Factors that influence treatment choices made by people with depression

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Abstract

Background: People with depression should be actively involved in deciding what treatment they are prescribed. In order to facilitate informed decision-making, healthcare professionals need to be aware of, and respond to the decision-making issues patients find important. Whilst a number of factors have been related to particular treatment decisions in depression, little is known about how these factors relate to each other and how influential people think they are in relation to treatment decision-making.

Aim: To better understand what factors influence treatment decisions made by depressed people.

Method: Using concept mapping, an established mixed methods design, I collected and compared the views of patients (n=28), their family and friends (n=14) and healthcare workers (n=22). The method involves three data collection tasks.

1. Brainstorming – within the group or in individual sessions, participants brainstorm about the factors that influence treatment decisions made by depressed people. The factors are recorded as individual 'statements', and pooled at the end of the phase in order to be reviewed and reduced to below 98. All participants are invited again to take part in the following tasks.

2. Clustering – participants individually put together into groups the statements that they consider to be related based on their own criteria.

3. Prioritising – participants individually rank their perceived relative importance of each statement with regards to its effect on patients' treatment decisions.

Results: The three stakeholder groups differed significantly in their opinions about which factors they considered to be most influential l of patients' treatment decisions. These factors included patients' insight, emotional states (i.e. how I feel right now), external views about depression (stigma) and doctors' advice. I also identified five subgroups of patients with depression who differed significantly in their views about how they make treatment decisions.

Conclusion: To facilitate more considered decisions about depression treatment, mental health professionals need to better understand how treatment choices are made. Health professionals should be more vigilant to the differences of individual patients.

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Chapter 1 Introduction to thesis

1.1 Introduction

Depression is a mood disorder with a profound impact on wellbeing of the patients and their close family and friends. Depression affects up to one in ten people in their lifetime (Waraich et al., 2004) and it is the leading cause of burden of disease (Ferrari et al., 2013b). At the same time, depression is treatable and with appropriate intervention most people could fully recover and lead healthy lives (Dawson et al., 2004). Treatment of depression, including less severe forms of the illness is important, since even mildly depressed mood can significantly impact on a person's wellbeing (Klein et al., 2006). But research shows that only a limited proportion of depressed people seek help for their symptoms (Alonso et al., 2000). Moreover, receiving appropriate treatment is not very common (Kessler et al., 2003) and most patients discontinue their treatment too early and without prior consultation with their physician (Olfson et al., 2006).

In recent years, patients' active engagement in treatment decisions has received considerable attention. The practice guidelines recommend that professionals should involve patients in the treatment decision-making (NICE, 2009), whilst research shows that many professionals perceive considerable barriers to doing so (Legare et al., 2008). But regardless of the professionals' views, many patients also make their own decisions about what treatment they would prefer, which health professional they visit, whether they follow the tasks involved in psychological therapies or whether they take the medication as prescribed. Patients have become more autonomous in their healthcare choices and in order to provide adequate help, mental health professionals should understand how depressed people make decisions about treatment. I therefore aimed to explore the factors affecting patients' treatment decisions about depression treatment. Rather than viewing depressed people as detached individuals making solely independent decisions, I

sought to understand their treatment choices within the context of their family and friends and healthcare professionals.

1.2 Study aims and objectives

This study was designed to help develop understanding about how people with depression decide about their treatment for the illness.

1 To explore what factors influence treatment decisions made by people with depression from the perspectives of the patients, their family and friends, and healthcare workers who have professional contact with people with depression.

2 To gain insight into how these three groups understand the relative importance of the factors identified, and compare and contrast their views about patients' depression treatment choices.

3 To explore the possibility of identifying different types (categories) of patients, family and friends and professionals, based on their opinions about the factors affecting patients' treatment choices.

To achieve these aims I worked with people with depression; partners, family members or close friends helping these patients (family and friends) and healthcare workers currently or recently involved in the treatment of people with depression. This study provides an in-depth analysis of the aspects people with depression consider when making a decision about treatment for depression and the perspectives of family and friends and healthcare workers about this issue. The overall objective was to obtain a better understanding about how depressed patients consider and select the different treatment options. In this study I did not distinguish between the individual types of decisions, e.g. help-seeking or adherence. Instead, I worked with an assumption that all types of treatment decisions are influenced by the same set of factors. This was based on the similarity of the factors previously identified as important in the individual types of treatment choices, such as health professionals, access to treatment or stigma. Moreover,

since people often make irrational rather than fully informed decisions, the factors that are important for a person in a given period of time might affect their choices regardless of type.

1.3 Contribution of the thesis

The need to understand how patients with depression make treatment decisions has been articulated in previous research. In this thesis, I explored the factors that influence treatment decisions made by depressed people. Specifically, I focused on the views of patients, their family and friends and healthcare workers about the relative importance and relationships between the individual factors. Whilst a number of factors have previously been identified as impacting on patients' treatment choices, this study is the first to systematically involve three stakeholder groups in order to explore their perspectives about the topic.

This study provides a novel observation about the relationships between the individual factors participants identified. This is also the first study to show the relative importance of the individual factors from the participants' views. Using concept mapping method enabled the collection of invaluable information about how the stakeholders perceive patients' treatment choices. The views of the individual groups about the factors' influence can therefore be compared and contrasted. Such comparisons show to what extent the groups agree about how decisions are made about depression treatment. Based on this information, future interventions can be developed to address the identified issues, and help professionals to facilitate effectively patients' involvement in the decisions.

1.4 Structure of the thesis

In Chapter 2 I describe depression, its epidemiology and recommended treatment. Research shows that despite availability, adequate treatment is not provided to most depressed patients. In Chapter 3 I provide an overview about decision-making and the potential effects of depression on the related cognitive processes. I then

review the literature about the factors influencing patients' treatment choices. In Chapters 4 and 5, I explain and justify the methodology, procedure and data analysis used in this study. Descriptive results are shown in Chapter 6, the individual factors affecting choices are presented in Chapter 7 and the perceived relative importance of these factors, as viewed by the three stakeholder groups is shown in Chapter 8. I present the differences between types of participants in Chapter 9. The study findings are discussed in detail in Chapter 10, and conclusions and future recommendations are provided in Chapter 11.

Chapter 2 Depression and treatment

2.1 Introduction

In order to review the literature about depression and treatment decisions made by depressed patients, I searched the main medical and psychological databases, including Medline, Psychinfo and Cinahl. In the searches I combined the term depression with relevant keywords, including adherence, help seeking, treatment preference, treatment choice, patient choice, patient preference, decision, belief and attitude. I included peer reviewed research articles written in English, published from year 2000 onwards as the original criteria but included a few key earlier papers. In the process of the review, these papers were signposted in other publications. I specifically looked at systematic, scoping and other comprehensive reviews of the relevant literature and reports of primary research using qualitative, quantitative and mixed methods with participants aged 18 years or older. I also included relevant practice guidelines as appropriate.

2.2 Depression

Whilst everyone can feel down and sad in response to various life stressors, depressive episode can be diagnosed when such emotions impact significantly on everyday life and are experienced over a prolonged period of time.

2.3 Severity of depression

Depression can be diagnosed as a single episode, recurrent or chronic illness. Based on the assumed aetiology, it has been described as endogenous, when there is no apparent environmental trigger for the illness, or reactive, when patients can identify stressful life events prior to developing an episode. It is typically described as mild, moderate or severe, depending on the number and severity of symptoms. Some authors have suggested that it might be better understood on a continuum from normal mood to severe depression, rather than as three distinct types. For

example, Cuijpers et al (2004) in a Dutch population-based interview study with 7,076 respondents described depression within 5 categories based on the number of symptoms and functional disability. They found that even mild depression had an impact on patients' functionality.

Additionally, even sub-threshold depression often has a strong impact on people's health and wellbeing. In a World Health Organisation Survey based on a sample of 252,503 members of general population from 68 countries, Ayuso-Mateos et al (2010) reported that impact of depression on health status is similar in patients with any severity. Similarly, Nuevo et al (2010) found in a general health survey with 551 participants, that quality of life appears to decrease significantly after becoming depressed regardless of diagnostic severity. Sub-threshold depression has also been associated with an increased probability of developing a depressive episode and suicide attempts, based on an epidemiological community study (N=10,526) (Judd et al., 1997). A chronic type of sub-threshold or mild depression is dysthymia, characterised by at least four symptoms present on most days for duration of at least two years (APA, 2010).

2.4 Symptoms

Depression affects people on emotional, cognitive and somatic levels. Key symptoms include depressed mood, loss of pleasure in most activities and fatigue. Based on the widely used diagnostic manuals, the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (APA, 2013) and the International Classification of Diseases (ICD-10) (WHO, 2010), at least one or two of these symptoms need to be present for a diagnosis respectively. In addition, four out of ten symptoms are required by the DSM-V or at least five out of nine depressive symptoms according to the ICD-10. The symptoms should be present almost every day, most of the day for at least two weeks (APA, 2013, WHO, 2010). These additional symptoms include appetite/weight disturbances, too much or too little sleep, notably slower activity (for example, speech), fatigue, tiredness or loss of energy, thoughts of excessive guilt, desperation, worthlessness, lower concentration and attention, and thoughts

of self-harm, death or suicide (APA, 2013, WHO, 2010). People with depression also often report medically unexplained physical pain. Overall, the particular set of symptoms varies considerably among different people and in different times during the illness (Judd et al., 1997). In a selective review, Patten et al (2008) suggested that even people with a diagnosable syndrome might not require intensive treatment and that patients should be treated in a more individual manner.

2.5 Impact

Depression has a substantial impact on life and wellbeing of patients and their social environment. Based on a systematic review and meta-analysis of epidemiological data, Ferrari et al (2013b) found that depression is a leading cause of years lived with disability (YLD). In another review of epidemiological studies, Moller et al (2003) found that nearly 70% of suicides in England were related to depression. Additionally, they reported that between 60% and 70% of patients with acute depression considered suicide and 10-15% attempted a suicide. In a pan-European cross-sectional study, the lifetime risk of suicide attempt in depressed people was around 28% (Bernal et al., 2007). The authors also reported that almost 8% of the population have experienced suicidal thoughts (Bernal et al., 2007). In England in 2000, depression resulted in a loss of almost 110 million working days and a loss of 2,615 lives (Thomas, 2003). The author reported that the total estimated cost of depression in people over the age of 15 years in England was more than £9 billion, while the cost of direct treatment was £370 million.

2.6 Epidemiology

Depression is a common mental illness and affects approximately 350 million people around the world (WHO, 2012). Despite the general consensus that the illness is common, the reported prevalence of depression varies considerably across continents and individual countries. In a review of epidemiological studies, Waraich et al (2004) found that depression is approximately three times more common in Europe, and seven times less common in Asia than the rest of the world.

Authors of the Adult Psychiatric Morbidity Survey in England (n=7,403) reported that at any one time, approximately 2.3 percent of the general population in England aged over 16 meet the diagnostic criteria for depression (Deverill and King, 2009). Studying specifically the UK primary care population (n=47,170), Martin-Merino et al (2010) found that the prevalence of depression in this sample was more than 11%. They reported findings of a cohort study using data from a primary care research database (THIN) with nearly 50,000 primary care patients and matched controls (Martin-Merino et al., 2010).

Reports of the 12-month and lifetime prevalence of depression vary across studies, as well. In a US-based general population survey conducted using face-to-face interviews (n=9,090), 12-month prevalence of depression was 6.6 percent (Kessler et al., 2003). On the other hand, Waraich et al (2004) systematically reviewed 23 studies conducted in different countries and found that depression globally affected just over 4 percent (range of 0.6 to 15.4 per 100) and dysthymia affected 2 percent (range of 0.8 to 3.3 per 100) of the general population in the previous year. In terms of lifetime prevalence, Waraich et al (2004) found that nearly 7 percent (range between 0.9 and 29 per 100) of the general population have depression and almost 4 percent (range of 0.9 to 14 per 100) have dysthymia. On the other hand, Kessler et al (2003) reported the lifetime prevalence of depression to be over 16 percent. Kessler et al (2003) also found that of people with 12-month depression, 10% had a diagnosis of mild, 39% had moderate, 38% had severe and 13% had very severe depression.

Whilst the authors of these studies aimed to calculate the prevalence of depression within the general or primary care populations, the reported data should be compared carefully due to differences in inclusion criteria, study populations and assessment methods. For example, while Martin-Merino et al (2010) included primary care patients aged 10-79 years, Deverill and King (2009) included members of the general population older than 16 years, with no upper age limit. Additionally,

Waraich et al (2004) included people aged over 16, but Kessler et al (2003) only interviewed people aged over 18 years, although the studies were generally focused on the adult population. Another issue is the diagnostic manual used to determine a diagnosis, as some authors used the DSM-III and ICD-10 criteria, but in more recent studies, the DSM-IV was used. Additionally, some authors have criticised the varying definitions of the term 'prevalence' and the resulting differences in the prevalence periods reported (Waraich et al., 2004). All of these variations make it more difficult to compare the results across studies.

2.7 Course of depression

As required by diagnostic manuals, a depressive episode typically lasts for at least two weeks, but can vary considerably among individuals. Findings from general population surveys in the US and Netherlands (n=7,076) suggest that an average episode lasts between 3 and 8 months (Kessler et al., 2003; Spijker, 2002). Spijker (2002) also reported that approximately half of all patients reached remission of symptoms after three months. About 30 percent of patients do not recover within six months, 25 percent are depressed after one year and almost 20 percent of patients still meet diagnostic criteria after two years (Spijker, 2002). Based on the findings of a systematic review, Holzel et al (2011) suggested that chronicity of depression was associated with its onset at age below 21-25, a longer duration of episodes and a family history of affective disorders.

2.7.1 Demographic characteristics

In a large US-based household survey (n=14,710), the average age of depression onset was found to be 24 years for 12-month prevalence and 26 years in case of lifetime depression (Gonzalez et al., 2010). The results of another US household survey (n=9,282) showed that half of all people with depression have their first episode before the age of 14 and 75% before age 24 (Kessler et al., 2005).

In a large European general population survey (n=1,884), Angst et al (2002) found that depression appears to affect men and women in different ways in terms of symptoms and disability based on a number of symptoms. Other population-based studies showed that depression is more common in women than men with a risk ratio of almost 1.5 (Ferrari et al., 2013b). Whilst this might be caused by women's higher susceptibility to depression, Doherty and Kartalova-O'Doherty (2010) suggested that this might be because women are also more likely to disclose the symptoms and seek help. Conversely, men are more likely to die by suicide accounting for up to 75 percent (ONS, 2012). This might suggest that men might address emotional difficulties in different ways. In the European survey, depression with more than five symptoms was most common in people aged 45-54 (8.9% in men and 16.6% in women) (Angst et al., 2002). Mild depression (up to four symptoms) was most common in young men aged 16-24 (6.6%), in women aged 65-74 (7.9%) and in young women (7.3%) (Angst et al., 2002).

2.8 Risk factors

The cause of depression is often unknown, but multiple factors contribute to the development of an episode. Meng and D'Arcy (2014) reported that modifiable risk factors such as chronic illness, smoking and low income might explain approximately 40% of depression cases. Their findings were based on a 16-year cohort study in a sample of 15,254 participants in the Canadian general population. Other risk factors include previous episodes of depression, family history and genetic factors, adverse life events and individual characteristics such as personality.

2.8.1 Previous episodes

Depression is highly recurrent. Results of a 15 year follow-up study (n=485) showed that female gender, the duration of a depressive episode and quantity of previous episodes increased the risk of recurrence (Mueller et al., 1999). Approximately one in five patients treated with antidepressants relapse within one year after diagnosis, compared to more than double in those treated with placebo, according to meta-

analysis of 11 studies (Williams et al., 2009). In a follow up of 37 depressed patients over 23 years, Yiend et al (2009) suggested that almost two in three patients experience at least one further episode within 23 years after diagnosis. The authors reported that most people had at least two additional episodes that were often chronic. In a systematic review of epidemiological studies, Hardeveld et al (2010) reported that, in a specialised mental health setting, 60% of patients have another depressive episode within 5 years and 85% have another episode after 15 years.

2.8.2 Comorbidity

Depression has been associated with a number of comorbid illnesses. Mergl et al (2007) reported findings of a cross-sectional primary care-based study (n=394) and suggested that a combination of depression and anxiety or somatoform disorders were the most common, affecting more than 6 times more patients than depression alone. In a longitudinal study of 8,387 people aged between 51 and 61 years, Polsky et al (2005) found that, within two years of diagnosis, depression affected approximately 13% of people with cancer and chronic lung disease, 9% of patients with stroke and 5% of people with heart disease, diabetes and arthritis. Over an eight-year study period, patients with chronic lung disease and heart disease were at the highest risk of depression (Polsky et al., 2005). Findings of a meta-analysis showed that the risk of depression was doubled for people with diabetes compared to people without diabetes (OR=2.0; 95%; CI 1.8-2.2) (Anderson et al., 2001). Reviewing the literature, Robinson (1998) found that between 20 and 40 percent of post-stroke patients develop depression. Additionally, approximately half of patients after myocardial infarction (MI) become depressed, based on the findings of a prospective study with 288 patients (Lane et al., 2002).

2.8.3 Personality

Personality characteristics, mainly neurotic and distressed traits, have been associated with increased risk of becoming depressed. In a large pan-European study across 21 countries, Kupper et al (2013) found that a combination of increased negative affectivity and social inhibition to express emotions (Type D

personality) was significantly related to a depressive episode. Additional personality traits, such as increased trait neuroticism and low conscientiousness were related to depression in a recent prospective community-based study with 500 older adults (Weiss et al., 2009).

2.8.4 Stress, adverse life events and genetic predisposition

Adverse and stressful life events such as loss of job, divorce, bereavement have been identified as a risk factor for developing a depressive episode. Farmer and McGuffin (2003), in a study with 108 depressed patients and 105 controls, found that having experienced a severe humiliating or loss-related life events was linked to developing depression, but encountering a large number of non-severe events was not. Zubenko et al (2001) in a diagnostic study involving 81 depressed people and their nuclear families suggested that genetic predisposition is linked to depression with onset before age 25. In a 9-year longitudinal study with twins, Kendler et al (2001) linked these effects with genetic predisposition, suggesting that people with an increased genetic risk for depression reported fewer stressful life events prior to having an episode.

2.9 Diagnosis

Most people with depression are diagnosed and treated in primary care. Screening using a two-question test (Whooley et al., 1997) can detect the illness in 86% of depressed people. To determine the diagnosis and severity, further testing is needed since its specificity was found to be 78% in a New Zealand validation study with 2,642 primary care patients (Arroll et al., 2010). In primary care, the Patient Health Questionnaire is commonly used (Kroenke et al., 2001). It contains nine questions about individual symptoms based on the diagnostic criteria in DSM IV, and patients are asked to rank how frequently they experienced the symptoms over past 2 weeks. The questionnaire has been tested in a number of studies. In an US-based study with primary care and obstetrics-gyneacology patients (n=6,000), Kroenke et al (2001) reported both the sensitivity and specificity of PHQ-9 to be 88% (Kroenke et al., 2001). Arroll et al (2010) tested the questionnaire against a

structured interview (CIDI) and found the sensitivity and specificity to be 74% and 91% respectively.

A full diagnosis of mental illnesses can be determined by a clinical fully structured interview (Composite International Diagnostic Interview) (WHO, 1990). It is based on the mental illness diagnostic criteria of ICD-10 and DSM-IV (Kessler and Ustun, 2004).

2.10 Treatment

The majority of people with depression are seen in primary care where optimised treatment should achieve remission in about 50-67% of patients, based on a meta-analysis of 13 randomised controlled trials (n=3,202 patients) (Dawson et al., 2004). In the UK, treatment of depression in primary care should be based on the clinical guidelines published by the National Institute of Health and Clinical Excellence (NICE, 2009). Other influential guidelines include those published by the British Association for Psychopharmacology (Anderson et al., 2008) and the American Psychiatric Association (APA, 2010). The guidelines comment on the recognition and diagnosis of depression, recommendations about the clinician's approach to patients and strategies of treatment selection.

