally predictive of inclusive practice, it appears that more work need to be done in identifying what else it is that prevents or stops clinicians from more regularly including family members and carers of people with depression. Similarly more work needs to be done to further explore what enables some clinicians to engage in inclusive practice.

Overall, our findings are similar to previous research. Our findings build on the growing body of research in this area and provide a specific example of Australian clinicians’ perspective in supporting those who care for or love a person with depression. Previous research in the field has largely focused on the attitudes of clinicians working with psychiatric illness generally. It is interesting to see that the experience is similar when looking at those with a diagnosis of depression.

In summary, this study provides a snapshot of clinicians’ attitudes towards, and actual clinical practices with, those who care for a loved one with depression. Inclusive practice was reported as occurring to some degree, however efforts need to be made to ensure that this happens more routinely. While there is a likely sampling bias in this study, the picture provided is promising regarding clinicians’ positive recognition of the importance of supporting and including in treatment family members and carers of people with depression. The barriers identified give us some indication of the difficulties that clinicians face when including family members and carers. They also suggest that significant reform is needed to increase the capacity for clinicians’ and family members and carers to work collaboratively. While more work needs to be done, the positive attitudes of clinicians provides hope that clinical practices can improve and family members and carers can feel more supported by the services supporting those they care for.
4. REFERENCES


Appendix A: Information / Consent Form
You are invited to take part in the above research project identified which is being conducted by Ms Katie McGill from the Hunter Institute of Mental Health, Dr Pete Kelly from the University of Newcastle, and Ms Joanne Wirrell. The research is part of Joanne Wirrell’s postgraduate studies at the University of Newcastle, supervised by Ms Katie McGill and Dr Pete Kelly. This study is investigating mental health clinicians’ attitudes towards, and current professional practice with, those who are supporting a person with depression.

Why is the research being done?
The mental health system relies heavily on carers. While there has been some research conducted on the needs of carers and how the service system supports them, it has generally been limited and often has specifically investigated the experiences of carers of people with schizophrenia, eating disorders or those who care for the elderly. There is very little known about the attitudes and professional practices of mental health clinicians when working with those who care for a person diagnosed with depression. By better understanding the types of barriers or experiences of professionals working with those who support a person with depression, we can begin to identify what would help ensure that the best type of support is offered at the right time to those in the caring role.

Who can participate in the research?
We are inviting all health and community professionals who attend the Partners in Depression facilitator training to participate in the research. Anyone who is attending this training is welcome to take part. This will include those who work primarily with mental health consumers as well as those who work primarily with carers, family or support people.

**What choice do you have?**

Participation is entirely your choice. Whether or not you decide to participate in this research, your decision will in no way affect your training outcomes. If you do decide to participate you may withdraw from the project at any time without giving a reason. If you decide to withdraw from the study, you have the option of withdrawing all data relating to you. This would require you to provide us with your identifying code.

**What would you be asked to do?**

The first thing you need to do is carefully read this ‘information sheet’ to ensure that you understand what is required. In order to protect your privacy we will not request written consent to participate in this study. Instead by completing and returning this questionnaire you will be providing your consent to participate. You will be asked to complete a questionnaire about your experiences of working with family members, support persons or carers of those diagnosed with depression. The questionnaire contains 76 questions and should take approximately 15-20 minutes to complete. You will also be asked to answer a short questionnaire following your training which consists of 16 questions and should take approximately 5 minutes to complete.

**What are the risks and benefits of participating?**

People often find that when they complete the questionnaire it helps them reflect on their own clinical practice. There are no risks associated with participating in this research however we cannot promise you any immediate benefit from participating in this research. Participating in the research will help us to better design professional development activities and advocate for how systems could address the issues that impact on professionals’ capacity to provide support to carers of people with depression.

**How will your privacy be protected?**

You will not be asked to record your name on your questionnaire. However you will be asked to provide a code that is unique to you. This is because if we conduct a follow up questionnaire we want to be able to link data over time. The code will allow us to link data without knowing specifically which individual it came from. The code will be used only for the linking of initial and follow up data and we will not have a list of which codes relate to which individuals.
How will the information collected be used?

Any information collected by the researchers which might identify you will be stored securely and only accessed by the researchers unless you consent otherwise, except as required by law. We will be recording your information to find out more about the current clinical practices of those who work with family members, support persons or carers of people with depression. At the completion of the study we will be collating the information in a report and seeking publication. These documents will not include any identifying individual information and will only describe results at a group level.