All three guidelines recommend that professionals should involve patients in treatment decision-making (NICE, 2009, APA, 2010, Anderson et al., 2008). The NICE guidelines also advise that professionals should encourage patients to play an active role during prescription of treatment for depression. Health professionals should also sensitively explore and address patients' concerns about the illness and treatment (NICE, 2009). The factors that should be considered when making a choice include patients' preferences and experiences, evidence of treatment effectiveness, side effects and its availability.

The NICE guidelines recommend a stepped care approach to patients with depressive symptoms. In this approach patients with any depressive symptoms are offered an appropriate intervention that is minimally intrusive. If the desired effects are not achieved, a more intense treatment should be recommended. The other two guidelines also recommend different treatments for people with various symptoms, but do not specifically mention the stepped care model.

For sub-threshold depression, the NICE guidelines recommend watchful waiting, lifestyle changes and guided self-help programmes. For mild to moderate depression all three guidelines recommend psychological therapies such as cognitive behavioural therapy (CBT) and interpersonal psychotherapy (IPT) (Anderson et al., 2008, APA, 2010, NICE, 2009). Only one of the manuals endorsed counselling (NICE, 2009). The NICE and BAP guidelines also suggest regular exercise or self-help therapies. The APA and BAP guidelines recommend medication for people with mild and moderate depression, but the NICE guidelines do not recommend medication for mild depression due to lack of evidence of efficacy. In a meta-analysis of antidepressant trials, Kirsch et al (2008) found that the effect of the medication was greater in more severe depression. The clinical guidelines consistently advise prescription of mediation to people with persistent dysthymia, moderate and severe depression (Anderson et al., 2008, APA, 2010, NICE, 2009).

2.10.1 Antidepressant medication

Antidepressants are prescribed for depression based on evidence that they increase the levels of available neurotransmitters such as noradrenaline, dopamine and serotonin in the brain areas including the prefrontal cortex, hippocampus, amygdala and thalamus (Willner et al., 2013). Whilst Andrews et al (2011) in a literature review suggested that the evidence that low levels of these neurotransmitters cause depression is inconclusive, Dawson et al (2004) in a meta-analysis of 13 studies (n=3,202 patients), found that antidepressants can effectively reduce symptoms in 50-67% of patients, compared to 32% remission in placebo conditions. In a secondary analysis of an earlier longitudinal study with 225 patients starting to

take antidepressants, 45% of people reached remission within two years from start of treatment (Simon, 2000). There are four main types of antidepressant medication, including Selective Serotonin Reuptake Inhibitors (SSRIs), Tricyclic antidepressants (TCAs), Mono Amine Oxidase Inhibitors (MAOIs) and third-generation antidepressants. The drugs differ in the effects and side-effects.

All guidelines recommend that treatment with antidepressants should continue beyond patients' remission, but they differ in the suggested duration. The APA guidelines suggest a continuation phase of between four and nine months, whilst the NICE recommend at least 6 months and the BAP a duration of 6 to 9 months after full remission. If the risk of relapse is considered to be high, guidelines recommend at least 1 to 2 years (Anderson et al., 2008) or at least 2 years (NICE, 2009) of maintenance treatment.

Results of a primary care cohort study showed that antidepressants are prescribed to approximately 90% of patients with depression (Martin-Merino et al., 2010). Despite their frequent use and the evidence of effectiveness in reducing depressive symptoms (Dawson et al., 2004), antidepressant medication is commonly perceived in a negative light. For example, in a Danish postal survey involving 500 hospital patients with depression or bipolar disorder, Kessing et al (2005) found that between 40 and 80 percent of respondents had negative views about the effect of antidepressants. Jorm et al (1997), in a large Australian survey, compared the perceptions of 2,031 members of the public and 2,454 health professionals about the helpfulness of mental health treatment. The authors found that professionals had more positive views about medication, while members of the public more often thought that people with mental illness should take dietary supplements and read self-help books. On the other hand, reporting findings of an Australian national survey (n=1,796 adults), Reavley and Jorm (2012) found that almost 64 percent of the general population viewed the medication as helpful, whilst almost 20 percent thought it was harmful. One of the most common worries about antidepressants is that they are addictive, even though these medications do not cause addiction. For

example, Stone et al (2004) reported results of interviews with 89 neurology outpatients, suggesting that almost three in four people thought that antidepressants were addictive and almost half of the sample considered them to be harmful.

2.10.1.1 SSRIs

SSRIs are generally recommended as the first line treatment when medication is indicated. They are the most frequently prescribed treatment for depression, and include citalopram, fluoxetine, paroxetine and sertraline among others. Their main effect is to block the reuptake of serotonin, with the intent to stimulate the neural pathways to improve mood and increase activity, but some of the drugs also affect reuptake of noradrenaline and dopamine (NICE, 2009). Their first effect can be felt almost immediately (Symonds and Anderson, 2012), although part of it is thought to be a result of placebo effect, which is a positive effect patients might perceive and attribute it to their therapy or treatment. In a meta-analysis of 96 antidepressant drug trials, Rief et al (2009) found that as much as 68% of the medication effect was accounted for by placebo. Some researchers suggested that due to the high placebo effect and limited 'true' effect of the medication, antidepressants should not be prescribed as widely as they are (Kirsch et al., 2008). Others, on the other hand, have argued that antidepressants are effective and even if they have a clinical but non-significant impact, the drugs should be made available to all patients, including people with milder depressive symptoms (Hegerl et al., 2012).

Contrary to popular belief, SSRIs are not addictive, but due to a short half-life many types need to be discontinued gradually, in order to prevent withdrawal symptoms (NICE, 2009). Side effects of SSRIs are generally less severe than the older TCAs and MAOIs, yet are persistent and common in around two in three patients, as shown in a Dutch study with naturalistic primary care setting (n=927 patients) (Bet et al., 2013). Most often the side effects include headache, nausea, diarrhoea, sexual difficulties, sweating and weight gain (Bet et al., 2013).

2.10.1.2 TCAs and MAOIs

Tricyclic antidepressants (such as amitriptyline and imipramine) and monoamine oxidase inhibitors (MAOIs), for example moclobemide, were among the first medications for depression, developed in the 1950s (Kuhn, 1958). Their main effect is to block reuptake of monoamines and increase availability of noradrenaline and serotonin. The TCAs and MAOIs are toxic in overdose and have severe side effects including blurred vision, constipation, sedation, hypotension and cardiac toxicity (NICE, 2009). Anderson (2000) conducted a meta-analysis of data about the efficacy and tolerability of TCAs and SSRIs from 102 trials (n=10,706 patients) and 95 trials (n=10,553 patients), respectively. He reported that SSRIs were slightly better tolerated, but less effective than TCAs in hospitalised patients (Anderson, 2000).

Monoamine oxidase inhibitors (MAOIs) and TCAs have mostly been replaced by the SSRIs and they are now suggested only for patients who do not respond to newer antidepressants (APA, 2010, NICE, 2009).

2.10.2 Psychological therapies

Psychological therapies recommended for depression are based on the principles of cognitive behavioural therapy (CBT), structured to help patients develop skills enabling them to identify and challenge their irrational thoughts. The therapy is based on cognitive theories suggesting that people's automatic negative and dysfunctional thoughts influence emotions and behaviours, which are acting as an underlying risk factor for developing depression (Beck, 1967, Ellis, 1987). Beck (1967) referred to a cognitive triad, suggesting that a person's dysfunctional or irrational thoughts about themselves trigger negative thoughts about their experiences and subsequently about the future. The two models describe depressed people's thoughts as automatic, emphasising the negative and self-criticising attitudes, over-generalisation of negative events, excessive personalisation and self-blaming, ignoring or dismissing positive aspects and minimising positive aspects of situations (Beck, 1967, Ellis, 1987). The aim of the

psychological therapies is to replace the negative thinking with a more effective approach to self and to external situations.

NICE divides the therapies recommended for depression into two categories, which are low- or high-intensity (NICE, 2009). Low-intensity treatments are recommended for people with sub-threshold and mild depression and are based on principles of cognitive behavioural therapy (CBT). They are offered as a set of six to eight sessions of self-help and guided self-help (with brief contact with a health professional), such as computerised CBT, over a period of 9 to 12 weeks. Low-intensity therapies have been found beneficial for people with mild to moderate depression. For example, Matcham et al (2014) systematically reviewed self-help interventions for psychological distress in people with physical comorbidities. In a meta-analysis of 25 studies and 421 patients, they suggested that the interventions had a significant positive effect on patients' depressive symptoms.

High intensity therapies are recommended for people with persistent mild or moderate to severe depression (NICE, 2009). They include individual or group CBT and interpersonal therapy (IPT), which should be provided for up to 16 to 20 sessions over three to four months. Studies show that cognitive therapies can be effective for depression and prevent relapse. For example, Hollon et al (2005) found that cognitive therapy had a preventive effect on patients even after withdrawal of therapy, which was comparable to the effect of medication maintenance treatment. The authors reported findings of a randomised controlled trial with a 12 month naturalistic follow up with 104 patients with moderate to severe depression (Hollon et al., 2005). Despite the effectiveness of cognitive therapies, some authors questioned the causal effect of automatic negative thoughts on depression. For instance, reporting results of a 12-week group cognitive behaviour therapy programme with 168 depressed people, Oei et al (2006) suggested that treatment might affect patients' depressive symptoms prior to helping them reduce the negative thoughts. For mild to moderate depression, the NICE guidelines also

suggest psychodynamic psychotherapy or counselling provided for up to 20 sessions within three to four months.

2.10.3 Mindfulness-based therapy

Mindfulness is a meditation technique originating in Buddhist philosophy (Kabat-Zinn, 1990). To prevent and treat depressive symptoms, Segal developed mindfulness-based cognitive therapy (MBCT), in which people focus on their present state of mind with the aim of observing their emotions and thoughts and of interrupting the negative thinking modes as soon as they occur (Segal et al., 2002). It was developed as an 8-week individual or group-based therapy. During its course, patients also learn to identify the triggers of their negative thoughts and approaches to address them. The therapy is based on a theory that after experiencing a depressive episode, people are emotionally more vulnerable and sensitive to stress. Adopting a conscious awareness of thoughts could therefore help prevent further relapses (Segal et al., 2002).

Research shows that the mindfulness based therapies can effectively reduce depressive symptoms. For example, Britton et al (2012) reported findings of an 8-week randomised controlled trial with 52 people with depression in partial remission. They compared the effects of the MBCT and a waiting list condition, suggesting that participants in the experimental group had improved emotional reactivity to stress, whilst the control group showed anticipatory anxiety (Britton et al., 2012). In a larger trial with 60 people in remission from depression, Bondolfi et al (2010) compared the protective effect of MBCT and treatment as usual over a period of 14 months. The authors found that mindfulness therapy prolonged the time before relapse by almost 200%, although rates of relapse were similar in both groups (Bondolfi et al., 2010). Their findings were supported by the findings of a similar RCT by Van Aalderen et al (2012), who suggested that adopting MBCT effectively reduced the patients' depressive symptoms through reducing rumination and anxiety.

2.10.4 Other treatment

General lifestyle changes including healthy diet and regular exercise can effectively reduce depressive symptoms and can be recommended for patients in addition to their usual care (NICE, 2009). Findings of a recent Cochrane systematic review showed that exercise can be as effective as cognitive therapy in alleviating symptoms of depression, but that more research is needed to determine the most suitable type (such as aerobic, anaerobic) and the exact therapeutic effect (Mead et al., 2009). The treatment guidelines also comment on alternative medicines, such as light therapy, nutritional and herbal supplements (for example St. John's Wort) and generally do not recommend them as treatment for depression (APA, 2010, NICE, 2009, Anderson et al., 2008). Light therapy is an exception, as it has been suggested as a potential choice for Seasonal Affective Disorder (APA, 2010, NICE, 2009, Anderson et al., 2008).

2.10.4.1 Electroconvulsive therapy (ECT)

ECT involves inducing an epileptic-like seizure through an electrical current applied to a patient's brain. The therapy is provided under general anaesthesia. The therapy can have serious side effects, such as short-term or partial memory loss (amnesia), and it is generally recommended as a last resort treatment or treatment of choice in patients who do not respond to other treatments or are in a risk-of-life situation (APA, 2010, NICE, 2009, Anderson et al., 2008).

2.11 Conclusion

Depression is a distressing and potentially serious illness that has a profound impact on a person's mental state and day-to-day functioning and treatment is recommended for all types of depression. An important aspect of treatment of depression is the ability and opportunity for patients to actively contribute to the treatment decision-making.

Chapter 3 Patients' treatment decision-making

3.1 Treatment decisions

Despite the availability of effective treatment in primary care, depression is often under-treated. This is largely caused by patients' and professionals' need to make decisions about treatment. Before selecting an appropriate treatment option, depressed people need to seek medical help and disclose their symptoms to their doctor in order to access the formal treatment options, and physicians need to recognise the symptoms and provide an appropriate diagnosis.

The factors associated with the suboptimal treatment of depressed people are related to health professionals as well as patients. For example, in a systematic review and meta-analysis, Cepoiu et al (2007) found that non-psychiatric primary care physicians often fail to recognise the illness. Goldman et al (1999), in another literature review, suggested that only half of all patients with depressive symptoms are given a diagnosis. Other issues are more associated with the patients, for example deciding to seek professional help and adherence to prescribed treatment regimen.

Even when people consult their doctor and receive a diagnosis, prescription of adequate treatment is not guaranteed. Reporting findings of a large European study with 21,425 participants, Alonso et al (2004) found that 21 percent of people with mood disorders were not receiving any treatment at the time of the study. Results of large household surveys with around 10,000 respondents showed that between 14 and 52 percent of people with depression or other neurotic disorders were receiving treatment (Bebbington et al., 2000, Kessler et al., 2003). Despite this, adequate treatment as recommended by practice guidelines was prescribed to only half of those people (Kessler et al., 2003).

3.2 Treatment decision-making framework

According to the practice guidelines, depressed patients should be given an opportunity to take an active part in treatment choices and professionals should facilitate shared decision-making (NICE, 2009). Shared decision-making (SDM) is one of three main models of approaching patients, the others including paternalistic model and patients' informed decisions (Charles et al., 1997). Rather than three unrelated models, the authors described the approaches as a continuum of the involvement the doctor and patient have in decisions, and communication between them.

In the paternalistic approach, the clinician is viewed as the dominant figure and consultations are focused on collecting information about symptoms and giving advice about the best treatment, or persuading the patient to consent to the advice (Charles et al., 1997). In the model of patients making informed decisions, one of the parties is also expected to have a dominant role in the decision-making process, although it is the patient in this model. When patients are expected to, or they prefer to make their own informed choices, health professionals have limited involvement in the process, assuming that the patient is fully autonomous. The main problem with these two models is their emphasis on sole dominance of one of the involved parties, rather than a constructive conversation between them (McCabe et al., 2013). Within another approach, the preferred concept of shared decision-making, the professional and patient are both involved in the process of making treatment choices (Charles et al., 1997).

According to the basic principles of SDM, the patient and at least one health professional should play an active role in the decision-making process (Charles et al., 1999). To do this, they are expected to share information (such as symptoms, diagnosis and treatment options) with each other. The aim is to determine a treatment schedule on which both doctor and patient agree. As part of respecting the patients' views, physicians should facilitate discussions about treatment choice,

initiation, but also its discontinuation or change if patients wish (McCabe et al., 2013).

3.2.1 Impact of patients' involvement

Many patients want to have an opportunity to influence their treatment choices, but the reported numbers vary considerably. For example, Patel and Bakken (2010) surveyed 60 people who were seeking medical care for depression and reported that 98% of the sample wanted to be involved in the decisions. In another questionnaire survey with 94 depressed patients, Stacey et al (2008) found that half of the participants wanted to make the decisions alone, 40 percent wanted to share the decision and 10 percent wished to rely completely on the advice of physician or a relative. Moreover, Chewning et al (2012) found in a systematic review that up to 71 percent of patients with a range of conditions wanted to be involved in their treatment choices. On the other hand, in a narrative review of the factors affecting preference for engagement, Say et al (2006) found that patients' favoured levels of involvement can vary across different conditions. The differences might be explained by variations in how patients interpret the concept of active engagement (Entwistle, 2009). Other influential factors include demographic characteristics, experience with the illness, health status and experiences with their health professionals (Say et al., 2006).

Treatment for depression is considered as 'preference-sensitive', since several options are recommended as adequate and effective (O'Connor et al., 2007). The importance of patients' choice about treatment has been widely recognised, and patients' active involvement in the treatment decision-making is also advocated by the practice guidelines (APA, 2010, NICE, 2009, Anderson et al., 2008). The relatively recent focus on patients as consumers' rights and professionals' respect for patients' autonomy have been cited as factors contributing to the emphasis placed on involving patients in treatment decisions (Entwistle, 2009).

Patients' active engagement in the decision-making process often has many positive effects on satisfaction, adherence and even treatment outcomes. For example, in a 3-year follow-up study with 205 patients, Hack et al (2006) suggested that being involved in decisions about breast cancer treatment had positive effects on the patients' wellbeing and quality of life. The authors found that, regardless of patients' preference for active engagement in the decisions, those who reported having contributed to the choices also reported better social and physical functioning. Similar findings were reported in relation to depression. For example, in a follow-up study with 30 GPs and 207 patients, Loh et al (2007a) found that patients' engagement in treatment choices has been related to improved satisfaction and adherence, although not treatment outcomes directly. The benefits were further supported in a cluster RCT of a shared decision-making intervention with 23 GPs and 405 patients (Loh et al., 2007b). Symptom improvement was reported to result from patients' active engagement in treatment decisions and consequent receipt of adequate treatment in a prospective cohort study (Clever et al., 2006).

3.2.2 Patients' involvement in treatment decisions

Despite the practice guideline recommendations and the positive influence of patients' involvement in treatment choices, professionals often fail to facilitate shared decision-making. The health professionals' lack of cooperation was demonstrated in a secondary analysis of 287 recordings of doctor-patient consultations (Young et al., 2008). The authors found that most physicians did not support patients in contributing to their treatment choices. One of the reasons might be that doctors lack the skills that would enable them to facilitate shared decision-making in consultations, such as communication and understanding of the SDM principles. This can be questioned based on a trial followed by focus groups with 20 GPs (Edwards et al., 2005). The authors found that even after receiving specific training to deliver SDM in practice, clinicians often reported barriers to engaging patients in shared decision-making about their care and can be reticent about patients' involvement.

Reporting findings of a systematic review, Legare et al (2008) proposed that professionals' barriers include time constraints and thinking that the approach is not suitable for particular patients or illnesses. This suggests that doctors might often decide whether they involve patients in treatment decisions based on their subjective judgements of patients' preference and ability or based on their own desire for including patients in the decision-making process (Legare et al., 2008). Whilst professionals might perceive patients' involvement as an additional complication during consultations, some research shows that adoption of SDM principles need not increase the time of patient visit (Loh et al., 2007b). Similarly, in an observational study where 20 psychiatrists were recorded during a total of 72 consultations, McCabe et al (2013) found that patients' involvement was not related to the length of consultations. Instead, it was influenced by professionals' individual characteristics, patients' symptoms and the length of time spent discussing the particular choices.

Regardless of the professionals' consultation style or an opportunity to engage in shared decision-making, people with depression make their own treatment choices. Patients often have preferences for specific treatment options such as alternative therapies that lack evidence, decisions about whether or not to seek medical advice for depression, and whether or not to adhere to medical advice. Conceptualising how depressed people make treatment choices is therefore important. Facilitation of patients' active involvement in treatment decision-making can be easier and more straightforward when professionals empathise with patients and have an understanding of the factors that influence their choices.

3.3 Decision-making principles

Decision-making is a set of complex cognitive processes, some of which take place below people's conscious awareness. Our choices are therefore often influenced by factors about which we are not cognizant, including mental shortcuts, i.e. heuristics and biases, and emotions. In order to explain and predict decision-making,

researchers have proposed a number of theories. For example, the central assumption of the economic models of decision-making is that choices result from conscious processes. When making choices, people are assumed to systematically evaluate the costs and benefits of an anticipated outcome, while also considering their likelihood (Oliveira, 2007). Such models have, however, been criticised for over-emphasis on rational choices, which rarely reflect the way people make decisions in real life. Another type of decision-making model assumes that the rational aspect is intertwined with an intuition- or emotion-based process (Reyna, 2008).

Evidence from economic and cognitive psychology research suggests that a number of factors are involved in decision-making, including individual differences, cognitive abilities, past experiences and cognitive biases (Juliusson et al., 2003). Some decisions appear to be made with the aim of avoiding physically or mentally demanding tasks in the future, for example, attempting to avoid future regret (Kool et al., 2010). Also relevant in cognitive psychology are heuristics, i.e. cognitive shortcuts people use to aid in making choices. Heuristics and biases are cognitive shortcuts in which people save effort due to ignoring part of information (Gigerenzer and Gaissmaier, 2011).

Another important, but not very well-understood, aspect of decision-making is emotion. Paulus and Yu (2012) suggested that emotions can explain changes in people's perceptions of the situation and consequently the decisions made. Research shows that depressed people might engage in different decision-making strategies compared to healthy people. For example, van Randenborgh et al (2010) asked 40 depressed inpatients and 45 healthy people to fill in questionnaires about depression, decision-making processes and decision conflict. They suggested that depressed people experience more decisional conflict due to their symptoms, including low self-efficacy and rumination. In addition, reporting findings of the Iowa gambling task (IGT) experiment with 19 depressed and 20 healthy participants, Cella et al (2010) suggested that depressed people are less responsive to reward

and punishment. The IGT (Bechara et al., 1994) is a card game involving five blocks of 20 trials during which participants make decisions about drawing cards from one of the four decks for monetary gain. The task involves learning from previous losses and wins, and Cella et al (2010) found that depressed people performed worse on the task. Consequently, people with depression were thought to show less flexibility in making decisions.

3.4 Health related decision theories

In order to understand and predict health-related behaviours, several psychological models have been developed and tested. For example, models such as Theory of Planned Behaviour (Ajzen, 1991), Health Belief Model (HBM) (Rosenstock et al., 1988) and the Self-regulation Model (Leventhal et al., 1992) have been applied in attempts to explain and predict behaviours such as adherence to treatment. The models share several common aspects, including acknowledging the importance of patients' individual beliefs, attitudes, intention to engage in the predicted behaviour and self-efficacy, but their assumed roles vary (Conner and Norman, 2008). For example, the Self-regulation Model assumes that people form representations about their illness (i.e. identity, consequences, causes, time-line and control) and use them as clues in development of preferences for treatment options.

The Self-regulation Model (Leventhal et al., 1992) has been used in a systematic review of literature to explain people's preferences for various treatments for depression and anxiety (Prins et al., 2008). For instance, people who think that antidepressants are addictive tend to prefer counselling in a cross-sectional survey with 895 primary care patients (Churchill et al., 2000a). In an Australian postal survey (n=3,109 adults) with a 6-month follow-up of 422 depressed people, Jorm et al (2000) reported that individuals' beliefs about particular treatments were associated with the actual use of those treatments. A number of beliefs were linked to particular preferences, but it is not clear what roles the beliefs and attitudes play

in decision-making, what other factors are important in the process and how the factors interact.

3.5 Patients' treatment decisions

Treatment decisions people commonly face are complex and many are made by patients outside of consultations with health professionals, even though their impact is large.

3.5.1 Help-seeking

Despite the debilitating effects of depression, most depressed people do not seek medical help. Based on the findings of a large UK based household survey of psychiatric morbidity with a sample of 10,000 respondents, Bebbington et al (2000) reported that only a third of people with neurotic disorders, such as mixed depression and anxiety, sought medical help for their problem. European population-based studies show help-seeking rates between 13% and 36% in people with mood disorders (Alonso et al., 2004, Roness et al., 2005). On the other hand, based on a US-based general population survey with over 8,000 respondents, Kessler et al (1998) suggested that most depressed people will eventually seek help, although with average delays lasting between 6 and 14 years. Similarly, in a representative sample of 3,516 psychiatric patients across 11 European countries, the average delay was 8 years (Christiana et al., 2000).

In a retrospective questionnaire study with 273 people with depressive or anxiety conditions, delay in help-seeking was associated with more severe symptoms at the start of treatment and poorer treatment outcomes (Thompson et al., 2008). Despite the benefits of receiving treatment, delays in seeking medical help are common. Bell et al (2011) found in a Californian telephone survey with 1,054 adults that 43 percent of depressed people appear to have at least one reason why they would not disclose their symptoms to their physician. The reasons were often related to beliefs about the illness and patients' expectations of professionals (Bell et al.,

2011). Other factors commonly associated with seeking help for depression include perceived need for care, recognition of depression, personal beliefs and attitudes, personal stigma, past experience and views about health professionals.

3.5.2 Treatment preferences

Developing a preference for a particular treatment option is another type of decisions people often make, although treatment preferences can also influence other treatment decisions. For example, a mismatch between a received and preferred treatment can negatively impact on patients' adherence (Raue et al., 2009). Studies show that most depressed people have a specific preference for depression treatment. A systematic review showed that approximately 51%-66% of people with depression would choose psychological therapies over medication if given the choice (van Schaik et al., 2004). Results of a more recent cross-sectional survey of 88 depressed people showed that antidepressant medication might be becoming more preferred, since psychotherapy was favoured by 41 percent, while medication by 31 percent of people (Houle et al., 2013). A general trend towards a preference for psychotherapy was not confirmed in a US study of 1,439 patients who were given the choice of second-step treatment (Wisniewski et al., 2007). Only three percent of the patients accepted switching to CBT alone and 26 percent were willing to switch to a combined treatment of antidepressants with CBT. However, as the authors pointed out, the relatively low number of CBT-accepting patients might have been caused by recruiting only participants who had already been treated with antidepressants, as an unsatisfactory first step treatment (Wisniewski et al., 2007). Despite people's preferences, antidepressants are in practice prescribed to about 90% of primary care patients with depression (Martin-Merino et al., 2010). Many patients feel uncomfortable if a treatment they do not want is given to them, as shown in qualitative study with 60 depressed participants (Nolan and Badger, 2005).

The authors of a literature review about the effects of patients' treatment preferences on health outcomes suggested there is little difference in symptom

change between patients receiving their preferred or random treatment (Winter and Barber, 2013). For example, some researchers have used partially randomised preference trials to compare effectiveness of either choosing or being randomised to a psychological therapy or medication. In a trial in which 220 patients received their preferred treatment and 103 were randomly assigned to treatment, Bedi (2000) found no difference between the groups at 8 weeks follow up, although those receiving preferred counselling had better outcomes than those randomised to counselling at 12 months (Chilvers et al., 2001). In another trial with 60 patients, Raue et al (2009) found that adherence to treatment was related to the strength of patients' preference, rather than the type of treatment favoured. The findings of a systematic review of the impact of patients' preferences showed that receiving their preferred treatment may have had a greater impact on the professional patient relationship and treatment adherence, rather than on treatment outcomes (Gelhorn et al., 2011).

3.5.3 Adherence

Another problem related to patients' acceptance and receipt of prescribed treatment is adherence. Patient adherence to treatment has been described as an active involvement in the treatment or health behaviours agreed together with a health professional (Meichenbaum and Turk, 1987). A systematic review of adherence to depression treatment showed that patients' adherence to treatment varies between 30 percent and 97 percent (Pampallona et al., 2002). Non-adherence rates in both unipolar and bipolar depression ranged between 10 percent and 40 percent in a review (Lingam and Scott, 2002). Reporting the findings of analysis of a household survey data, Olfson et al (2006) found that within a sample of 829 depressed patients, 42 percent discontinued the treatment within the first month and less than one in three continued the treatment at 3 months.

Adherence is commonly studied as a health behaviour that patients do and researchers apply theoretical models of behaviour change in order to understand or address it (Gray et al., 2010). Additionally, it can also be explored in terms of a

treatment-related decision or set of decisions that patients make on a regular basis. Pompili et al (2013) reviewed the literature about predictors of medication adherence in mood disorders. They identified a number of various factors, many of which were similar to those found influencing other treatment decisions such as patients' beliefs and attitudes to illness and treatment, therapeutic alliance, symptom severity and poor insight. Additional factors include comorbidity with personality or substance disorders and side effects of medication (Pompili et al., 2013).

3.5.4 Are all types of treatment decisions affected by the same factors?

Previous studies showed that many influential factors are shared across different types of treatment decisions. Based on the factors' similarity and the close relations of the individual types of decisions, I decided to work with an assumption that all types of treatment choices could be considered as a result of interplay of the same set of factors. This assumption was also supported by research in cognitive psychology suggesting that depression causes more decisional conflict (Randenborgh et al., 2010). Consequently, people might find it more straightforward to make a decision if they follow a simple and familiar pattern. In the following sections, I explore the factors identified in previous research as important for depressed people's treatment choices.

3.6 What factors influence treatment choices made by people with depression?

3.6.1 Demographic and individual characteristics

The evidence about the influence of demographic and socio-economic characteristics on patients' treatment choices is inconclusive. Epidemiological studies with 1,400 respondents in the UK (Meltzer et al., 2003) and more than 90,000 respondents in Norway (Roness et al., 2005) showed no effects of demographic or socio-economic characteristics on people's reluctance to seek

treatment for mood disorders. Another UK-based telephone household survey of 382 people with mental problems showed that more women than men consulted health professionals for symptoms of mental distress (Doherty and Kartalova-O'Doherty, 2010). Being female and under 65 were also related to more positive attitudes to help-seeking in a pan-European epidemiological study with 8,796 participants (ten Have et al., 2010). Similarly, Segal et al (2005) found in a cross-sectional survey of 175 depressed patients, that older people had more negative views about depression and perceived it as a weakness. The authors, however, found no effect of age on willingness to seek treatment.

In relation to treatment preferences, a survey with 104 depressed people showed that people vary in their values when selecting treatment (Thacher et al., 2005). Using a latent-class analysis, the authors identified three groups of patients holding different preferences and attitudes towards treatment for depression, based on how sensitive they were to either side effects of treatment, its costs or to its effectiveness. Male and younger patients showed higher sensitiveness towards treatment costs and side effects (Thacher et al., 2005). Supporting these findings, Prins et al (2008) in a literature review reported that people were more likely to prefer counselling over antidepressants if they were female, had better knowledge about this therapy, had previous experience with counselling but not medication, and those who had paid sick leave. Although talking therapies are more commonly preferred by women (Prins et al., 2008), almost one in four men also prefer psychotherapy and more than two in three men would choose a combination of talking therapy and medication. This was shown in a trial testing collaborative care, involving `500 people with depression or dysthymia (Lin et al., 2005).

Using self-administered questionnaires in addition to a telephone survey with 1,187 depressed people in the US, higher income and more knowledge about antidepressants were associated with preference of active treatment for depression over 'watchful waiting' style (Dwight-Johnson et al., 2000). Preference for psychological therapy was more common in participants of African-American origin

(p<0.04) and those with more knowledge about counselling (p<0.01). On the other hand, the authors of a UK-based cross-sectional survey (n=8,978) found that, although gender, previous experience with counselling and believing in the addiction of antidepressants were related to counselling preference, age was not a significant predictor of outcomes (Churchill et al., 2000). Furthermore, in a US National Comorbidity Survey with 1,792 respondents with a common mental health problem, the authors found no effects of demographic characteristics such as age, gender or marital status on help-seeking in people with a perceived need for treatment (Mojtabai et al., 2002).

3.6.2 Symptom severity

Severity of depression has been associated with patients' perception of need for help and receipt of treatment. For example, reporting data of the British National Survey of Psychiatric Morbidity with over 10,000 respondents, Bebbington et al (2003) found that symptom severity was one of the largest determinants of receiving treatment for depression. Severity of symptoms has also been related to delayed care-seeking. Reporting findings of the same survey, Meltzer et al (2003) reported that people with more severe depression were also more likely to have avoided help-seeking in the past. A follow-up questionnaire study involving 110 depressed people from 18 community pharmacies showed that that together with beliefs about illness, severity of patients' depression was strongly related to failing to initiate treatment (van Geffen et al., 2010). Having moderate-to-severe depressive symptoms was also related to the perception of more barriers to seeking professional care for the condition according to a Californian telephone survey (Bell et al., 2011). On the other hand, reporting findings of a qualitative study with 20 depressed participants, Farmer et al (2012) suggested that with increasing severity of depression people would be more likely to seek professional help as a result of decreased ability to function. In relation to treatment preferences, in a US-based study (n=1,187) using questionnaires and interviews, Dwight-Johnson et al (2000) found that severity of depression was related to specific preferences only in patients who were already receiving treatment. Severity of depression was not

found to be a strong predictor of adherence to antidepressant medication in a systematic review of literature by Pompili et al (2013).

3.6.3 Perceived need for care

Patients' perception of a need for care has been cited as one of the most important factors affecting help-seeking for mental distress in population-based studies. Andrews described unmet need as having a disorder, but not being seen by a professional (Andrews, 2000). The patient's perception of need is therefore their subjective view about requiring attention from a mental health professional, and is commonly measured by a validated scale (Meadows et al., 2000). Research shows that a large proportion of people with a diagnosable mental illness do not seek help because they do not think they need it.

Population-based surveys showed that people often postpone consulting health professionals for mental problems due to a lack of perceived need for care and not recognising having symptoms of a mental illness. In a systematic review about the perceived need for care of patients with depression and/or anxiety, Prins et al (2008) reported that between 49% and 84% of patients with depression or anxiety had experienced an unmet need for care. Also, Thompson et al (2008) found that if people with depression or anxiety did not recognise their symptoms within one year of onset, they were twenty times more likely to delay help-seeking. Nevertheless, the perception of need alone does not predict seeking treatment.

3.6.4 Problem recognition and insight

The perceived need for help is closely related to patients' recognition of symptoms and their association with an illness, which have been identified as important in population-based surveys in a Dutch interview study (n=743) (Verhaak et al., 2009) and a British survey (n=1,400) (Meltzer et al., 2003). Recognition of experiencing depressive (or other) symptoms is related to having insight into one's condition. Insight into illness was originally formulated in relation to psychosis and was

described in three dimensions, including recognising symptoms, awareness that the symptoms are part of an illness, and accepting treatment (David, 1990). This factor was also associated with decisions made by depressed people.

Lack of insight and not recognising depressive symptoms as a problem has been related to delayed care-seeking and general lack of involvement in treatment decisions (Thompson et al., 2008). Similar findings were reported by Ng et al (2008) in a Singaporean interview study (n=2,801) and in a German qualitative study with 40 depressed people (Simon et al., 2007). Results of a large German lay public survey (n=5,015) showed participants vignettes of a person with either depression or schizophrenia and asked them to suggest the best way of dealing with their problem (Riedel-Heller et al., 2005). The authors found that participants judged an action as appropriate based on their understanding that a vignette character had an illness. Illness recognition and decision about its management were also found to be related in a pilot study using interviews and questionnaires assessing depression, coping strategies and other health behaviours in 41 depressed patients (Brown et al., 2001).

Another concept that has been explored as a factor affecting people's decision to seek help for emotional problems, is patients' insight. For example, Epstein et al (2010) conducted interviews with 116 people with experience of depression and found that knowing, naming and explaining depression were three main stages which depressed people were thought to go through during the process of seeking help. Participants in this study thought that the process was influenced by their personality, their understanding of a relationship between their experience and the symptoms of depression, and their perceived stigma. In a similar attempt to explain how depressed people make sense of their condition and make an actual decision to seek professional care, Farmer et al (2012) interviewed 20 participants. The researchers developed a theoretical framework suggesting that with depressive symptoms people first experience a sense of an identity crisis and therefore rarely seek help immediately after becoming depressed. As a solution, they proposed that

people need to accept the threat they feel and deal with the change in perception of their own self (Farmer et al., 2012). This process might be helped by factors such as support from family and friends. Alternatively, the increasing burden and distress due to depressive symptoms might lead the individual to seek medical care.

3.6.5 Past experience

People's own and indirect experiences have been found related to patients' treatment decisions. For example, people who had previously sought help for depressive symptoms were more likely to consult a professional again, according to a study interviewing 25 currently depressed people (Schomerus et al., 2009a). Moreover, preference for treatment has been related to the type of treatment patients had previously received, although the evidence is inconclusive about whether people want the same type of treatment or specifically different (Churchill et al., 2000). Previous experience with treatment is also related to adherence in a systematic review of factors affecting it (Pompili et al., 2013).

People's decisions about depression treatment can also be influenced by experience that is not directly personal, but lived by close family or friends, i.e. vicarious experience. Findings of a telephone follow-up of a national survey with 1,054 respondents in California, showed that depressed people who had a vicarious experience with depression had more positive attitudes to medication, irrespective of other factors (Berkowitz et al., 2012).

3.6.6 Beliefs and attitudes

A number of beliefs and attitudes have been associated with particular treatment decisions. Vogel et al (2005) found in a cross-sectional questionnaire study with 354 university students that psychological factors and attitudes explained more than 60% of the variance of intention to seek medical help. The authors suggested that use of health-professional services was related to people's expectations about treatment outcomes.

Patients' beliefs about treatment have also been found important in explaining preferences for treatment. For example, people who think that antidepressants are addictive appear to prefer counselling (Churchill et al., 2000). An Australian postal survey with over 3,000 respondents showed that if individuals believe a particular treatment can help them, they are more likely to use it (Jorm et al., 2000). Similarly, a systematic review of patients' preferences and factors affecting them showed that many people thought that antidepressants are addictive and that counselling or other psychological therapies would address the root of depression (van Schaik et al., 2004).

A review of studies about treatment preferences has shown that a large number of beliefs, such as perceived consequences of the illness, and beliefs about the importance of treatment and its side effects, have an effect on patients' preference for therapy (Prins et al., 2008). Side effects, especially those of a sexual nature, dizziness, emotion and memory related were also reported to be the most important factor affecting adherence to antidepressants in a systematic review (Pompili et al., 2013). Similarly, authors of a cross-sectional study with 225 people with depression found that believing that the antidepressants work was related to better adherence. While worries about side effects were common, they did not impact on adherence (Wouters et al., 2014). Common side effects were, on the other hand, rated as the most important factor affecting selection of antidepressants in a survey with 127 depressed patients and 110 physicians (Gardner et al., 2007).

People's beliefs about the need for treatment and their worries about their medication have been used to develop the Necessity-Concerns Framework in order to explain and predict adherence (Horne et al., 1999). In a meta-analysis of 94 studies using the framework across a range of different long-term conditions, Horne et al (2013a) found that people's beliefs and concerns could effectively predict both observed and self-reported adherence.

3.6.7 Stigma and relying on self

Stigmatising views are a specific type of belief that some people hold about depression and depressed people. Stigma is frequently associated with patients' treatment decisions and nearly 80 percent of depressed people encounter discriminatory or stigmatising attitudes in everyday life, as shown in a cross-sectional survey with 1,082 people in 35 countries worldwide (Lasalvia et al., 2013). Link and Phelan (2001) conceptualised stigma as a process involving four steps, including labelling, stereotyping, separating and emotional reaction. Whilst the word 'stigma' is used commonly as a general term for negative attitudes, it describes different types of negative views about a person, which are a patients' personal stigma and the stigma perceived or anticipated in society and/or close social circles (Corrigan et al., 2005). In addition, Lasalvia et al (2013) suggested that anticipated and experienced stigma should be considered separately, since people who expect negative views in their social environment might not also come across such views. This distinction is important because the personal and perceived types of stigmatising views can have different effects on people, even though they are related to the same concept. Self-stigmatising attitudes about depression were found to be related to stigmatising views in the society and to decreased willingness to seek help in a large European general population survey (n=29,248) (Mojtabai, 2010). The author also emphasised that the influence of the specific beliefs and attitudes can differ and while thinking that mentally ill people are dangerous might support help-seeking, blaming and shaming mental illness appeared to decrease the willingness to seek care.