What do you need to do to participate?

Please read this information sheet and be sure that you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researchers: Katie McGill on (02) 49 246 870 or pid@hnehealth.nsw.gov.au.

If you would like to participate please complete the attached questionnaire and return it to the box located outside the training room or by using the reply paid envelope attached.

Thank you for considering this invitation to participate.

Ms Katie McGill
Program Manager
Hunter Institute of Mental Health

Complaints

This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 10/11/17/5.08. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is being conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager, Research Ethics and Governance, Hunter New England Health, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email Nicole.Gerrand@hnehealth.nsw.gov.au
Appendix B: Questionnaire for PID trained participants
We would like to know more about the work that you do with those who are in a caring role for a person diagnosed with depression. We will refer to these individuals as ‘family members, carers or support persons’. This term refers to those people who provide unpaid practical and emotional support to a person with depression; and for whom this role impacts on their own day to day functioning, mental health or routine responsibilities.

We would like you to create a unique code based on your mothers’ maiden name and the month of your birth. The code provides an opportunity for the researchers to connect your data with future data should you decide to participate in our follow-up study. At the same time you remain anonymous to the researchers. For example, if your mothers’ maiden name was Smith and you were born in July, your code would be SmiJul

What are the first three letters of your mother’s maiden name? __________

What is month of your birth? __________
Part 1: Background Information- Please circle/ write your response

1. Age: _______ years

2. Gender:
   Male  Female

3. Discipline/Profession (Please circle):
   Psychologist  Social Worker  Occupational Therapist
   Nurse  Counsellor  Welfare Worker
   Other (please specify): _________________________________________

4. How long have you been working in this profession? _______ years

5. What is your primary area of work (Please circle one)?
   Therapy  Care coordination/case management  Counselling
   Education  Provision of information and advice
   Other (please specify): _________________________________________

6. Who do you primarily work with? (please circle one)
   Directly with mental health consumers
   With family members, carers or support people
   With family members, carers or support people of those diagnosed with mental illness

7. In which sector do you work?
   A. Area Health Service         B. Non government sector
      - Mental Health Service     - Carers organisation
      - Community Health Service  - Mental health organisation
      - Population Health         - Division of General Practice
      - Other: ____________________  - Other: ____________________

   C. Private practice         D. Other (please specify): __________________

8. Have you had any previous training in working with family members, carers or support people?
   Yes  Please specify particular courses & duration: _______________________________

   No
9. What is your primary reason for attending the training today (Please circle one)?

- Management directive
- To improve clinical practice
- Personal interest
- Other (please specify): ______________________________________________________

10. Please rate the importance of including family members, carer and support people in the assessment and treatment for those with:

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Not at all Important</th>
<th>Somewhat Important</th>
<th>Important</th>
<th>Very Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Eating Disorders</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Drug and Alcohol</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Dementia</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

11. How often do you work with family members, carers or support people in your current role?

1 2 3 4 5
- Never
- Rarely
- Sometimes
- Often
- Always

12. What percentage of your case load would have a primary diagnosis of depression or are supporting a person with a primary diagnosis of depression?

<table>
<thead>
<tr>
<th>Percentage</th>
<th>0-20%</th>
<th>20-40%</th>
<th>40-60%</th>
<th>60-80%</th>
<th>80-100%</th>
</tr>
</thead>
</table>

13. What do you think are the most important things to offer a person who is supporting someone with depression?

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

14. What do you think are the most challenging aspects for those who support a person with depression?

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
15. What do you think are the main benefits to involving family members, carers or support persons in the care provided to those with depression?

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

**Part 2**  *Please answer the following questions based on your experience of working with family members, carers and support persons.*