In a systematic review about stigma and its impact on health behaviours, Livingston and Boyd (2010) found that internalised stigmatising views were related to poor adherence and to having more depressive symptoms. The importance of personal stigma was also demonstrated by Coppens et al (2013). In a cross-sectional questionnaire survey of the general population in four European countries (n=4,011), they reported that people with stigmatising attitudes were less likely to

be open about their emotional problems and thought that professional treatment was less valuable than people without stigmatising views (Coppens et al., 2013).

In relation to the impact of external stigma, the evidence is contradictory. For example, Griffiths et al (2011) in a national household survey (n=2,000) used vignettes showing depressed or suicidal people to elicit the respondents' views. They found that embarrassment about being depressed and other self-stigmatising views, but not perceived stigma, were found associated with thinking that dealing with depression alone would be most helpful (Griffiths et al., 2011). While perceived stigma was reported as a barrier to help-seeking in a population-based study (Meltzer et al., 2003), the findings of a systematic review of help-seeking interventions showed no impact of strategies aiming to reduce stigma in society (Gulliver et al., 2012). On the other hand, results of a 3-month follow-up interview study with 134 depressed adults showed that lower perceived stigma was associated with a better self-reported adherence to antidepressants (Sirey et al., 2001). However, a systematic review of factors related to adherence in mood disorders showed no significant influence of stigma (Pompili et al., 2013).

3.6.8 Health professionals

Important factors affecting help-seeking and symptoms disclosure to physicians include patients' perspectives about their doctors and their interpersonal relationships. For example, a qualitative US-based study with 116 depressed people showed that many appear to be confused about the appropriateness of consulting primary care practitioners for depression and their competence in dealing with patients with emotional difficulties (Kravitz et al., 2011). Using focus groups, the authors found that participants often had doubts about the physicians' competence or the appropriateness of primary care for treatment of depression. Similarly, in a telephone survey with 1,054 respondents in California, Bell et al (2011) found that people are often unsure whether a primary care practitioner would see patients with depression. Others said that they delayed seeking help due to axiety about being referred to a psychiatrist (Bell et al., 2011). The authors also reported that

almost 1 in 4 people feared that doctors would prescribe antidepressants. Such reports suggest that people have specific views about health professionals, which may be based on anecdotal evidence rather than on physicians' real behaviour. Patients' perceptions about the professionals' ability to help with depression was also found related to attitudes to help-seeking in a study in six European countries (n=8,796) (ten Have et al., 2010). The findings of this study showed that almost one in three people thought that professional help for mental conditions was not more effective than receiving no help.

On the other hand, population surveys and other large studies showed that GPs are often viewed as the primary source of help for depression. For example, in an Australian population survey (n=1,312) using vignettes of depressed people, Barney et al (2006) found that around two in three people would most likely consult a GP for depression, although most people also viewed GPs as most stigmatising (18%) and patronising (20%). On the other hand, the authors of a German population survey with 5,015 respondents found that most members of the general public would recommend help from mental health professionals, once they recognised the symptoms of depression (Riedel-Heller et al., 2005).

Despite people's concerns about health professionals' attitudes and appropriateness for consulting depressive symptoms, professionals are generally perceived as an important factor affecting patients' decisions. For example, Cooper et al (2000) asked depressed people (n=76) to rank the importance of 126 factors related to their depression treatment and found that professionals and their opinions were among the most valued aspects. While related to treatment perceptions, the authors did not directly focus on the importance or perceived influence of the factors on patients' decision-making. Health professionals' communication style and the therapeutic alliance were identified to be among the most important predictors of adherence in a systematic review (Pompili et al., 2013).

3.7 The value of self-reports

Self-reports about decisions or past events are often used in research and whilst they are useful for understanding people's perceptions, people's memory is not always a reliable source of information. For example, cognitive research shows that we remember emotionally charged situations (Sakaki et al., 2014). Research also shows that we automatically think that we make rational decisions and when asked to explain past choices that were in fact a result of chance or external factors, we tend to provide justifications that fit our current thinking about the decision (Andrade and Ariely, 2009). It therefore appears that what people say might not always reflect past events due to cognitive and memory biases that often slip our awareness, such as individual perceptions of experiences. In addition, for various reasons, people might try to consciously avoid bringing up certain memories or ideas. This is, for instance, commonly observed in people who fail to disclose to their doctor symptoms or observations they find embarrassing or distressing, such as mental health problems (Farmer et al., 2012).

People's self-reports are a crucial part of clinical practice when patients consult their clinician about their symptoms. Some clinicians perceive self-reports as an issue in the treatment of people with mental conditions (Whitebird et al., 2013). The authors interviewed 81 clinicians about the barriers to improving depression care and reported that one of the barriers to improving depression treatment is professionals' concerns about patients' self-reports being the only way of assessing their depressive symptoms and treatment outcomes.

Despite the potential problems such as patients over-estimating their desired behaviour and under-reporting the unwanted actions, self-reports are a widely used technique for eliciting information about patients' beliefs and attitudes towards treatment. Self-reports are a valuable way of exploring people's perceptions and opinions. Garfield et al (2011) reviewed the literature about self-report measures used to determine patients' adherence, suggesting that they are an accurate

method. This was confirmed in a meta-analysis of the impact of beliefs about medication on patients' adherence (Horne et al., 2013a).

3.8 Summary of the literature

Overall, a body of research has been conducted aiming to explain the decisions people with depression make about their treatment. Whilst a number of factors have been found to be associated with individual choices, it is not yet clear how people make particular decisions about how to deal with their depressive symptoms. Researchers have linked certain personal characteristics to particular treatment preferences or decisions. For example, women appear to be more likely to prefer psychological therapies (Prins et al., 2008) and younger men appear to be concerned about side effects (Thacher et al., 2005). Despite their clear influence, the demographic and socioeconomic characteristics alone cannot explain fully the decisions patients make about their treatment for depression. There is evidence, although contradictory, about the impact of symptom severity on decisions about dealing with depression (Bebbington et al., 2003), but people's personal beliefs and attitudes also play an important role. Evidence supports the predictive validity of patients' beliefs about the necessity and concerns in explaining adherence to medication (Horne et al., 2013b). Beliefs and attitudes can, however, predict adherence to a limited extent (Horne et al., 2013a). Instead, the authors suggested that people's beliefs and attitudes should be viewed within the context of other factors, such as experience and health professionals, in order to help facilitate shared decision-making. In relation to help-seeking decisions, research shows that recognition of symptoms and awareness of the need for treatment are important (Farmer et al., 2012, Epstein et al., 2010). Instead, rather than developing in a vacuum, patients' awareness of their symptoms and the decision to consult a health professional are a result of the influences of various factors. There is also conflicting evidence about the effects of personal and perceived stigma on the different decisions people make about treatment. In addition, little is known about how depressed patients perceive the process of making treatment decisions. Although a number of factors have been associated with specific choices, there is a paucity of

literature about how patients' views relate to these factors and how people say they make decisions.

Understanding how people say they make decisions about treatment for depression is important in order to facilitate shared decision-making about treatment and support patients in making choices in collaboration with their physicians (Gray, 2014). Shared and collaborative decision-making is based on effective communication and understanding of the involved parties. Giving patients an opportunity to say how they make decisions will therefore help professionals better facilitate the shared decisions and tailor the consultations and treatment to better meet patients' individual needs.

In this study I aim to explore the depressed patients' views about how they make treatment decisions. In order to understand their perspectives within the wider context, I also aimed to explore and compare the views of people's family and friends and healthcare workers.

Chapter 4 Methodology

4.1 Study design

I adopted a pragmatic approach to research and used a mixed methods design. The purpose of the study is exploratory, that is, to better understand how people with depression make treatment decisions, and how patients, their family and friends and healthcare workers perceive this process. For this reason I involved these stakeholder groups in the research processes, which allows the study to be described as participatory. The qualitative part of the study was conducted in accordance with the COREQ framework for qualitative research (Tong et al., 2007).

4.2 Approach to the study

According to Cresswell (2013) research has three components that relate and interact with each other. They are philosophical worldview (for example, post-positivist, constructivist, pragmatic), research design (such as quantitative, qualitative or mixed), and research methods (such as questions, data collection, data analysis). The design and methods used in a study impact on the way results are produced and interpreted. Selecting the appropriate approach is therefore an important part of the research planning (Muncey, 2009).

4.2.1 Pragmatism

Pragmatism is focused on searching for information which is relevant to a particular situation and can be used as a tool to inform action (Cornish and Gillespie, 2009). This approach allows a shift of the focus from search for 'the truth' to attempts to understand an issue from a particular perspective, relevant to a particular situation. Cornish and Gillespie (2009) argued that health and other researchers usually do not attempt to uncover the one 'Truth' about the world, but aim to provide answers to specific questions. The proposed purpose of such research is therefore to generate knowledge that would serve a specific use, for example, developing

suggestions for appropriate solutions (Cresswell, 2013). Consequently, different research methods are deemed to have their place and use, according to the type of information that is required and the types of questions that are posed. For example, when determining the effects of an intervention, using randomised controlled trials might be most appropriate, but if seeking to understand patients' opinions about their new treatment, methods such as interviews are likely to be useful.

4.2.2 Positivism and quantitative methods

The positivist approach to research is based on a view that truth is independent of human perception and observation (Proctor, 1998). It is focused on the measurable facts and discredits subjective explanations of observations as it is held that research should be quantitative and researcher should be objective. As a result, within this approach all data is supposed to be quantitative, aiming to reveal the underlying causal relationships between the individual variables (Cresswell, 2013). This would then allow the findings to be interpreted independently from researcher's own beliefs and opinions (Crossan, 2003).

Quantitative methods have been used extensively in cognitive research. The designs can be broadly described as experimental and non-experimental. Non-experimental designs include surveys using questionnaires to detect causal relationships between particular variables (Cresswell, 2013). Decision-making is often studied using experiments with arranged situations, in which people are expected to make choices. In some experiments, participants may be unaware of the true aim of the research. This is due to cognitive and memory biases which commonly influence our behaviour (Tversky and Kahneman, 1974) and the way we justify our actions (Chance et al., 2011). For example, participants in different study groups are faced with the same choice under different study conditions (for example, varying numbers and types of pens or jams to choose from). Participants' decisions are recorded and the factors that supposedly influence them are discussed (Shah and Wolford, 2007, Iyengar and Lepper, 2000).

In relation to healthcare decisions, researchers have used vignettes and theoretical scenarios to connect people's hypothetical preferences of treatment types to certain beliefs (Griffiths et al., 2011). Such methods can be used to test different conditions and their effects on people's decisions, and provide important information about the studied populations' preferences (Griffiths et al., 2011, Bedi, 2000). Purely quantitative designs can, however, rarely provide in-depth explanations of human behaviour and reasoning. A special type of quantitative methods is a discrete choice experiment in which participants are asked to select their preferred option (such as the treatment they would want to receive) and define attributes of conditions under which they would be willing to take the selected option (Mangham et al., 2009). The method is designed to determine the participants' decisions in situations that resemble the real world, but similarly to validated questionnaires, the variables and attributes of the offered options need to be established in advance (Mangham et al., 2009). This suggests that using a discrete choice experiment or other quantitative methods alone might not be appropriate if the research aim is to identify the different factors affecting the patients' decision-making. Although quantitative methods can be used, such approaches often require a list of existing factors which can be studied in terms of their relationships, causal effects, perceived importance and the like. They are, therefore, not considered to be sufficient to fully explore the topic and generate novel concepts.

4.2.3 Constructivism and qualitative methods

The meticulous and objective positivist approach is countered by constructivism, a philosophical paradigm which emphasises people's subjective interpretations of their reality, i.e. recognition of the complexity and multiplicity of 'truths' (Cresswell, 2013). Strong constructivism approaches problems in a more relative way. It is best adopted using qualitative research methods, such as interviews and participant observations. Emphasis is placed on obtaining an in-depth understanding of perceptions of a small number of participants, rather than an attempt to produce generalisable and universally applicable conclusions (Malterud, 2001, Cornish and Gillespie, 2009). Consequently, it is difficult to provide accurate measures of

participants' beliefs, which could then be compared or applied to other groups of population.

Qualitative designs include, for example, phenomenological research, ethnography, or grounded theory and the methods often used are, such as interviews, observations and focus groups (Cresswell, 2013). Such methods can be useful tools when investigating the participants' experiences and aiming to understand their reasoning for particular preferences. They may be especially helpful if researchers use open and eliciting questions that enable participants to access memories related to preferences. For example, utilising interviews, Farmer et al (2012) provided detailed self-reported accounts about how people make a decision to seek help for depression. Based on their findings the research team developed a conceptual framework describing the decisions preceding help-seeking and identified aspects of this process, which needed further study. Focus groups can also be useful in exploring participants' views and identifying aspects relevant for a particular population (Cooper-Patrick et al., 1997). Using appropriate qualitative methods would enable an in-depth exploration of individual factors related to patient decision-making, and participants' perceptions about them. Conversely, such methods alone would not allow to fully achieve the aims of this study, i.e. to provide comparisons of the perspectives of people with depression, their families and health professionals.

4.2.4 Pragmatic approach to this study: a mixed methods design

Considering the aims of the study, using either qualitative or quantitative methods as a single approach would be insufficient, although both methods have their advantages. For example, qualitative methods such as phenomenological interviews or focus groups allow researchers to explore the participants' perspectives in depth, and identify novel viewpoints and concepts (Farmer et al., 2012). One of the limitations of such methods is an increased risk of researcher's subjectivity in data collection and analysis. Additionally, they offer limited empirical generalisability of the findings to the wider population, often because of generally smaller sample

sizes (Cresswell, 2013). Quantitative methods, such as surveys and experiments, which often involve larger samples, enable greater generalisability and are less susceptible to researcher subjectivity. Although such methods could be used to collect data about perceived importance rankings of various decision factors and their effects on other factors, they would not allow in depth exploration of participants' views about what concepts should be considered as factors affecting treatment choices.

A mixed methods design allows researchers to harness the strengths of the individual methods (Crossan, 2003, Malterud, 2001). They are combined in two main ways, i.e. concurrently and sequentially within the research process timeline (Cresswell, 2013). Further interpretation of the findings is informed by the priority assigned to each method in the process of analysis, the phase at which the data are integrated, and the presence or absence of theoretical perspective (Cresswell, 2013). Triangulation is one of the most common mixed methods, in which the individual findings from the qualitative and quantitative methods are interpreted either together to enhance the completeness of the data or to confirm the results. Consequently, they provide a more complete picture of the investigated phenomenon. Methods combined sequentially are utilised in a particular order, and can be explanatory, exploratory and transformative (Cresswell, 2013) depending on the specific objectives of using mixed methods design. Using such design in this study will allow a detailed exploration of the participants' perspectives about the factors affecting patients' treatment choices, and subsequent collection of quantitative data about the factors' importance and interrelationships. This design will allow possible identification of novel decision factors, and collect information about the participants' understanding of their effects.

4.2.5 Mixed methods explored

Mixed methods studies previously used to explore participants' opinions and perceptions about development of problem-solving strategies and conceptual frameworks include Delphi study (Okoli and Pawlowski, 2004, von der Gracht,

2012), nominal group technique (Gallagher et al., 1993), cultural domain analysis (Collins and Dressler, 2008) and concept mapping (Armstrong and Steffen, 2009, Kikkert et al., 2006). They all have been adopted with the aim to bring together different groups of experts (stakeholder groups) and exploring their views in order to aid decision-making. All four methods were designed to use open questions and encourage participants' brainstorming in the first phase of data collection, as a means of identifying factors relevant to the given problem or question. The individual methods also differ in a number of aspects related to their purposes, further data collection and analysis.

4.2.5.1 Delphi study and a Nominal group technique

A Delphi method was developed by Dalkey and Helmer (1963) and has been widely used as a group consensus technique (Hsu and Sandford, 2007). Its ultimate goal is to find a solution to a query or a problem. Reaching an agreement of all groups involved with the final decision is therefore important (von der Gracht, 2012). A Nominal group technique (NGT) shares the aim of a Delphi method, i.e. to reach a group consensus about a problem (Gallagher et al., 1993). On the other hand, unlike Delphi, it is traditionally conducted in a group session where participants meet each other in person. As part of a brainstorming process to generate ideas, NGT involves six steps in which participants mostly work alone, although they are present in a group setting (Rohrbaugh, 1981).

The Delphi method is also designed to explore the views of the participating experts, but only to the extent which would allow identification of a solution they all agree with. The stakeholders are first presented with a list of factors or items relevant to the given problem (Minkman et al., 2009), and are given an opportunity to add issues they might feel are missing (Linstone and Turoff, 2002). In several subsequent steps the participants are then asked to select the items that they consider to be the most relevant to the query investigated (von der Gracht, 2012). Researchers after each round select the most frequently favoured items and send them to participants in the next step, omitting the remaining items. The whole

procedure takes place remotely via post or electronically in order to avoid stakeholders' interaction and group discussion (Linstone and Turoff, 2002).

Both NGT and Delphi methods have been used as brainstorming strategies and as simple decision-making tools (Aspinal et al., 2006, Minkman et al., 2009). Their main benefit lies in an ability to effectively prevent problems with group dynamics, for example, dominant or reserved individuals, which is achieved by not involving any group discussions in the brainstorming process (Gallagher et al., 1993, Rietzschel et al., 2006). Consequently, these methods do not allow benefiting from the participants' free association of ideas resulting from their exposure to others' suggestions and opinions. In addition, due to their emphasis on seeking the groups' mutual agreement in identification of a single solution or recommendation to a problem, the methods lack an opportunity to distinguish and compare the perspectives of different subgroups within the study sample. They cannot provide sufficiently detailed information about the different groups' perceived importance of the concepts, the perceived relationships between the generated ideas or other underlying features (Minkman et al., 2009). As methods on their own, Delphi and CDA are therefore considered insufficient for research intending to explore the views of different groups, and then compare and contrast their opinions, which is one of the aims in the present study.

4.2.5.2 Cultural domain analysis and concept mapping

Cultural domain analysis (CDA) and concept mapping (CM) differ from the Delphi and the Nominal group technique in their more complex analyses and the emphasis placed on the underlying relationships between the concepts. Both CDA and CM involve participants in brainstorming and in expressing their views about the concepts' relationships (for instance, by ranking their closeness. This data is analysed using similar multivariate techniques (Kane and Trochim, 2007, Borgatti, 1994). The differences between the methods reside in their focus. Unlike concept mapping, CDA aims to involve participants who already share a viewpoint about the concepts' relationships and underlying structure, i.e. have similar perspectives due

to having a 'culturally correct view' (Borgatti, 1994). This allows CDA to investigate in greater depth how the domains mentioned by most participants relate to each other. On the other hand, Cultural domain analysis is limited in the types of participants who can be involved in the research, and it is not suited for comparisons of stakeholder groups whose opinions are likely to vary (Borgatti, 1994).

Concept mapping is a widely used method for bringing together and comparing the views of different stakeholder groups, for example, patients, carers and professionals in a study about adherence to medication in schizophrenia (Kikkert et al., 2006). In CM all groups express their opinions about the concepts' relationships and an overall result for the whole group of participants is generated. Similarly to CDA, Concept mapping aims to reveal the underlying structure of the concepts generated, but it also looks at the items' importance as perceived by participants, in order to understand how the different groups' views contrast.

Concept mapping allows an in-depth exploration of the groups' views, and it provides a unique combination of data collection and analysis methods. Unlike the other techniques, it allows comparison of different groups' perceptions about concepts' importance and the underlying relationships characterising them. As a result, I select concept mapping as the most appropriate research method for this study.

4.3 Concept mapping

Concept mapping is a commonly used method, which has been applied in more than 80 individual studies over the past ten years (Rosas and Kane, 2012). It was described by Trochim (1989) in an attempt to aid organisation of a large number of ideas into a structured 'map' which can be used to inform decision-making or planning processes. It can also be described as 'structured conceptualisation' (Trochim and Kane, 2005), and it is an established method developed to help create

a structured representation of views held by participant groups (Rosas and Kane, 2012).

The purpose of concept mapping is to explore a variety of ideas about a focus question, and collect participants' perspectives about the relations and the importance of the generated ideas (statements). This is done using qualitative and quantitative phases systematically and in an exact sequence, and concept mapping can therefore be described as a sequential exploratory method. Each of the phases has its exact place in the procedure and the results of one part are used as data in the other (Rosas and Kane, 2012). First, participants brainstorm about the focus question, to generate ideas related to it. Only after all the stakeholders have completed this phase, can the second part of the research take place, when participants evaluate the ideas in terms of relations to each other, and their importance. The information collected in this phase is quantitative, since by completing the two tasks, participants are in fact assigning numerical values to each factor (i.e. importance rankings on a Likert-scale, and data reflecting which statements were put together into groups). Use of these tasks limits room for possible subjective interpretation of data by the researcher, in contrast to other more qualitative methods, and enables statistical comparison of the stakeholder groups' relative importance ratings to take place (Kikkert et al., 2006).

In addition to comparing the participants' perceptions of importance, concept mapping allows for an exploration of participants' perceptions about how the generated statements relate to each other. Analysis of this information reveals the structure of the topic represented by the individual statements. A graphical representation of this structure is produced, called a concept map, which demonstrates the proximity of the ideas. As a result, the individual concepts are not only listed, but it is possible to explore their relationships with each other as perceived by participants, which has been a highly valued feature of the method (Burke et al., 2005, Kikkert et al., 2006).

4.3.1 Concept mapping: an illustrative example of its application

Concept mapping is an effective method producing findings with many potential applications, including in developing conceptual frameworks about the studied phenomenon, and in clinical practice. In the following section I will explain a study conducted by Kikkert et al (2006) using concept mapping in a related area (i.e. patient treatment decision-making in mental illness). The findings of this study were used to develop adherence therapy (AT), which is an intervention to improve adherence to medication in schizophrenia patients (Gray et al., 2010). This section is provided as an illustrative example of how findings from a concept mapping project can be utilised to develop an effective intervention that directly targets the issues identified in the study process. This demonstrates that concept mapping is a powerful research tool and its results can be successfully applied in clinical practice.

Kikkert et al (2006) used concept mapping to explore the views of patients with schizophrenia, their carers and health professionals about the factors affecting adherence to antipsychotic medication. In the study, they involved 91 participants from four different European countries, and held 12 brainstorming sessions during which the participants generated 769 statements about the factors affecting patients' adherence. Participants prioritised and clustered together a final set of 82 statements – factors affecting adherence, according to their own views. The authors identified six main factors that affect patients' adherence, i.e. efficacy of medication, side-effects self-management, clinician characteristics, medication side-effects, subjective experiences of medication and illness, and beliefs and attitudes about medication (Kikkert et al., 2006, Gray et al., 2010). The six factors were viewed differently by the participant groups, suggesting that professionals did not fully understand their patients' priorities. The professionals thought that patients did not take medication due to the side effects, whilst patients and carers said that it was more important to have effective medication and to be able to manage side effects.

Gray et al (2010) recognised the importance of a patient-centred approach and empowerment in the treatment of people with mental illness. They developed an adherence therapy based on three aspects, directly linked to the six factors, i.e. professionals' skills, therapy cornerstones, and adherence therapy assessment and exercises. This intervention is intended to run for up to an hour for 8 sessions. To deliver the therapy a trained professional uses a set of skills to enable patients to make informed and shared decisions about their treatment, and to help them learn about how to deal with treatment difficulties. This is to be achieved by a professional using active and reflective listening and working collaboratively with the patient. The aims of the individual sessions are to be set by both, the professional and patient to maintain patient engagement about medication choice, whilst managing and developing a patient-professional relationship. The ultimate goal of the therapy is for patients to develop a set of skills which can help them deal with possible future problems and their future decisions about medication (Gray et al., 2010). The effects of AT have been tested in nine trials focusing on a variety of conditions, showing significant results in six of the studies. For example, AT has been shown to significantly improve self-reported medication adherence and quality of life in Parkinson's Disease (Daley et al., 2014) and medication adherence in hypertension (Alhalaiqa et al., 2012). AT trials also showed a significant improvement in psychopathology of patients with schizophrenia (Schulz et al., 2013; Maneesakorn et al., 2007; von Bormann e al., 2014). Brown et al. (2013) explored the effects of AT training in the management of early psychosis and found significant reduction of relapse rates. These promising trials demonstrate that the findings of a concept mapping study can be used to inform the development of an effective intervention.

Using findings of a concept mapping study to develop a therapy targeting patient treatment decision-making represents an important milestone for the method, and for exploratory and participatory research. It emphasises the importance of conducting research in which patients and their carers are encouraged to be active in informing the research topic and providing their own perspectives about treatment choices. In this research I aim to understand how people with depression

make treatment decisions, and concept mapping is considered to be a resourceful tool that can facilitate studying this topic in depth by incorporating the different stakeholder groups' perspectives.

4.3.2 Concept mapping: a participatory method

Participatory research can be broadly characterised as an active involvement of the study participants or their representatives in the process of planning and conducting research, and in interpreting the findings (Cornwall and Jewkes, 1995). It is based on the view that people who take part in research about a particular illness, for example, patients with a condition, or carers and clinicians treating the patients, are and should be considered the experts in their area. Their perspectives and experiences can therefore add a valuable angle to the issues under investigation (Entwistle and Watt, 2006). By exploring the participants' personal experiences, researchers can develop strategies that maximise relevance of the research and utilisation of findings (Kikkert et al., 2006, Gray et al., 2010).

Entwistle (2006) suggested that the conduct of participatory research might be rising in response to issues such as increased public awareness of and resentment over unethical research practices (Goodare and Smith, 1995). Patients' active engagement in research conduct appears to be related to their involvement in treatment decision-making (Entwistle and Watt, 2006) and is in line with a person-centred approach to healthcare (NICE, 2009).

The level and type of public involvement in research vary considerably across studies. The term participatory research is often used to describe various levels of involvement, which can include participants' brief brainstorming and feedback about research, an involvement of health service users in a study planning phase, but also continuous consulting of the study conduct with the stakeholders (Cornwall and Jewkes, 1995). Concept mapping offers opportunities for stakeholders' involvement in each step of the study process, which are, developing the research question for the qualitative study phase, generating responses to the question, and

interpreting the findings (Kane and Trochim, 2007, Burke et al., 2005). The objective for using concept mapping is often to develop or inform planning or decision-making about a particular problem, and the stakeholders' perspectives can help identify the most appropriate solutions. For example, Kikkert et al (2006) involved patients with the condition as well as their carers and health professionals in the formulation of the study focus and in the interpretation of the generated concepts. They were then able to recognise all three groups' perspectives (Kikkert et al., 2006) and utilised them in the development of a person-centred adherence therapy (Gray et al., 2010).

Chapter 5 Methods

5.1 Introduction

In order to achieve the study aims, I used concept mapping and in this chapter I describe in detail the method procedure of the study.

5.2 Concept mapping procedure: an overview

There are six accepted phases in concept mapping: preparation, generating the ideas, clustering and prioritising tasks, data analysis, interpreting the results and implementation of findings (Severens, 1995b, Kane and Trochim, 2007).

5.2.1 Phase 1: Preparation

I organised to meet with my academic supervisors, a health professional and a relative of a person with depression, in order to develop the focus question for the study. The participant (stakeholder) groups were selected to allow exploration of the views of the people most involved in the process of decision-making concerning treatment for depression. Ethics and governance approvals, recruitment, planning of data collection and obtaining consent from participants also took place in this this stage, in order to prepare for the subsequent phases of the study.

5.2.1.1 Choice of a specialised software

In concept mapping, a specialised software package is used to analyse data in step 4, and it can aid data collection in steps 2 and 3 (Severens, 1995b, Kane and Trochim, 2007). The choice of the software is done early in the preparation stage, since its selection influences some of the decisions made in the planning phase of the project, such as data collection modes and maximum number of statements that can be used in the prioritising and clustering tasks. Two main software packages are currently used within concept mapping. These are: Ariadne (Severens,

1995a) and Concept Systems, Inc., and both are widely used in peer-reviewed concept mapping research (Kikkert et al., 2006, Windsor, 2013, Rosas and Kane, 2012). The most important differences between the packages lay in their price and in several specific features in data analysis. The cost of Concept Systems software is $1,000 for a single graduate student project, whilst Ariadne was provided for free by the software developer.

Both packages perform established multivariate data analyses, which are done in two consecutive steps, i.e. multidimensional analysis and a cluster analysis (Kane and Trochim, 2007, Severens, 2012). The specific types of these analyses in the two packages are pre-determined, but the data can be exported to other statistical software that allows performing several types of cluster analysis, such as SPSS for Windows. I planned to use SPSS in addition to Ariadne, because the results of the cluster analysis are used as the main study findings and a choice of its type can directly influence the factors' formation.

In addition to the main analyses, Concept Systems software allows evaluating reliability of the statements' representation on the concept map, reliability of the cluster analysis, and of the importance rankings of the statements (Rosas and Kane, 2012). Whilst these are not possible to determine in Ariadne, the software has previously been used in large studies (Kikkert et al., 2006, Armstrong and Steffen, 2009) whose findings were effectively utilised further (Gray et al., 2010). In addition, SPSS can be used to perform a reliable cluster analysis and statistical analysis to compare importance rankings of the groups. I decided to use Ariadne in combination with SPSS because this option allows an opportunity to make informed selections of the analyses to perform.

5.2.1.2 Mode of study

In concept mapping data can be collected either during face-to-face meetings and group sessions with participants, or remotely via post, email or a specialised website (i.e. provided by Concept Systems, Inc.). Most authors tend to use a

combination of these methods to allow participants more flexibility and reduce the burden (Rosas and Kane, 2012). Using the web-based method is linked to larger sample sizes, but lower rates of completed clustering and prioritising tasks than the face-to-face method (Rosas and Kane, 2012). The authors reported that the task-completion rates were the lowest in studies using a combination of the methods, but they also had the lowest attrition rates, compared to the single-mode methods. To reflect these findings, I used face-to-face mode as the main data collection method. Participants were able to submit their responses by telephone, email or post if they were not otherwise able to take part in the study.

5.2.1.3 Selection of participants

The goal of this research project is to enhance understanding about how people with depression make treatment decisions, by exploring the views of those who are involved in, and affected by this process. The stakeholder groups were purposively selected to include people with depression, their family and friends, and healthcare professionals who work with people with depression in either primary or secondary care.

5.2.1.4 Number of participants

Average number of participants in concept mapping studies varies depending on their mode; it is 62 in studies with face-to-face data collection mode, and 122 participants in studies combining the modes (Rosas and Kane, 2012). The authors reported that the internal reliability of study results increases with a growing sample size, and they recommended that the clustering task should be completed by a minimum of 20-30 participants. Larger numbers of participants in prioritising task were also linked to better reliability of the scale, but no specific recommendation was suggested. The mean number of respondents in this task was 82 for studies using any of the modes (Rosas and Kane, 2012). In order to allow a strong statistical comparison of the groups' views, and to allow for possible loss of participants due to follow up throughout the concept mapping process (3% of participants in Kikkert et al, 2006; task completion rates between 50-66%, Rosas

and Kane, 2012), I intended to recruit 30 members of each stakeholder group, i.e. approximately 90 altogether.

5.2.1.5 Development of focus question

The focus question within concept mapping studies is an open-ended question presented to participants during brainstorming sessions. It is a subject which they are encouraged to openly discuss in order to think of all possible issues that are relevant for them. The focus question for this study was developed during numerous discussions with my supervisors and people affected by depression but not directly involved in this study. We intended for the aim of this study to be the main topic discussed during brainstorming sessions, and therefore articulated the following questions.

People with depression answered the following focus question: 'My most recent choice of treatment for depression was influenced by…?'

Family and friends and healthcare workers were asked: 'Treatment choices made by people with depression are influenced by…?'

The focus questions were formulated to reflect an assumption made in this study, i.e. that all treatment choices are influenced by the same set of factors. This was a decision made by all members of our research group after numerous discussions. The purpose of this exploratory and rather broad question was to allow participants to explore all potentially relevant factors affecting their real-life treatment decisions. Asking about their most recent decisions gave participants an opportunity to consider a decision that was most recent and relevant for them.

5.2.1.6 Ethics and Governance approvals

Prior to recruitment of participants and conduct of any study procedures, the study was reviewed and approved by a local NHS Ethics Committee and the Governance committees of the NHS Trusts involved in the study. The ethics and governance

approval letters are shown in Appendices 1-4 and the study protocol is in Appendix 7. Appendices 5 and 6 show my Good Clinical Practice certificates. I applied for two substantial amendments to the protocol, which are detailed in section 5.5. A full description and the ethics and governance approval letters for the first amendment are provided in Appendices 8-10 and Appendix 14. The description of amendment 2 is in Appendix 11 and the ethics and governance approval letters are in Appendices 12-14.

5.2.2 Phase 2: Generating the ideas

The aim of this phase is to generate as many statements as possible in response to the focus question. Statements can be generated using several different methods. The most commonly used is brainstorming led by a trained facilitator within group or individual sessions during personal meetings or remotely, for example by telephone or email (Kikkert et al., 2006, Kane and Trochim, 2007). Other options of generating ideas can include a Delphi technique (Minkman et al., 2009), and Nominal group technique (Rohrbaugh, 1981), although these methods can also be used as data collection methods on their own (Linstone and Turoff, 2002, Rohrbaugh, 1981).

The remote methods of generating ideas, such as submitting statements via email, or the structured methods Delphi and Nominal group techniques, have an advantage of reducing the participant and researcher burden and allowing larger numbers of participants to take part in the process (Kane and Trochim, 2007, Rosas and Kane, 2012). Such methods may also allow identification of sensitive concepts, which the stakeholders might not be willing to discuss within groups, but also more duplicate statements are likely to be produced (Kane and Trochim, 2007). On the other hand, when using techniques that limit participants' communication with each other, the free association of ideas and concepts is not enabled. Consequently, some ideas, which are less apparent to a person, might not be generated (Kane and Trochim, 2007). Group brainstorming sessions can provide an environment where stakeholders freely discuss the factors that had influenced their treatment choices,

but the situation depends on the group dynamics and skills of the facilitator to allow participants to think freely about a given topic. Unlike in the other techniques, when running face-to-face brainstorming sessions, the facilitator can directly communicate with the stakeholders, ask about specific issues, or use active listening to help participants focus on the research question. For this reason I decided to facilitate generating the ideas within face-to-face brainstorming sessions where practically possible. In order to counter the disadvantages of this approach, I decided to give participants an opportunity to take part in brainstorming within other settings as well, including individual and remote modes.

5.2.2.1 Brainstorming sessions

During brainstorming group sessions a trained facilitator and assistant lead the group discussions and worked with participants to maintain a non-judgemental and comfortable atmosphere. This was to aid participants to relax, and to use free association to think about the relevant ideas. The generated ideas were noted down as statements, which needed to be clear, understandable and singular. An example of a statement generated in response to the focus question could be 'severity of depression'.

5.2.2.2 Refining the statements

Once all brainstorming sessions have been held, all the statements that have been generated are pooled together and reviewed. The purpose of this exercise was to discard any duplicate responses and reduce the total number of statements in the final set to below 98, a maximum number of statements that the software Ariadne can use in the analyses (Severens, 1995b)

5.2.3 Phase 3: Prioritising and clustering tasks

Participants from the brainstorming phase completed the prioritising and clustering tasks either individually during group sessions or in their own homes. This phase is separate from the brainstorming phase. It is, therefore, possible for additional

members of the three stakeholder groups to take part in the structuring phase even if they had not been involved in brainstorming. Whilst it is not intended to initiate a new recruitment process in this stage, any members of the three stakeholder groups who are interested in taking part in the study, and meet the inclusion criteria are allowed to join in.

5.2.3.1 Clustering

When undertaking the clustering exercise, the task for participants is to put the statements that seem to go together into groups, using criteria that they think are most appropriate and relevant. The criteria are therefore based on individual interpretation and are not pre-determined by the researcher. Data collected in this task therefore represents the participants' perceptions of how related the individual statements are to each other, or how 'close to each other' they are.

5.2.3.2 Prioritising

When prioritising, participants were asked to place the statements into five equal piles, based on their perceived importance (i.e. using a Likert-type scale from 1 - the least to 5 - the most important).

In both tasks, participants were instructed to use all statements and not to create any 'miscellaneous' clusters or piles.

5.2.4 Phase 4: Data analysis

Data from the two tasks is analysed using a specialised concept mapping software called Ariadne (Severens, 1995a).

5.2.4.1 A concept map

Information about participants' perceptions of the relations between statements is analysed using multivariate statistical techniques (Kane and Trochim, 2007). A procedure called principal component analysis (Severens, 2012) is used to identify

five main dimensions (axes) in the data, and to assign each statement a value for each dimension. The first two axes are used to generate a graph labelled a concept map, and the statements' values are used as their coordinates on the concept map.

5.2.4.2 Cluster analysis

Data from the PCA procedure is further analysed using a cluster analysis. This technique groups the statements that are related to each other based on the distances between them (as identified within the PCA). The clusters are also indicated on the concept map, to aid visual understanding of the underlying relationships between them.

5.2.4.3 Prioritising

Data from the prioritising stage is then used to calculate mean relative importance rankings for each statement and cluster. The perceptions of the stakeholder groups are contrasted against each other, in order to better understand the groups' views about what is important in terms of the depression treatment choices that patients make.

5.2.4.4 Subgroups of stakeholder groups

Using the data produced in the PCA analysis, it is possible to explore the identification of subgroups of the original stakeholder groups. Such subgroups would be characterised by their participants' common preferences for particular clusters.

5.2.5 Phase 5: Interpreting the results

5.2.5.1 A concept map

The concept map produced using this process is a graphical illustration of the relationships among statements. The more often that any two statements were put into the same group during the clustering task, the closer they are placed on the

final concept map. The same is true for the final clusters. The closer they are located to each other, the more related are the concepts they represent. Interpretation of the concept map, therefore, entails understanding the underlying relationships between the individual clusters. It is useful to distinguish between the clusters which are positioned close to each other, since their concepts might be related, and the clusters positioned apart. The combination of a PCA procedure followed by a cluster analysis helps to identify and differentiate between the individual factors that influence patients' treatment choices.

5.2.5.2 Differences between groups and subgroups

The average importance ratings calculated for clusters allow for comparisons of the stakeholder groups' views, as well as the differences between any subgroups which may have been identified. Due to the relatively small number of participants, between- and within-group comparisons need to be interpreted carefully.

5.2.6 Phase 6: Implementation of findings

The implementation of findings from the study involves their dissemination to healthcare professionals dealing with people with depression, and to members of the general public who could benefit from understanding the differences between the views of patients, family and friends, and professionals. Researchers have previously used concept mapping, for example, to develop conceptual frameworks of issues related to occupational health (de Vries et al., 2012), to understand the views about adherence to treatment in schizophrenia (Kikkert et al., 2006) and to develop an assessment instrument (Armstrong and Steffen, 2009, Ahmad et al., 2012). The findings of this study could be used to inform clinical practice about factors affecting patient treatment decision-making, and to develop strategies to support patients in making considered and well-informed choices. Identification of different 'types' of patients or health professionals might also be important for clinical practice. It could be beneficial for health professionals to be aware of the potential patient types according to their decision-making needs and preferences.

Similarly, it might prove beneficial for professionals to better understand their own perspectives, in order to help to support patients in their decisions.

5.3 Participants

This study was planned with the aim to improve understanding about how people with depression make their treatment decisions. I therefore recruited members of three groups of people who are involved in the process of patients' treatment choices: people with depression, their family and friends, and healthcare workers. Each of these groups plays their role when a person is deciding whether to seek help for depression or which professional to visit. The aim was to recruit approximately 30 members of each stakeholder group to allow for possible attrition within the phases of data collection, and to ensure a sufficient sample size for reliable data analyses.

5.3.1 Sampling strategy

Participants were selected and recruited purposively for pragmatic reasons, that is to maximise the sample size and specifically target recruitment methods to access various difficult to access groups of participants. These included, for example, people with depression who had sought medical help and were or had been receiving treatment, people who thought had depression but had decided not to seek help, and family and friends of such people with depression.