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>16. Providing information and skills for family members, carers and support persons reduces relapse rates for their loved one</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>17. Families, carers and support persons are an important source of information for mental health clinicians</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>18. I work hard to involve (or support involvement of) family members, carers and support persons in the treatment for the person diagnosed with depression</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>19. Family members, carers and support persons are co-partners with providers in the rehabilitation/recovery of the person diagnosed with depression</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>20. Family members, carers and support persons are an important resource for providers in advocating for change in mental health system</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>21. Supporting someone with a diagnosis of depression can have an impact on the family member, carer or support person’s own mental health</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>22. Family members of people with depression often have their own mental health problems</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>23. Family members, carers and support persons want to work more closely with staff</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>24. Many family members, carers and support persons have learnt how to manage the depression fairly well</strong></td>
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<tr>
<td><strong>25.</strong> Family members, carers and support persons often have unrealistic expectations for the person's (diagnosed with depression) improvement</td>
<td>1</td>
<td>2</td>
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</tr>
<tr>
<td><strong>26.</strong> Family members, carers and support persons generally have little knowledge or understanding about depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>27.</strong> Family members, carers and support persons have difficulty communicating with mental health clinicians</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>28.</strong> Family members, carers and support persons are often resistant to mental health clinicians’ suggestions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>29.</strong> The involvement of family members, carers or support persons in the care planning process is often harmful to the person with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>30.</strong> Family members, carers and support persons are generally cooperative in the treatment process of the person with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>31.</strong> Many family members, carers and support persons are too emotional to deal with information about depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>32.</strong> Family members, carers and support persons of people with depression are generally satisfied with the level of support they are provided with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tbody>
</table>

Please circle to what extent the following are obstacles to developing and providing services that involve or are for family members, carers or support persons of people with depression

<p>| | | | | | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td><strong>33.</strong> Organisations not being able to provide services out of usual business hours (e.g. weekends, nights) when it may be more convenient for families, carers or support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
<tr>
<td><strong>34.</strong> Services not being available in certain geographic regions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
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<tr>
<td><strong>35.</strong> Families, carers and support persons not being able to afford to pay for services</td>
<td>1</td>
<td>2</td>
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<tr>
<td><strong>36.</strong> Mental health clinicians not knowing how to work with a person's culture to encourage family member, carer or support person involvement</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>37.</strong> Consumers refusing to allow involvement of family members, carers and support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>38.</strong> The complexity of the work required for mental health clinicians when family members, carers and support people are involved</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>39.</strong> The lack of knowledge/ understanding about depression that family members, carers and support persons have</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>40.</strong> Lack of knowledge or scepticism of mental health workers about the benefits or added value to be obtained by involving family members, carers and support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>41.</strong> Lack of interest of the family members, carers or support persons in being involved in the care planning for the person with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>42.</strong> Family members, carers and support persons difficulties in communicating with mental health workers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>43.</strong> There is a lack of agency support to provide services for family members, carers or support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>44.</strong> Confidentiality regulations make it too difficult to involve family members, carers or support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>45.</strong> There is a lack of guidance and leadership from my organisation about how family members, carers and support persons should be involved</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>46.</strong> Limited skills and confidence of mental health workers in working with family members, carers and support persons of people with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>47.</strong> Mental health workers are overstretched with too many other demands from their workload to work with family members, carers or support persons of those with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>48.</strong> There is a lack of interest from mental health workers in wanting to work with or involve family members, carers or support persons of people with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
</tbody>
</table>
Part 3
Please complete this section if you work directly with family members, carers or support persons of those with depression.

If you DO NOT work directly with family members, carers or support persons of those with depression, please skip this section and go to Part 4.

For those who work directly with family members, carers or support persons of people with depression, please use the example of the most recent family member, carer or support person you worked with to answer the following questions.

<p>| | | |</p>
<table>
<thead>
<tr>
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<th></th>
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</thead>
<tbody>
<tr>
<td>49. I provided an orientation to the services available to support the family member, carer or support person</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>50. I provided information about the illness and treatment (including medications) to the family member, carer or support person</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>51. I taught the family member, carer or support person methods for monitoring their loved one’s medication</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>52. I taught the family member, carer or support person stress management strategies to deal with their caring responsibilities</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>53. I discussed with the family member, carer or support person how to respond in crisis situations</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>54. I worked with the family member, carer or support person on how to identify early warning signs of relapse</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>55. I mediated conflicts between the family member, carer or support person and the person diagnosed with depression</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>56. I helped the family member, carer or support person identify ways in which they could be kept up to date on treatment progress for the person diagnosed with depression</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>57. I provided the family member, carer or support person with therapy or counselling to address their own needs</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>58. I referred the family member, carer or support person on to another service who could provide additional assistance</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
59. I advocated on behalf of the family member, carer or support person for access to services or better treatment

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
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</table>

60. I provided the family, carer or support person with assistance during crisis periods

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>Frequently</th>
</tr>
</thead>
</table>

**Part 4.** If you work **directly with mental health consumers** please answer the following questions.

*If you DO NOT work directly with mental health consumers, you have finished. Thank you for your time.*

61. As part of your routine care for a person, how often do you involve family members, carers or support people in the assessment and treatment process?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
</table>

*Please reflect back on the last client that you worked with who had a primary diagnosis of depression and answer the following questions.*

62. I involved a family member, carer or support person in the assessment, treatment or care planning for the person with depression.