5.3.2 Inclusion criteria

In developing the sample frame for the study, it was decided in general terms that participants should be over 18 (no upper age limit) to enable providing a fully informed consent. They also needed to be able to verbalise their thoughts in English, in order to take part in discussions with other participants and researcher about the focus question. There was no funding available for commissioning translation services. Each stakeholder group was recruited and involved in data collection separately, but people with depression and family and friends were accessed using the same methods, in order to maximise intake of participants in the

study. Members of these groups were able to join in the study, regardless of whether a person close to them was taking part, since limiting recruitment to people who were directly associated with each other would not have added a tangible benefit to the study findings.

During typical brainstorming sessions, stakeholders were expected to talk about the factors affecting depression treatment decisions made by themselves or someone close to them. The inclusion criteria were therefore set to ensure that we involved the people who are able and competent to provide perspectives relevant to the focus question.

5.3.2.1 People with depression were required to:

a) Confirm by self-report that they had been recommended or receiving treatment for unipolar depression of any severity, currently or within past 12 months. Treatment is considered to include any activity recommended with the intent to help relieve depressive symptoms, for example, taking antidepressant medication, talking therapies, alternative therapies, self-help activities. It was not possible to include people who report having bipolar disorder due to different treatment options that are recommended for such conditions.

b) Be aged over 18 years, and for participants to be adults with the capacity to consent. I intended to include 10 people aged over 65 to ensure representation of the elderly population in the study.

c) Provide written informed consent prior to taking part.

5.3.2.2 Family and friends were required to:

a) Be close to a person with unipolar depression as their family member or a friend, in order to be able to describe their views of the factors affecting the person's treatment choices.

b) Be aged 18 or above, to ensure participants are adults with the capacity to consent

c) Provide written informed consent to participation.

5.3.2.3 Healthcare workers

I aimed to include a multidisciplinary group of healthcare workers, in order to collect a variety of views about different treatment choices people with depression make. For this reason, I wished to recruit General Practitioners (GPs), psychiatrists, nurses, mental health nurses, psychological therapists, psychologists, occupational therapists, alternative medicine (AM) practitioners or other healthcare workers. We considered but rejected including case managers, psychoanalysts, family therapists and other healthcare workers to participate. This was decided based on the practical difficulties of accessing and inviting them.

To take part, healthcare workers were required to:

a) Be working or had worked with people with unipolar depression currently (at time of study) or within past 12 months. This is to ensure healthcare professionals have a recent experience with helping patients make depression treatment choices.

b) To provide written informed consent to take part in the study.

AM practitioners were expected to demonstrate a low interest in taking part in the study. I believe that this is an important population to access because there is a public perception that treatment such as herbal therapies, homeopathy or light therapy, although not evidence-based, may be effective against depression. To help me access the relevant therapists, in addition to the above, I set the following inclusion criteria for AM practitioners:

c) Practice a therapy for which there is at least anecdotal evidence for effectiveness in depression.

d) Practice in the Norwich area.

5.3.3 Information collected about participants

Before taking part in the study, all participants were asked to provide their informed consent to involvement in the study, and complete a short questionnaire to provide basic information for descriptive purposes. The questionnaires used for this purpose are in Appendices 32 and 33. In addition to name and preferred contact details, I asked participants to answer questions about the following domains:

5.3.3.1 People with depression

a) Demographic information: gender, age, ethnicity, marital status, level of education and employment status
b) The most recent treatment prescribed and received for depression
c) Year of first depressive episode
d) Relationship with the family and friend (if a person close to them was taking part)

5.3.3.2 Family and friends

a) Demographic information: gender, age, ethnicity, marital status, level of education and employment status
b) Relationship with the person with depression who was close to them (regardless of whether taking part)
c) Whether they were receiving treatment for depression and any details
d) Whether a person with depression who was close to them was taking part in the study

5.3.3.3 Healthcare workers

a) Type of profession
b) Length of time spent helping people with depression

5.4 Study procedures

5.4.1 Recruitment of participants

In order to access the stakeholder groups required for this research, I combined purposive and convenience sampling and applied multiple recruitment strategies. I made attempts to specifically involve participant samples which would be representative of the target populations and would involve participants with a variety of opinions and clinical backgrounds. Participants recruited in each stakeholder groups were therefore expected to reflect the wide spectrum of treatment decisions people make and the treatment options people use.

People with depression and family and friends did not have to be related or recruited together, but I anticipated that asking the potential participants to invite a member of the other group (for example, a partner or a friend), might help me reach the target numbers of participants (30 in each group). The strategies I used to invite these two groups will, therefore, be described for patients and family and friends together. All invitation letters and adverts used for recruitment are shown in Appendices 15-23. Prior to commencing recruitment, all strategies and materials were reviewed and approved by the relevant NHS research ethics and governance committees.

5.4.1.1 People with depression and their family and friends

People with depression were recruited using several recognised strategies, including the assistance of a familiar health professional, adverts published in the local media, the assistance of the local charities specialised in helping people with mental illness, and snowballing. The use of different strategies was thought to maximise the effectiveness of the recruitment process and to allow the inclusion of depressed people and their family or friends from various clinical backgrounds. This was thought to reflect the trends in the population, such as the proportion of depressed people seeking medical help, or those seeking psychological, alternative

or no treatment. Additionally, the use of a number of different recruitment strategies was expected to minimise the risk of selection bias.

Recruiting patients with the assistance of their health professionals who identify the potentially eligible patients is a common technique, used in a number of studies (Kikkert et al., 2006; Carder et al., 2003). However, the health professionals might also unconsciously introduce the risk of bias by selecting the patients with less severe illness, or those adhering to the professionals' own opinions. Inviting depressed people and their family and friends through the local media (i.e. newspapers and magazines) and posters (i.e. flyers) distributed to GP practice waiting rooms, was expected to make the study known and accessible to the population within the county. On one hand, a limitation of these methods is their reliance on the aspiring participants to initiate contact with the researcher, which might be a barrier to some people. On the other hand, their benefit lies in the potential to reach out to the wider audience who read the particular newspapers or visit the GP practice, without the decision made by the health professionals about who can see the information. Flyers and media articles are recruitment methods commonly used in qualitative health research and in postgraduate research (Namageyo-Funa et al., 2014), and I considered them to be potentially useful in this study, as well.

Snowball sampling is another type of recruitment method, commonly used in qualitative research. It involves an informal sharing of the information about the research study by individuals (for example, current participants) to their family or friends, who can then tell other people, and so forth (Vogt, 1999). This type of sampling can enable researchers to access specific or difficult to reach populations (Sadler et al., 2010), but it is also associated with selection bias (Groger et al., 1999). In order to address these risks, I used snowballing as a complementary recruitment method, rather than as a main strategy.

a) Press release in the local newspaper: Following an NHS research ethics and governance approvals, a press release (Appendix 15) was published on the University's website and sent to the local newspapers in November 2011. The articles provided brief information about the study and what would be expected from prospective participants. The article primarily targeted people with depression, but it was noted that family and friends were also needed in the study. My email and phone details were listed, and readers were encouraged to get in touch if they were interested in having more information or in taking part in the study. Having proved to be a successful recruitment strategy, I published a second press release (Appendix 16) in April 2012, focusing mainly on family and friends. Snapshots of the media articles published in the newspapers and magazines are shown in Appendices 17-19.

b) An article in the Mind charity newsletter: In June 2012, I published a brief article in a local mental health charity's newsletter (Mind), describing the study and inviting people with depression and their family and friends to take part (Appendix 20).

c) Snowballing technique: people who had agreed to take part in the study were asked to tell their relatives, friends or colleagues about the project, and to provide the researcher's contact details to anyone that might be interested in potential participation.

d) Advertising in GP surgeries: In the waiting rooms of 5 Norwich General Practitioner surgeries I distributed posters that provided brief information about this study and invited patients and their family and friends to join in the research (Appendices 21 and 22). This was discussed and approved by the GP practice managers at their discretion, in addition to the approval granted by the NHS Research Ethics Committee for this to happen.

e) Contact via healthcare workers: as agreed with team leaders in a local NHS Trust, I asked healthcare workers in the Trust to briefly explain my research project to their clients who were meeting the inclusion criteria. Healthcare workers also made the information sheets about the study available for people with depression with whom they were in touch.

f) Contact via the Age UK charity: I contacted this charity with the aim to specifically invite a group of older people with depression. Facilitator of the support groups held in the Norwich branch of the charity Age UK distributed the information sheets about the study to the clients meeting the inclusion criteria, and organised for those interested in further information to meet with me, and discuss the research process.

5.4.1.2 Healthcare workers

a) Team leaders in the NHS Trusts: I presented the study to workers in 6 team meetings in the local NHS Trust. Their team leaders supported the study and handed out study information sheets and my contact details. This strategy was used to recruit the majority of healthcare workers. The team leaders were also asked to approach GPs with an interest in mental health and send them information sheets to invite them to take part in the study.

b) Alternative medicine practitioners: In order to identify the relevant AM practitioners in this study, I first listed the alternative therapies with anecdotal evidence for depression. I searched the Yellow Pages and Google, in order to create a directory of practitioners offering such therapies in Norwich. I purposively selected ten practitioners from this list, in order to include as many different therapies as possible, and sent them an invitation letter (Appendix 23). This was repeated, with the aim to include at least one AM practitioner in the study.

c) Snowballing techniques: Healthcare workers who knew about this study were encouraged to tell their colleagues about the study, and invite them to contact the researcher if interested in the project.

d) GP practice managers: I contacted practice managers and research managers of several medical practices in the Norfolk area to invite GPs and nurses to take part in the study. The managers who agreed to help with recruitment of healthcare workers distributed information sheets about the study to the potential participants, and suggested they could contact me for further details about the research.

All of the recruitment posters, adverts and information sheets listed my study email and phone details and potential participants were encouraged to use them to contact me for more information about the study. All people who contacted me and expressed interest in more information about the study were sent information sheets with reply slips and stamped-addressed return envelopes, together with a sheet containing useful information about depression (Appendices 24-26). Those who identified themselves as people with depression or family and friends were sent an information pack for both of these groups, with a suggestion that they could also invite a person close to them to join in the study, if they wished so. In order to prevent over-recruitment of people with depression or family and friends, a 'Refusal letter' was developed (Appendix 35), but it was never used.

5.4.2 Participants' consent

Prior to taking part, potential participants were required to provide written informed consent, usually during a personal meeting with me, which was scheduled mainly for the purpose of obtaining consent. Healthcare workers were assumed to have a professional capacity and it was not necessary to meet them personally for consent. They could send their reply slips and signed consent forms by post or before the first data collection session that they took part in. This was a way of reducing the burden on participating healthcare workers, and it might have positively affected how the workers responded to study invitations. All consent forms are shown in Appendices 29-31 and the questionnaire, participants were asked to fill in are in Appendices 32 and 33.

5.4.2.1 Consenting meetings

In order to obtain informed consent, meetings were held with people with depression and family and friends who contacted me and were interested in taking part, before their first data collection session. The meetings were scheduled to take approximately 30 to 60 minutes and their purpose was to provide an opportunity to discuss the study in detail and to explain the ethical issues related to the study. People who agreed to take part then signed the consent form and filled in a short

questionnaire about personal and clinical information. Some participants, if assumed full capacity to decide about taking part in research, were not required to provide written consent during face-to-face meetings. This decision was based on the participants' individual situations. All people were given an opportunity to discuss the study and any queries they might have had regarding the research in a personal meeting, via telephone or email. Reasons for any distance-based communication were practical and financial barriers to personal meetings, since some people who wished to take part in the study were either based outside of Norfolk, or were unable to meet due to their other commitments. Since they met the study inclusion criteria, I considered it unethical to deny them participation solely on the basis of practical barriers, such as location. Consent was re-confirmed verbally with participants prior to the start of all data collection meetings, regardless of the mode.

5.4.3 Data collection

5.4.3.1 All meetings

Data collection in concept mapping consists of two main stages. First, all participants join in brainstorming sessions to generate statements in response to the focus question. In the second phase of data collection participants are invited to perform two tasks: prioritising and clustering of the statements, decisions being made according to their own opinions.

5.4.3.1.1 Conduct of the meetings

All sessions were held separately for each stakeholder group to prevent interaction between the different groups, and I facilitated most of the groups with the help of one trained assistant who took notes. When two groups were held for practical reasons at the same time, another trained facilitator and assistant facilitated the other session. All group sessions lasted up to two hours, including a short break for refreshments, which I had provided.

5.4.3.1.2 Location of the meetings

Most sessions for people with depression and family and friends were in groups and took place in rooms at the University of East Anglia. In order to meet the participants' particular needs (for example practical reasons or anonymity issues), they were also able to take part during individual meetings or telephone conversations (only for the brainstorming stage). When required, I offered participants an opportunity to complete the brainstorming task in their own time, and to submit their suggested statements by email.

Sessions for healthcare workers were organised individually or for the whole teams together, depending on the willingness of the workers to take part in the study. Team leaders were very cooperative and supported this research wherever possible. For example, they allowed the study sessions to take place during their team meetings if majority of healthcare workers in their team decided to join in. When necessary, I held individual brainstorming discussions either in person or as a phone conversation. Personal sessions always took place either at healthcare workers' workplace or in University rooms. Participants also had the opportunity to submit their responses via email if they so wished.

5.4.3.2 Brainstorming

The aim was to generate as many statements as possible, in response to the focus questions: 'My most recent choice of treatment for depression was influenced by…?'(for people with depression) and 'Treatment choices made by people with depression are influenced by…?' (for family and friends and healthcare workers). All statements used in the subsequent phases of the study were generated in the brainstorming phase. The sessions were, therefore, audio-recorded in order to capture the group discussions and ensure that all the concepts discussed in the sessions were included in the final set of statements.

5.4.3.2.1 Generating the statements

During the face-to-face brainstorming sessions the relevant focus question was always visible to all participants to help them remember the focus of discussions. During the telephone sessions and when sending the instructions via email, I suggested to the participants that they might note down the focus question, to help them brainstorm about the topic. I encouraged them to use free association of ideas in order to help them recall as many different factors that influenced their treatment choices, as possible. Participants were assured that the environment within sessions was non-judgemental towards any ideas presented, in order to respect other people and facilitate the brainstorming process. When generating the statements, it was emphasised that there were no right or wrong answers, since the statements generated reflected the factors that had influenced their own decisions and these were individually based. Family and friends and healthcare workers were also assured that their own views were of interest, and no judgement would be imposed on their opinions.

No consensus was sought regarding the content of statements, to allow me to include all generated statements, which could have been applicable to all, regardless of whether everybody agreed on the factors' effects. If someone at the session did not agree about an issue raised, they had an opportunity to generate an opposing statement (for example, my doctor being supportive versus the lack of my doctor's support). Participants were encouraged to note any ideas on Post-it notes if they felt uncomfortable discussing them in the group setting. All statements submitted this way, by email or by post were added to the overall list of statements generated, and considered in the final review process.

5.4.3.3 Prompts

Based on the factors identified in previous literature (Prins et al., 2008) I created a list of prompts and topics relevant to decision-making about depression treatment (Appendix 36). These topic areas were used as prompts during brainstorming sessions, if not mentioned already spontaneously by participants. The prompts

were restricted to be used only as general topics for further group discussion if needed. This was decided to help participants cover a variety of factors, while not influencing the nature of statements they generated.

5.4.3.3.1 Number of attendees

Sessions were held for 2-8 people, or on an individual basis. Telephone meetings were held for one person at a time.

5.4.3.3.2 Characteristics of statements

The facilitator and the assistant at brainstorming sessions were responsible for the data collected and quality of the statements. In concept mapping it is important to generate statements which are clear, singular and understandable, in order to allow their use in the subsequent stages of analysis and evaluation (prioritising and clustering tasks). Participants could discuss these issues during the brainstorming sessions, to help generate statements, which made sense to all of them.

   a) Clear: Statements were required to be of sufficient clarity, in order to be potentially applicable to other participants, as well (for instance, they could not include specific names or medicine labels). It was also important not to generate statements that were too specific and covered too large an area of topics (for example, 'my doctor').

   b) Singular: It was important to keep statements simple, containing only one topic. An example of a statement that contains more than one concept is: 'my doctor and my family'. Such issues were discussed at the sessions, and the concepts separated into multiple statements.

   c) Understandable: All statements needed to contain vocabulary that would be easily understood by all members of the stakeholder groups. I ensured that they contained no highly medical or technical words, for instance 'euthymia' or 'remission'.

5.4.3.4 Reviewing the statements

All statements from all brainstorming sessions were pooled and reviewed. The goal of this process was to discard all duplicates, and reduce the number of statements in the final set to below 98. This is the maximum number the software package Ariadne can process in analysis (Severens, 1995b). Another reason for keeping the total number of statements lower is the consideration of the possibility of participants' increasing fatigue and decreasing concentration if they are given too many items to sort in the later phases of the study (Rosas and Kane, 2012).

Refining the statements was an iterative process which involved numerous discussions with my academic supervisors and two participants, all of whom provided feedback in the process of generating the final set of statements to be used. At this stage some of the concepts originally generated were combined into broader ones, to achieve similar levels of clarity and detail in all statements in the final set. This was to allow participants to compare and evaluate the statements during the prioritising and clustering tasks.

5.4.3.4.1 The process of refining the statements

To allow me to review the statements, discard duplicated items and to combine those that were very similar or too concrete, all statements were printed individually on paper strips. I sorted them according to the main topic they described. The topics included, for example, healthcare professionals, beliefs about depression, stigma, and so forth. Then I put together the statements that covered the same aspects of these themes (i.e. duplicates) and all items that appeared to be closely related to them. For clarity and my own navigation in the set of statements, I gave all groups of items working labels, capturing the main idea common for each group. These helped me to keep structure in the process, and take note of all similar or identical statements. During the review process, I put aside all statements that I considered to be too ambiguous or not answering the focus question, and attended to them again at the end of the process. Then, I checked relevance of these items with the research team members.

When reviewing the statements, my goal was to produce a final set with items that were equally specific, to allow participants' evaluation of them in the successive data collection phases without undue difficulty. In this process I combined some items and aimed to reduce their overall number to a manageable set (up to approximately 200 items). These were then presented to the other members of the research team and two people with depression. In the course of several group discussions the items' content, level of detail and wording were reviewed, making sure that the original statements were well represented by the final items. Relevant literature on factors affecting treatment decision-making in relation to depression was checked to ensure no items previously identified as important were missing. In this iterative process a final set of statements to be used in the structuring sessions was generated.

Statements were then allocated a number for identification and were printed on paper cards (10x7cm). An example of a final statement on a card, as used in the prioritising and clustering tasks, is shown in Figure 1.

Figure 1: Example of a card used in structuring sessions

My most recent choice of treatment for depression was influenced by...

Financial costs related to the particular treatment option

1
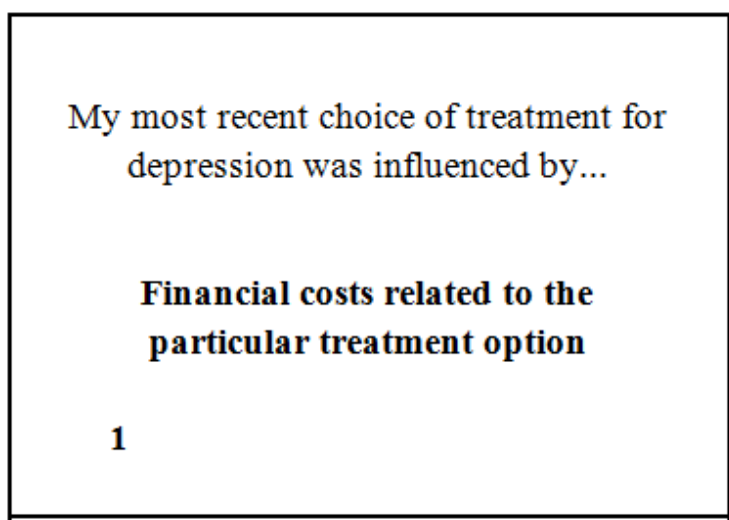
5.4.3.5 Structuring sessions: Clustering and prioritising tasks

When the final set of statements was reviewed and agreed by members of the research team, all participants were invited to take part in the second data collection phase of the study. This was labelled as a structuring phase, and involved two individual tasks: prioritising and clustering of the statements in the final set. Participants could perform these tasks during group sessions organised for this purpose for each stakeholder group separately, or individually, within their own homes. The following tasks could be completed in no particular order. It was emphasised, that there were no right or wrong answers, and the purpose was to understand people's own perspectives. In both tasks, all statements had to be used, and each could only be put into one group. For both tasks, I provided an answer sheet with pre-printed tables (Appendix 37), and asked participants to record their responses in the tables.