<table>
<thead>
<tr>
<th></th>
<th>Yes- continue to Q. 63</th>
<th>No- go to next question and finish there</th>
</tr>
</thead>
</table>

62 a) If no, why not? (e.g. was not needed; client did not want them involved; was not appropriate to involve them; no family members, etc)

__________________________________________________________________________

63. I provided an orientation to the services we provide to the family member, carer or support person

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
</thead>
</table>

64. I included the family member, carer or support person in the treatment planning for the person with depression

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
</thead>
</table>

65. I provided information on the illness and treatment (including medications) to the family member, carer or support person

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
</thead>
</table>

66. I taught the family member, carer or support person methods for monitoring their loved one’s medication

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
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<tbody>
<tr>
<td></td>
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<td>relevant</td>
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</tr>
<tr>
<td><strong>67.</strong> I informed the family member, carer or support person of the treatment progress of the person diagnosed with depression</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>68.</strong> I discussed with the family or support person how to respond in a crisis situation</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>69.</strong> I taught the family member, carer or support person stress management strategies to deal with their caring responsibilities</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>70.</strong> I taught the family or support person how to identify early warning sings of relapse</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>71.</strong> I mediated conflicts between the family member, carer or support person and the person diagnosed with depression</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>72.</strong> I provided family therapy to the family</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>73.</strong> I discussed future plans for treatment with the family member, carer or support person</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>74.</strong> I referred the family member, carer or support person to relevant support services as necessary</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>75.</strong> I advocated for access to services for the family member, carer or support person</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td><strong>76.</strong> I provided the family member, carer or support person with therapy or counselling for their own specific needs</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
</tbody>
</table>

**THANKYOU for completing this questionnaire.**
Appendix C: Questionnaire for Non-PID trained participants
Questionnaire: Caring for someone with depression -
Attitudes and clinical practices of mental health professionals

We would like to know more about the work that you do with those who are in a caring role for a person diagnosed with depression. We will refer to these individuals as ‘family members, carers or support persons’. This term refers to those people who provide unpaid practical and emotional support to a person with depression; and for whom this role impacts on their own day to day functioning, mental health or routine responsibilities.

We would like you to create a unique code based on your mothers’ maiden name and the month of your birth. The code provides an opportunity for the researchers to connect your data with future data should you decide to participate in our follow-up study. At the same time you remain anonymous to the researchers. For example, if your mothers’ maiden name was Smith and you were born in July, your code would be SmiJul

What are the first three letters of your mother’s maiden name?  ________

What is month of your birth?  ________
Part 1: Background Information

Please circle/write your response

1. Age: ________ years

2. Gender:
   Male     Female

3. Discipline/Profession (Please circle):
   Psychologist  Social Worker  Occupational Therapist
   Psych Nurse  Counsellor  Welfare Worker
   Other (please specify): _________________________________________

4. How long have you been working in this profession?

5. What is your primary area of work (Please circle one)?
   Therapy  Care coordination/case management  Counselling
   Education  Provision of information and advice
   Other (please specify):

6. Who do you primarily work with? (please circle one)
   Directly with mental health consumers
   With family members, carers or support people
   With family members, carers or support people of those diagnosed with mental illness

7. In which sector do you work?
   A. Area Health Service       B. Non government sector
     - Mental Health Service    - Carers organisation
     - Community Health Service - Mental health organisation
     - Population Health        - Division of General Practice
     - Other: ____________________        - Other: ____________________

   C. Private practice         D. Other (please specify): __________________

8. Have you attended any training specifically about working with family members, carers or support people?
   Yes    Please specify particular courses & duration:

   If yes, please go to Question 10.

   No
9. If not, how interested are you in training specifically about family, support persons or loved ones caring for someone with depression?

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<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>4</th>
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</thead>
<tbody>
<tr>
<td>Not at all Interested</td>
<td>Somewhat Interested</td>
<td>Interested</td>
<td>Very Interested</td>
<td>Extremely Interested</td>
<td></td>
</tr>
</tbody>
</table>

10. What is your primary reason for attending the training today (Please circle one)?

- Management directive
- To improve clinical practice
- Personal interest
- Other (please specify): ______________________________________________________

11. Please rate the importance of including family members, carer and support people in the assessment and treatment for those with:

<table>
<thead>
<tr>
<th></th>
<th>Not at all Important</th>
<th>Somewhat Important</th>
<th>Important</th>
<th>Very Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Eating Disorders</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Drug and Alcohol</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Dementia</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tbody>
</table>

12. How often do you work with family members, carers or support people in your current role?

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<tbody>
<tr>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Often</td>
<td>Always</td>
<td></td>
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</tbody>
</table>

13. What percentage of your case load would have a primary diagnosis of depression or are supporting a person with a primary diagnosis of depression?

<table>
<thead>
<tr>
<th></th>
<th>0-20%</th>
<th>20-40%</th>
<th>40-60%</th>
<th>60-80%</th>
<th>80-100%</th>
</tr>
</thead>
</table>

14. What do you think are the most important things to offer a person who is supporting someone with depression?

15. What do you think are the most challenging aspects for those who support a person with depression?

16. What do you think are the main benefits to involving family members, carers or support persons in the care provided to those with depression?

**Part 2** Please answer the following questions based on your experience of working with family members, carers and support persons.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>17. Providing information and skills for family members, carers and support persons reduces relapse rates for their loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Families, carers and support persons are an important source of information for mental health clinicians</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I work hard to involve (or support involvement of) family members, carers and support persons in the treatment for the person diagnosed with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Family members, carers and support persons are co-partners with providers in the rehabilitation/recovery of the person diagnosed with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. Family members, carers and support persons are an important resource for providers in advocating for change in mental health system</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. Supporting someone with a diagnosis of depression can have an impact on the family member, carer or support person's own mental health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. Family members of people with depression often have their own mental health problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. Family members, carers and support persons want to work more closely with staff</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Many family members, carers and support persons have learnt how to manage the depression fairly well</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>Not at all</td>
<td>Minor impact</td>
<td>Moderate impact</td>
<td>Great impact</td>
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<td>------------------------------------------------------------------------------</td>
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<td>-----------------</td>
<td>--------------</td>
</tr>
<tr>
<td>26.</td>
<td>Family members, carers and support persons often have unrealistic expectations for the person’s (diagnosed with depression) improvement</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27.</td>
<td>Family members, carers and support persons generally have little knowledge or understanding about depression</td>
<td>1</td>
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<td>4</td>
</tr>
<tr>
<td>28.</td>
<td>Family members, carers and support persons have difficulty communicating with mental health clinicians</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</tr>
<tr>
<td>29.</td>
<td>Family members, carers and support persons are often resistant to mental health clinicians’ suggestions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30.</td>
<td>The involvement of family members, carers or support persons in the care planning process is often harmful to the person with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>31.</td>
<td>Family members, carers and support persons are generally cooperative in the treatment process of the person with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32.</td>
<td>Many family members, carers and support persons are too emotional to deal with information about depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33.</td>
<td>Family members, carers and support persons of people with depression are generally satisfied with the level of support they are provided with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Please circle to what extent the following are obstacles to developing and providing services that involve or are for family members, carers or support persons of people with depression

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Not at all</th>
<th>Minor impact</th>
<th>Moderate impact</th>
<th>Great impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>34.</td>
<td>Organisations not being able to provide services out of usual business hours (e.g. weekends, nights) when it may be more convenient for families, carers or support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35.</td>
<td>Services not being available in certain geographic regions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>36.</td>
<td>Families, carers and support persons not being able to afford to pay for services</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>37.</td>
<td>Mental health clinicians not knowing how to work with a person’s culture to encourage family member, carer or support person involvement</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>38.</td>
<td>Consumers refusing to allow involvement of family members, carers and support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>The complexity of the work required for mental health clinicians when family members, carers and support people are involved</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>39.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40.</td>
<td>The lack of knowledge/understanding about depression that family members, carers and support persons have</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>41.</td>
<td>Lack of knowledge or scepticism of mental health workers about the benefits or added value to be obtained by involving family members, carers and support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>42.</td>
<td>Lack of interest of the family members, carers or support persons in being involved in the care planning for the person with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>43.</td>
<td>Family members, carers and support persons difficulties in communicating with mental health workers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>44.</td>
<td>There is a lack of agency support to provide services for family members, carers or support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>45.</td>
<td>Confidentiality regulations make it too difficult to involve family members, carers or support persons</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>46.</td>
<td>There is a lack of guidance and leadership from my organisation about how family members, carers and support persons should be involved</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>47.</td>
<td>Limited skills and confidence of mental health workers in working with family members, carers and support persons of people with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>48.</td>
<td>Mental health workers are overstretched with too many other demands from their workload to work with family members, carers or support persons of those with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>49.</td>
<td>There is a lack of interest from mental health workers in wanting to work with or involve family members, carers or support persons of people with depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Part 3

Please complete this section if you work directly with family members, carers or support persons of those with depression.