5.4.3.5.1 Clustering

When clustering, participants were asked to put together the statements that they thought were related, based on their own criteria. It was important to create a minimum of 2 and a maximum of 12 groups. Each group had to contain at least two statements, and a maximum of 20% of all statements in the set (due to the limitations automatically set by the concept mapping software Ariadne).

5.4.3.5.2 Prioritising

When prioritising, participants evaluated the perceived importance of the individual statements on a 5 point Likert scale (Likert, 1932), and sorted them into the following five piles according to the rankings:

Pile 1: The least important

Pile 2: Somewhat important

Pile 3: Moderately important

Pile 4: Very important

Pile 5: The most important

5.5 Ethical considerations

5.5.1 Research team

In addition to my academic supervisors and me, the research team included several people with depression and health professionals who offered feedback and help with decisions and planning of the study.

5.5.2 Study setting

This study took place in Norwich, England. It is a main city in the region, a county with a population of 862,300, mostly White British or White Irish people (91%) (Council, 2012). According to the Community Mental Health Profile, 12.5% of adults in Norfolk suffered from depression in 2011/2012, which is significantly higher than the average for England (11.68%) (NEPHO, 2013). The report, on the other hand, showed that wider determinants of health which are related to mental health, such as unemployment (2.25% in Norfolk) and the proportion of the population living in the most deprived areas (9.8% in Norfolk) were significantly better in Norfolk than in England on average (5.94% and 19.8% respectively).

Specialist mental health care in the area is provided by Norfolk and Suffolk NHS Foundation Trust, which is supported by 7 Clinical Commissioning Groups (CCGs) who offer mental health care in the community and GP practices in the area. The seven CCGs are as follows: Norwich, West Norfolk, North Norfolk, South Norfolk, Great Yarmouth and Waveney, Ipswich and East Suffolk and West Suffolk.

5.5.3 Potential bias

5.5.3.1 Sampling bias

Due to the geographical area where this study was conducted, people with depression and family and friends who are members of ethnic minorities, who do

not speak English and those who live in rural areas were likely to be underrepresented in the research. This can pose limitations on the generalisability of findings to wider populations in other parts of the UK with more diverse populations and different health services provided by their local NHS Trusts. In addition, there was a potential for selection bias due to recruitment strategies used in this study, which include purposive sampling and recruitment methods that rely on patient-initiated contact and self-reports. Consequently, some patients and their families might not have come into contact with the study-advertising materials.

In order to minimise the risk of sampling bias, I used multiple recruitment methods, including information shared via healthcare workers, two charities and adverts in GP practices. Due to the recruitment methods to be used, healthcare workers recruited in the study were likely to be working in the Norfolk area, within the same NHS Trusts and possibly within closely collaborating teams in this area. As a consequence, it is possible that the healthcare workers who took part in this study might have been representative of the professionals working in this geographical area, but not of the professionals across the UK.

5.5.3.2 Researcher bias

It has been suggested that people who are communicative and have more socially desirable opinions might be more likely to participate in research studies, and this may be especially true for group discussions where individuals might feel inhibited to express their views due to embarrassment (Lauber et al., 2005). To help participants feel comfortable during the study sessions, facilitators agreed with participants about the ground rules to refrain from any judgement of people or opinions, to respect all individuals, and to offer confidential means of submitting ideas to the researcher.

5.5.4 Legal and ethical frameworks guiding this research

This study is not a Clinical Trial of an Investigational Medicinal Product (non-CTIMP), and was therefore bound to be conducted in line with the following research standards: Research Governance Framework (DoH, 2005), Declaration of Helsinki (Helsinki.) and Good Clinical Practice (NIHR, 2011). Other relevant laws applicable to this study were The Data Protection Act 1998, Freedom of Information Act 2000 and Equality Act 2010.

5.5.5 Good clinical practice and The Declaration of Helsinki

I received and renewed my training in Good Clinical Practice (GCP) provided by the National Institute for Health Research during the course of this research, and conducted this study fully adhering to the principles of GCP and the Declaration of Helsinki (published in 1964 and last updated in 2008). Good clinical practice (GCP E6 R1) is a set of guidelines for medical researchers, monitors and sponsors, developed at the National Conference of Harmonisation (ICH, 1996), to ensure planning, conduct, audit and reporting of high quality scientific and ethically sound research. The GCP standards are based on the Declaration of Helsinki, and set out that the researchers conducting the study need to be adequately qualified and overseen by a medically trained professional. The most important objective of the guideline and the Declaration of Helsinki is the protection of the research participants over the research or the society. In order to ensure the research is conducted safely and lawfully, the guideline further sets out the specific responsibilities of the sponsor in relation to ensuring the overall adherence to the guideline, and the researcher's responsibilities. These include planning and fully adhering to a research protocol that needs to be approved by a relevant ethics committee, including research participants based on specifically set definitions, and recording and storing research data according to the relevant legislation.

5.5.6 Ethics and governance approvals

The study and all procedures described here were set out in a study protocol (Appendix 7), which was approved by the local NHS Ethical committee (NRES) in the process of a Proportionate review in November 2011, with an assigned registration number 11/EE/0321. The Research and Development Departments in the local NHS Trusts involved in the study also granted governance approvals, with a reference number 2011MH48. In February and April 2012 I submitted two substantial amendments to the protocol to the NRES committee, and both were fully approved in the subsequent months. The main reason for the amendments was to add new recruitment strategies (all listed in section 8) in order to improve the chance of achieving the target number of participants.

In the first amendment (Appendix 8) I proposed publishing a second press release and article in charity magazines, posters in community venues and snowballing via friends and relatives to recruit people with depression and their family and friends. I also added the use of a snowballing technique via colleagues to invite more healthcare workers. I submitted the second amendment to clarify wording of sections in the protocol relating to recruitment methods (Appendix 11).

5.5.6.1 Informed consent

In accordance with the GCP and the Declaration of Helsinki, all study participants were first provided a full explanation of the study aims, procedures and possible risks. They were asked to take at least 24 hours to think about their wish to participate in the study, and sign and submit a written informed consent form prior to taking part in the study. Verbal confirmation of informed consent was sought again before every data collection session.

5.5.6.2 Distress, safety and withdrawal of participants

This study was considered to pose a low risk to participants and the researchers, since the aim was to discuss the participants' views about how people with

depression make treatment decisions. Participants were advised that they could submit any additional factors to the researcher in confidence via email, Post-it notes after the sessions or via telephone, if they did not want to discuss them within the group session. During all data collection sessions a group facilitator and an assistant were present, and for sessions with people with depression and family and friends there was also a professional available in case participants became upset and wished to talk to someone in private. Participants were informed about this option but it was never needed.

All participants were advised that if any of the research team through discussion became aware of any unprofessional practice (for example, health care workers prescribing inadequate treatment), abuse or maltreatment of a vulnerable person, such information would have to be shared with the appropriate authority.

In line with the Equality Act 2010 participants were treated equally, and were not discriminated against on the basis of age, gender, ethnicity, disability, language, sexual orientation or other characteristics, if in line with the inclusion criteria necessary to be met for this research. For example, it was only possible to include adults aged over 18 due to their legal right to provide informed consent. Also, we could only involve people with full capacity to consent to participation, and people who spoke English, in order to involve them in discussions about the focus question.

5.5.6.3 Anonymity and confidentiality of participants' data

All data were collected and processed, and has been stored according to the Data Protection Act 1998. In this study no member of the research team had any access to medical history or other clinical or personal information about the participants, except for the information they voluntarily shared in order to fill in the basic information questionnaire and during the brainstorming sessions. Personal information, such as names, was recorded on the questionnaires and consent forms, whilst the consent forms also contained additional demographic characteristics and self-reported depressive histories of people with depression. All

brainstorming sessions were audio-recorded after the participants agreed to it. All recordings and documents with personal and confidential information was transported from site to the University in a locked briefcase, and stored in a locked cabinet in a room accessible to a group of researchers by card. All information was transferred to electronic password-protected documents, which have been saved on the University of East Anglia's central network server within the University's firewall. In accordance with the study protocol, all research data were anonymised within 12 months of the end of the study. In accordance with the Freedom of Information Act 2000 all data stored about any of the participants has to be shared with them upon request. No such request was received before the data were anonymised.

5.6 Data analysis

5.6.1 Descriptive statistical analysis

Demographic, clinical and professional characteristics of the participant groups were analysed first, to describe the study population in this project. This information was entered into a statistical analysis package for Windows, SPSS version 18 (SPSS, 2009). The characteristics measured by continuous variables (i.e. age, number of depressive episodes, number of years with depression, and the number of years of professional experience of working with people with depression) are described by the means, standard deviations and information about the minimum and maximum values reported. Categorical variables were used in the following demographic characteristics: gender, highest level of education, marital status, employment status; and in these clinical characteristics: treatment history: treatment prescribed, treatment participants reported to have been taking and reported adherence to the type of treatment prescribed. For these variables I provide the number of participants (N) and the proportion of the relevant stakeholder group (in percent).

5.6.1.1 Characteristics of the participants in two study phases

Not all people who took part in the brainstorming phase also continued to take part in the clustering and prioritising phase of the study. To test whether the people participating in the two phases have different characteristics, I compared their demographic, clinical and professional data. Continuous variables were contrasted using a two sample t-test and data recorded in categorical variables were tested using a Chi-Square test.

5.6.2 Concept mapping data analysis

Concept mapping analysis involves the following steps: 1) data entry, 2) computation of a distance matrix, 3) reduction of dimensionality of the matrix dataset, 4) generation of a concept map, and 5) cluster analysis.

5.6.3 Data entry

Data from the clustering and prioritising tasks were entered into a specialised concept mapping software, designed for this purpose (Severens, 1995a) and all entries were double checked against the original data sheets. For each task separately, I entered card numbers of statements, participant by the participant into a table, where columns represent groups (clustering) or piles (prioritizing). Data from the two tasks are initially analysed separately.

5.6.4 Distance matrix

In the first step of analysis, Ariadne uses data from the clustering task to calculate a distance matrix, where each column and each row represents one statement from the set (similar to a correlation matrix). Each value in the matrix is calculated by dividing the number of participants, who put the two particular statements in the same group, by the total number of participants who had used those statements (Severens, 2012). The values in the matrix therefore represent the participants' overall perception of how related (or distant) each statement was to every other statement in the set. Larger values in the distance matrix indicate that a larger

proportion of the sample placed the two statements in the same group, i.e. they thought that the two statements were related (Kane and Trochim, 2007). This matrix is calculated by Ariadne as an intermediate step in the data analysis procedure, and cannot be accessed for subsequent inspection (Severens, 2012).

5.6.5 Reducing the dimensionality of data

The distance matrix is highly multidimensional, and contains a large volume of information about the relations among statements, which cannot be interpreted purely by visual assessment of the matrix. To conceptualise the information it contains, its dimensionality (complexity) needs to be reduced using multivariate techniques (Roskos-Ewoldsen and Roskos-Ewoldsen, 2008). In concept mapping, this is done by performing a set of multivariate analyses, which first identify the main dimensions, and then separate the statements into appropriate groups (clusters).

5.6.5.1 Multivariate analyses

Various methods can be used to reduce dimensionality of a dataset, and in concept mapping these are multidimensional scaling (MDS) (Kane and Trochim, 2007), or principal component analysis (PCA) (Severens, 2012). A commonly known method, Factor analysis (FA), is also used for the purpose of reducing dimensionality of data, although not in concept mapping (Kane and Trochim, 2007; Severens, 2012). This method is often compared to PCA, but the latter is viewed as mathematically simpler and more stable (Pallant, 2001).

5.6.5.1.1 Multidimensional scaling (MDS) and principal component analysis (PCA)

Multidimensional scaling is a technique used to plot items (in this case, statements) on a graph, to demonstrate the distances (or dissimilarities) between the individual items (Jackson, 2005). While both MDS and PCA analyse a similarity matrix, MDS first estimates the distances among statements and then detects the characteristic

dimensions in the data (Jackson, 2005). PCA, on the other hand, identifies the dimensions (principal components) prior to calculating the statements' coordinates on each dimension (Jolliffe, 2002).

The results of these techniques are similar when applied to Euclidean distances (Williams, 2002), which is one of the standard measures of distances between items (statements) on a number of dimensions (Jackson, 2005, Quinn and Keough, 2002). Both methods have also been successfully used in combination with a cluster analysis (Jolliffe, 2002, Ben-Hur and Guyon, 2003) and in high quality concept mapping studies (Kikkert et al., 2006), despite some authors suggesting that PCA is less appropriate for this type of analysis (Yeung and Ruzzo, 2001). Researcher makes the choice of the technique to use in concept mapping when selecting a software package. Because of the similarity between the methods and the practical advantages associated with the software package Ariadne, I used PCA as part of the analysis for this study.

5.6.5.2 Principal component analysis (PCA)

The distance matrix generated in the first step contains information about statements' relations to every other statement in the set. To characterise the dataset and explain its variance, PCA identifies a set of principal components, and assigns values for every item on each component (Jackson, 2005, Pallant, 2001, Quinn and Keough, 2002). The components are dimensions, or themes, that run through the data, each capturing a proportion of the variance within the dataset. The variance is largest for the first dimension and gradually decreases for every subsequent one. In PCA, each statement is assigned a value for each of the dimensions, based on the 'average' distances of statements to each other.

The total number of components equals the number of items (i.e. statements), but usually only the first few are used in subsequent analyses. This decision is made by researchers and depends on the research aims and specific characteristics of the dataset in question (Jolliffe, 2002).

5.6.5.2.1 Eigenvalues

Each dimension identified in the PCA is described by an eigenvalue, which indicates the proportion of variance explained by the dimension (Jolliffe, 2002). These values are used to decide the number of dimensions that will be used in the interpretation of findings or in further analysis, which in concept mapping is cluster analysis. Ariadne by default displays the first five dimensions, altogether expressing 76% of variance in the data. The remaining 24% of variance is not accessible for further analysis, due to being contained in the subsequent dimensions with a rapidly decreasing size and the ability to capture meaningful information about the data.

5.6.5.2.2 A concept map

A concept map is usually a 2-dimensional graph (Kane and Trochim, 2007) and its axes are the first two dimensions identified by PCA. It is a scattergram where statements are pictured as dots, according to their dimension values, used as their coordinates. The purpose of the concept map is to graphically demonstrate the relationships between statements, and to aid their visual interpretation. The observed distance between any two statements represents how often participants had placed them in the same group, i.e. how related they were perceived to be. Each dimension can be thought of as a continuum of a theme (or criteria) used by participants when grouping the statements, and can be labelled accordingly (for instance, practical vs. emotional aspects). Any two statements can be located relatively close on one dimension but far apart on another dimension. Consequently, they can be closely related from one perspective, whilst rather different from another. This indicates the multiplicity of viewpoints from which the statements' relations can be considered.

5.6.5.3 Cluster analysis

The next step in the concept mapping analysis is to identify groups of statements, which are related to each other. This is done using cluster analysis; a method that separates the items in a data set into groups based on their relative distances on

the PCA dimensions (Jolliffe, 2002). Each cluster contains statements which are located close to each other, and therefore related to the same concept, but distinct from those in other clusters (Kane and Trochim, 2007, Rosas and Kane, 2012). They are portrayed on the concept map to graphically demonstrate the location of statements they consist of, and to illustrate the relations among the different clusters.

5.6.5.3.1 Data input: practical issues

The software Ariadne was used to calculate a distance matrix using raw data, which was inputted into the data sheets of the software package. After performing the first step, i.e. PCA on the distance matrix, Ariadne produces reports, including statements' coordinates for five dimensions, and the relevant eigenvalues. This data can be further analysed in Ariadne, or it can be exported to different software, such as SPSS. I decided to use SPSS, since it offers more options for analysing the PCA output than Ariadne. For instance, it is possible to specify the number of dimensions to be processed, and the type of the clustering method to be performed.

5.6.5.3.2 Number of dimensions to be used

A decision has to be made about the number of dimensions to be used, and there are several rules to guide this choice.

5.6.5.3.3 Two dimensions

Using two dimensions is common in concept mapping studies, because it allows a straightforward graphical representation of the statements and non-overlapping clusters to appear on the concept map (Kane and Trochim, 2007). A disadvantage of using only the first two dimensions is the loss of information (variance) contained in the additional dimensions. The amount of variance in each dimension can be determined based on the eigenvalues that characterise each of the dimensions.

5.6.5.3.4 More than two dimensions

Using additional dimensions in cluster analysis is common in other disciplines where large volumes of data are analysed (for example, studies on gene expression with 1,000 dimensions in a dataset) (Ben-Hur and Guyon, 2003). The reason for utilising more than two dimensions is usually a desire to include the proportions of variance contained in the higher dimensions (Jolliffe, 2002). This way, more information about the relationships of the items (statements) to each other can be considered when generating the clusters. The selection of the number of dimensions needs to be balanced, since using too many dimensions negatively influences the cluster solutions and their stability (Jolliffe, 2002).

The problem with utilising numerous dimensions is their graphical representation. A three dimensional graph would convey more information about the statements' distances from each other (due to displaying the 'depth' of the graph, in addition to its length and width). It is, nevertheless, difficult to display four or more dimensions in a graph. To deal with this issue, it is possible to display several concept maps, with only two dimensions at a time. Using this type of approach allows for visual inspection of the relations between statements and clusters on the additional dimensions.

5.6.5.3.5 How many dimensions?

The number of dimensions selected for further analysis can vary and there are several rules that have been used to inform this decision. These include 1) evaluating the amount of variance expressed by the dimensions to include between 70-90% of the total variance, and 2) including dimensions with eigenvalue l_k of more than $l_k>1$ (Jolliffe, 2002, Quinn and Keough, 2002). When using multidimensional scaling, for example, in Concept Systems software, a 'stress' value is typically calculated to determine how well the selected dimensions represent the original distance matrix (Rosas and Kane, 2012). Since this is not done in Ariadne, I decided the number of dimensions based on the proportion of variance explained by the

five dimensions reported in Ariadne, which is generally around 76%. I therefore used data for all five dimensions in the subsequent cluster analysis.

5.6.5.4 Clustering method

The aim of performing a cluster analysis is to identify homogenous groups of related items, which would be distinct from other groups (Burns and Burns, 2008). There are many different methods, but three main types exist: hierarchical, partitioning and two-step. The last one is a combination of the former two, specially used in analysing large data sets (more than 10,000 cases) (Norusis and Inc., 2011) and was not considered for this study. Depending on the method, clustering results can differ, since the algorithms vary considerably. Selection of a clustering method is therefore important and influences the final results, and depends on the size of a dataset as well as the objectives for using the analysis (Mooi and Sarstedt, 2011, Norusis and Inc., 2011).

5.6.5.5 Hierarchical clustering

Hierarchical clustering methods are used in concept mapping studies mainly because they are straightforward, and generally allow generation of clusters that do not overlap when portrayed on a graph (Kane and Trochim, 2007). This is because the statements are allocated into clusters according to their distances on the dimensions. The process is either agglomerative i.e. statement are first considered as individual clusters, which are merged with the closest neighbours in successive steps, or divisive, in which the process starts with one large cluster containing all statements, which is then divided into smaller groups in each step (Norusis and Inc., 2011). Examples of the commonly used hierarchical clustering methods include centroid and Ward's methods, both of which are typically used in concept mapping research.

5.6.5.5.1 Centroid method

The centroid method is used in the Ariadne software (Severens, 2012), the program that was used in the first step of data analysis to identify the principal components in the original matrix of data. This method identifies the cluster centre as a means of all its statements' distances (Norusis and Inc., 2011). Distance between any two clusters is considered to be the distance between their centres. After merging, a new centre is calculated, based on the clusters' original centres. A disadvantage of this method is the decreasing distance between the clusters in progressive steps, meaning that the clusters merged later on appear to be closer to each other, although they might in fact be less related than those merged earlier (Norusis and Inc., 2011). For this reason I decided to select one of the other clustering methods available.