If you DO NOT work directly with family members, carers or support persons of those with depression, please skip this section and go to Part 4.

For those who work directly with family members, carers or support persons of people with depression, please use the example of the most recent family member, carer or support person you worked with to answer the following questions.

<table>
<thead>
<tr>
<th>50.</th>
<th>I provided an orientation to the services available to support the family member, carer or support person</th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
</thead>
<tbody>
<tr>
<td>51.</td>
<td>I provided information about the illness and treatment (including medications) to the family member, carer or support person</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td>52.</td>
<td>I taught the family member, carer or support person methods for monitoring their loved one’s medication</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td>53.</td>
<td>I taught the family member, carer or support person stress management strategies to deal with their caring responsibilities</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td>54.</td>
<td>I discussed with the family member, carer or support person how to respond in crisis situations</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td>55.</td>
<td>I worked with the family member, carer or support person on how to identify early warning signs of relapse</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td>56.</td>
<td>I mediated conflicts between the family member, carer or support person and the person diagnosed with depression</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td>57.</td>
<td>I helped the family member, carer or support person identify ways in which they could be kept up to date on treatment progress for the person diagnosed with depression</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
<tr>
<td>58.</td>
<td>I provided the family member, carer or support person with therapy or counselling to address their own needs</td>
<td>Yes</td>
<td>No</td>
<td>Was not relevant</td>
</tr>
</tbody>
</table>
59. I referred the family member, carer or support person on to another service who could provide additional assistance

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
</thead>
</table>

60. I advocated on behalf of the family member, carer or support person for access to services or better treatment

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
</thead>
</table>

61. I provided the family, carer or support person with assistance during crisis periods

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>Frequently</th>
</tr>
</thead>
</table>

**Part 4** If you work **directly with mental health consumers** please answer the following questions.

If you **DO NOT** work directly with mental health consumers, you have finished. Thank you for your time.

62. As part of your routine care for a person, how often do you involve family members, carers or support people in the assessment and treatment process?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always (Where possible)</th>
</tr>
</thead>
</table>

Please reflect back on the last client that you worked with who had a primary diagnosis of depression and answer the following questions.

63. I involved a family member, carer or support person in the assessment, treatment or care planning for the person with depression.

<table>
<thead>
<tr>
<th></th>
<th>Yes- continue to Q. 63</th>
<th>No- go to next question and finish there</th>
</tr>
</thead>
</table>

63 a) If no, why not? (e.g. was not needed; client did not want them involved; was not appropriate to involve them; no family members, etc.)

64. I provided an orientation to the services we provide to the family member, carer or support person

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
</thead>
</table>

65. I included the family member, carer or support person in the treatment planning for the person with depression

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Was not relevant</th>
</tr>
</thead>
</table>

66. I provided information on the illness and treatment (including medications) to the family member, carer or support person

<table>
<thead>
<tr>
<th></th>
<th>Was not</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>67.</strong> I taught the family member, carer or support person methods for monitoring their loved one’s medication</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>68.</strong> I informed the family member, carer or support person of the treatment progress of the person diagnosed with depression</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>69.</strong> I discussed with the family or support person how to respond in a crisis situation</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>70.</strong> I taught the family member, carer or support person stress management strategies to deal with their caring responsibilities</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>71.</strong> I taught the family or support person how to identify early warning signs of relapse</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>72.</strong> I mediated conflicts between the family member, carer or support person and the person diagnosed with depression</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>73.</strong> I provided family therapy to the family</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>74.</strong> I discussed future plans for treatment with the family member, carer or support person</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>75.</strong> I referred the family member, carer or support person to relevant support services as necessary</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>76.</strong> I advocated for access to services for the family member, carer or support person</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>77.</strong> I provided the family member, carer or support person with therapy or counselling for their own specific needs</td>
<td>Yes</td>
</tr>
</tbody>
</table>

THANKYOU for completing this questionnaire.