5.6.5.5.2 Ward's method

Ward's method is the only hierarchical method to determine the clusters' distances based on the analysis of variance (Roskos-Ewoldsen and Roskos-Ewoldsen, 2008). It allocates statements into groups by calculating the sums of squared deviations from the cluster mean (Burns and Burns, 2008). The method is advantageous over te other hierarchical methods due to its more stable algorithm (Norusis and Inc., 2011) and is applied in concept mapping software Concept Systems (Kane and Trochim, 2007) to generate non-overlapping clusters.

5.6.5.5.3 Hierarchical clustering evaluated

In the hierarchical clustering methods the similarity of clusters is determined by the distances between them, with the algorithm for calculating the distances dependent on the specific method (Norusis and Inc., 2011). Their generally accepted advantage is an opportunity to inspect the steps of the cluster-forming procedure using a dendrogram, a graphical tree-like representation of the process produced by SPSS. This aids in the decision-making about the final cluster solution and the number of clusters (Mooi and Sarstedt, 2011). The feature viewed as an advantage in the examination of the cluster solution is a disadvantage in the

process of generating the solutions. Due to the tree-like process of generating clusters in each step, the clusters that have been combined cannot be further divided, which negatively affects their quality and ability to reproduce the statements' relationships from the original data matrix (Norusis and Inc., 2011). Considering this limitation, I decided that using other than hierarchical clustering would be ideal.

5.6.5.6 k-means clustering

K-means clustering is a partitioning method and is widely used in different disciplines, for instance environmental science and biology (Mooi and Sarstedt, 2011). In contrast to hierarchical methods, this algorithm does not need to calculate distances between all pairs of statements and only produces one cluster solution specified in advance, making it more appropriate for larger datasets (Norusis and Inc., 2011). It divides the data space into the set number of parts, and then locates the individual clusters and statements that belong to them (Burns and Burns, 2008). This is done by evaluating the within-cluster variation and keeping it at a minimum (Mooi and Sarstedt, 2011); this is similar to the Ward's method but is more effective (Punj and Stewart, 1983).

One iteration of k-means method yields only one cluster solution, which has two main consequences. Firstly, the desired number of clusters to be produced needs to be set in advance (Norusis and Inc., 2011). This can be an advantage in terms of saving time if the optimal number of clusters is already known, but would also be a disadvantage if one wished to explore different options. To address this feature, it is possible to rerun the algorithm several times, in order to view more than one set of clusters and select the best one. Secondly, whilst in hierarchical methods statements' cluster memberships do not change once items are allocated, rerunning k-means to produce a different number of clusters often results in the relocation of items (Norusis and Inc., 2011). Consequently, for example, statements' memberships in clusters in a 7-group solution can be different from those in an 8-group solution. This would depend on the optimal cluster centres identified in the

new cluster iteration. This also means that unlike in hierarchical methods, in a k-means analysis, it is not possible to watch the process of clusters being combined by the algorithm. This is because in hierarchical algorithms, the neighbouring clusters are combined/ separated at some stage of the analysis, whilst in the k-means method each cluster is generated independently. In both types of analyses, the items are being grouped into clusters based on their dimension scores, i.e. their position in space, in relation to other statements.

In addition to these differences, the k-means method picks up outliers (statements which are relatively distant from others) more easily than hierarchical methods, placing them into small clusters alone or with a few other items (Norusis and Inc., 2011). Some authors suggested deleting the outliers and advised against having clusters with a small number of items (i.e. fewer than four) (Burns and Burns, 2008). Within concept mapping, such small clusters are accepted, since they can provide valuable insight into participants' perspectives about relationships between statements (Kikkert et al., 2006).

5.6.5.7 Number of clusters

Deciding the final number of clusters, i.e. the final cluster solution, is an iterative and subjective process (Roskos-Ewoldsen and Roskos-Ewoldsen, 2008). Clusters are interpreted based on the items they contain, and the aim is to generate clusters which are as unrelated as possible (Norusis and Inc., 2011). Generally authors agree that no single best cluster solution exists, and different clustering outcomes should be compared to identify the one that seems to be most appropriate and best fits the research topic (Kane and Trochim, 2007). There are several techniques to aid this decision-making process, and the main ones are briefly explained below.

5.6.5.7.1 Dendrogram

A dendrogram is a special, tree-like type of graphical representation and is only produced in hierarchical clustering. It displays all original items (statements) and

demonstrates all steps at which the items were merged into clusters. Rescaled distances between clusters when combined are also annotated to help decision-making about the number of clusters and the 'acceptable' distances between them (Norusis and Inc., 2011).

5.6.5.7.2 An elbow graph of clusters' coefficients

An elbow graph can be generated to compare different cluster solutions produced by one clustering method (Sugar and James, 2003). In hierarchical methods one would plot the 'agglomeration coefficients' on this graph, which are automatically produced in SPSS to describe the distances (similarity) of clusters combined in each step (Norusis and Inc., 2011). Using a k-means these values are not produced because there is only one step where the required number of clusters is generated. Instead, SPSS calculates distances between each statement and its cluster, which can be used to calculate the clusters' ability to represent the data variability, i.e. entropy values (Hunter, 2012). Entropy values are sums of squared distances between all statements and their clusters (Hunter, 1989, Hunter, 2012).

The k-means analysis can be run repeatedly to produce a different number of clusters each time. I calculated entropy values for each cluster solution, and plotted them onto an elbow graph to visually inspect the differences between them. A line of best fit was generated to connect the plotted coefficients, and inspected to identify a point of change in its shape and direction (Hunter, 2012). The line typically shows a steep drop for the first few points (i.e. a 'jump'), which is followed by one or more points on the graph placed at a similar level, making the line appear flat (Sugar and James, 2003). The most appropriate number of clusters is then represented by a point at the bottom of the 'jump', which is followed by the flat part of the line. More than one suitable number of clusters can be present within a dataset, and each of them is identified as a bottom of a 'jump'. The selection of the most suitable option for a particular dataset is made by the researcher, and depends on the evaluation of the clusters and their interpretability (Kane and Trochim, 2007, Hunter, 2012).

5.6.5.8 Clustering in this study

After careful consideration of the different clustering methods, I decided to use k-means for its ability to identify outliers and the higher quality of clusters compared to hierarchical methods. To choose the final number of clusters I used the elbow graph plotting method, portraying the entropy values for several solutions on a graph. One or more points where the line on the graph sharply changes its direction, were investigated and evaluated within the research team, in order to select the most suitable cluster solution.

5.6.6 Participant subgroups

In addition to categorising of statements, it is also possible to identify subgroups or profiles of participants using cluster analysis (Thacher et al., 2005). The input variables for this analysis can be participants' Likert-type scale (Likert, 1932) importance rankings for the statements (Thacher et al., 2005). It is also possible to use data generated through the use of the Ariadne package as Pearson's R correlations between each statements' dimension coordinates (unit normalised) and participants' importance ratings of the statements (unit normalised) (Severens, 2012). These values are calculated for all five dimensions produced in Ariadne. I performed a k-means method on values assigned to participants on five dimensions, for the reasons explained in section 5.6.5.3.5. and section 5.6.5.6.

Thacher et al (2005) evaluated k-means clustering and a latent-class analysis in order to characterise a participant population into separate groups. The authors suggested that both were appropriate, but the latter was superior due to allowing participants to be considered in more than one category. In this study I decided to use k-means to allow generation of clusters that represent the original data as closely as possible, whilst avoiding the extra limitations posed by the hierarchical methods, i.e. the inability to re-categorise the items which were once placed in clusters. The main objective of clustering cases in this study was to explore the possibility of identifying different types of the stakeholder groups. In order to

decide the number of final clusters (i.e. stakeholder group types), I used the same method as in clustering of statements (i.e. entropy values for each cluster solution plotted on an elbow graph).

5.6.7 Differences between stakeholder groups

Once the final cluster solution was identified, the objective was to compare the three stakeholder groups' perspectives about the clusters' relative importance. Data from the prioritising task were used to calculate participants' average importance rankings for each statement and compare the groups' views. Using the 'Compute' option in SPSS I calculated participants' mean rankings for each cluster, and performed a one-way ANOVA to explore differences between the stakeholder groups and generate 95% Confidence Intervals. Tukey's post-hoc test was then performed and calculations made to identify the groups whose responses were significantly different.

5.6.8 Type of data

Information about participants' perceptions of statements' importance was collected using a 5 point Likert-type scale (from 1 – the least important to 5 – the most important). This type of data is considered to be ordinal since we cannot assume that all participants viewed the five Likert points as equally distinct, and authors often advise using non-parametric statistical tests (Clason and Dormody, 1994). This is because Likert-type data is not considered to meet the assumptions of parametric tests, such as one-way ANOVA, which are as follows: 1) the study samples are independent, 2) the means are normally distributed, 3) data is measured on an interval scale, and 4) the study groups' variances are homogenous (Jamieson, 2004). Inappropriate use of statistical methods was suggested to carry a risk of drawing inaccurate conclusions about the samples (Clason and Dormody, 1994). Despite this, analysing Likert-type and other ordinal data with parametric statistics is common and according to some authors, not even problematic.

Norman (2010) proposed that the question of type of scale should not be viewed too strictly, since the choice of the most appropriate data analysis method depends on more than simply labelling a scale. Parametric tests, such as one-way ANOVA, are more robust and powerful than their non-parametric alternatives (in this case, Kruskal-Wallis test) (McCrum-Gardner, 2008). The question should, therefore be asked: what are the consequences of violating these tests' assumptions (Norman, 2010). Large Monte Carlo simulations showed that not satisfying some of the theoretical requirements about data in fact does not always cause inaccurate results (Norman, 2010, Lantz, 2013). For example, normality of distribution of means is not an important requirement in samples of more than 5-10 participants, since the parametric tests are robust enough to deal with skewed data (Norman, 2010). In addition, when items scored on a Likert scale are combined into groups (i.e. clusters in this study), this data can be considered as interval rather than ordinal and the use of parametric statistical tests is then held to be appropriate (Norman, 2010).

5.6.9 Missing data

Missing data in this study could occur when participants were entering the statement IDs to the answer sheets, in order to record their responses about the statements' importance and the perceived relationships between them. It could be caused by random mistakes, for example forgetting to enter a number, or by mistake writing a different number. Participants could also generate missing data intentionally. For example, if they thought that a particular statement (or a group of statements) was not important enough to be entered into the answer sheet table, or if they thought that a statement was not related to any other items and should not belong to any cluster. The primary data could be missing in the records of participants' responses for the prioritising and clustering tasks.

The way missing data is dealt with depends on how an analysis is performed. Data from the clustering task are entered into Ariadne, to calculate a similarity matrix. This calculation involves dividing the number of times that any two statements had

been put together into one group, by the number of times the statements had been used in the participants' responses. If a participant omitted one of those items, the denominator in this equation is the total minus 1. The missing data is therefore dealt with during the calculation of the matrix.

There are several main strategies of treating missing data, which are: 1) excluding participants with any missing values from the analysis, 2) replacing the missing values with multiple imputation values, and 3) ignoring the missing data (Altman and Bland, 2007).

In order to deal with the missing data when computing the clusters' mean importance rankings (based on the statements' rankings), I excluded the data of any participant who had omitted 25% or more of the statements in that cluster. If less than 25% of the data was missing, the participant's responses were included in further analysis. This was a pragmatic decision to allow inclusion of participants who had omitted a random statement due to recording errors. Participants who explained in their answer sheets the reasons for omitting statements were excluded from the particular analysis, since their missing values could not be considered to be random.

5.7 Conclusion to the chapter

The aim of this research is to provide better understanding about how people with depression perceive their treatment decision-making, and how their views contrast with those of healthcare workers and family and friends. I selected concept mapping method as the method that could best help me accomplish the aims, and which could also add valuable information about the three groups' viewpoints.

Chapter 6 Descriptive results

6.1 Reflection on the research process

6.1.1 Research team

The first part of this study was characterised by qualitative data collection and subsequent analysis of this data. All of the facilitators and assistants helping with data collection were either PhD students or established researchers within the Faculty. We all had experience with qualitative data collection or facilitating group discussions and were at the time actively involved in health and social science research. In addition, the groups were run in accordance with the focus group plan I had prepared. This involved helping participants to come back to the focus question if the discussion diverged from the main topic. Facilitators were able to suggest prompts from the list provided in order to encourage further discussion and generation of ideas. The sessions were therefore maintained to a structure as similar as possible, in order to limit personal bias.

6.1.2 Relationship with participants

I scheduled a preliminary meeting prior to focus groups with most participants, which took approximately one hour and involved a relaxed discussion about the study aims, about my personal reasons for doing the study, about their role in the study and any other questions they might have. This allowed me to ensure that their consent to take part in the study was fully informed and they understood the aims and objectives of the study. Additionally, I was also able to establish a relationship appropriate for research study. Before asking people to talk about the factors they had found influential of their treatment choices, I made sure they were able to feel safe in the study setting. I aimed to maintain a relaxed professional relationship where my sole role was a researcher and purpose of the focus groups was research rather than a self-help or a therapy group. This setting was reinforced by facilitators reminding groups the study aims and by audio-recording the

discussions, if participants agreed. In order to maintain safe and professional but relaxed researcher-participant relationships, I did not meet participants outside of the study setting during the course of data collection. I also refrained from discussing personal topics that fell outside of the research topic.

6.1.3 Researchers' personal views

One of the potential biases posing risk to the scientific integration of this research were my personal views about depression, its treatment and decision-making, and the views held by other facilitators. In order to help participants feel safe and relaxed during study sessions, I always explained that the facilitators and participants would not judge anyone for their beliefs or thoughts.

Depression is an illness that can affect any person regardless of their social, socio-economic or educational status. People with this illness should be supported in accessing effective treatment and they should not be discriminated against, judged or blamed. Whilst some form of treatment is recommended for all people with depression irrespective of its severity (NICE, 2009), my view reflects the person-centred philosophy of practice guidelines, that people should be supported to make decisions based on their personal beliefs and they should not be judged based on their treatment choices. To my best knowledge and ability, I facilitated focus groups in a tolerant and open-minded way to encourage free sharing of opinions. When focus groups were held by other researchers, I briefed them to ensure they held a similar approach, in order to minimise personal bias and risk to scientific integration.

6.2 Recruitment methods

6.2.1 People with depression and family and friends

Table 1 shows the processes used to recruit people with depression and family and friends. A total of 104 people contacted me based on the articles published about the study, asking for more information about the study, and 70 of them self-

reported having depression, 31 said they were close to a person with depression, and 3 did not disclose which group they would belong to. Almost three quarters of all people with depression who made contact did so following the publication of the first article describing this study on the University's website and in the local newspapers in November 2011. One person was recruited via an article in the newsletter of the charity Mind. Approximately equal numbers of family and friends requested more information about the study after the publication of the two articles in November 2011 and April 2012.

Three other recruitment methods which were used but did not bring any participants to the study included posters displayed in GP practices, healthcare workers providing information to their clients, and support groups run by the charity Age UK.

Table 1: Recruitment processes used for people with depression and family and friends.

Recruitment method November 2011 – July 2012	Total N (%)	Made contact		
		People with depression N (%)	Family and friends N (%)	Undisclosed N (%)
Recruitment initiative 1 (Nov 2011) total	**75 (72%)**	**57 (73%)**	**16 (52%)**	**2 (67%)**
Article on the UEA website	14 (13%)	12 (17%)	2 (6%)	0
Article in the newspaper	42 (41%)	39 (55%)	1 (3%)	0
Snowballing[1]	19 (18%)	6 (9%)	13 (42%)	0
Unknown[2]	0	0	0	2 (67%)
Recruitment initiative 2 (April 2012) total	**28 (27%)**	**13 (19%)**	**15 (48%)**	**1 (33%)**
Article on the UEA website	7 (7%)	4 (6%)	2 (6%)	1 (33%)
Article in the newspaper	10 (10%)	1 (1%)	9 (29%)	0
Snowballing[1]	9 (9%)	7 (10%)	3 (10%)	0
Unknown[2]	2 (2%)	1 (1%)	1 (3%)	0
Article in the Norwich Mind newsletter	1 (1%)	1 (1%)	0	0
Total	**104 (100%)**	**70 (100%)**	**31 (100%)**	**3 (100%)**

[1] If people reported having read about the study in newspapers and told their partner about it, one of them was categorised as recruited via snowballing.
[2] Did not disclose where they had read about the study

6.2.2 Healthcare workers

The recruitment methods used for healthcare workers are shown in Table 2. At least 142 healthcare workers were given information about the study using the methods listed in the table. Most participants were recruited via the NHS Trust teams. Of the 89 healthcare workers who attended the presentations, more than 1 in 3 consented to take part in the research.

Table 2: Methods of recruiting healthcare workers

Recruitment method	Given information about study	Requested more information	Consented to take part in study
	N (%)	N (%)	N (%)
Attended NHS Trust team presentations [N of teams]	89 [6] (63%)	35 [4] (74%)	34 [4] (76%)
Snowballing[1]	33 (23%) [2]	11 (23%)	10 (22%)
AM therapist invitations[3]	20 (14%)	-	-
GP practices[3]	2 (1%) [4]	-	-
Total	**142 (100%)**	**47 (100%)**	**45 (100%)**

[1] Snowballing involved potential participants sharing information about the study and researcher's contact details with colleagues

[2] At least 33 healthcare workers were invited to take part in the study via the snowballing method but it is not possible to determine a total number of professionals who might have been contacted and never responded.

[3] Due to low numbers of AM therapists and GP practice health professionals responding to the study invitations, I only provide the total number of therapists who were sent the invitations.

[4] Practice managers or research leads in two GP practices were contacted, inviting health professionals to take part in the study. The number of professionals who received information about this study is unknown.

6.3 Participant flow

6.3.1 People with depression

Figure 2 shows the sequence of study events, which took place for people with depression. One person did not meet the inclusion criteria for unipolar depression (reported having bipolar disorder). Twenty-eight people did not return a reply slip and did not provide any reason for not expressing interest in taking part in the study. One person decided not to take part since they did not want to talk about their difficult experiences with depression. One person did not attend a scheduled consenting meeting due to health reasons, 1 due to time constraints and 1 gave no reason. Having consented to take part in the study, one person did not respond to an invitation to a brainstorming session. A total of 36 people with depression took part in the first study phase. Of the 8 people who withdrew before performing the prioritising and clustering phase, 3 had agreed to take part but never returned their answer sheets with recorded data, 2 did not respond to invitations to take part, 1 did not think they could be helpful for the project, 1 did not attend a meeting, and 1 was not interested in further participation in the study. Twenty-eight people with depression took part in the prioritising and clustering phase.

Figure 2: Recruitment flowchart for people with depression

Requested more information
(n=70)

Did not provide contact address
(n=1)

Were sent information sheets
(n=69)

Not meeting the inclusion criteria
(n=1, bipolar disorder)

-Not sending a reply slip – no further reason given
(n=28), fear of talking about own depression
(n=1);
-Not attending a scheduled consenting meeting
(n=3): no reason, health reason and time
constraint.

Consented (n=37)

Withdrew:
-Did not respond to invitation to a
session (n=1)

Took part in the brainstorming
phase (n=36)

Invited to take part in the
prioritising and clustering phase
(n=36)

Withdrew (n=8)

-Did not return answer sheets (n=3)

-Did not respond to invitations to prioritising and
clustering phase (n=2)

-Felt they could not contribute to the study any
more (n=1)

-Did not attend a scheduled session (n=1)

-Not interested in the study anymore (n=1)

Performed the prioritising and
clustering tasks (n=28)

6.3.2 Family and friends

Figure 3 shows the sequence of study events that took place for the group of family and friends. Among the people who were sent the information sheets, the most frequent reason for not taking part was not sending a reply slip expressing their interest in joining in the study. One person initially scheduled a consenting meeting but cancelled due to time constraints. Having consented to take part, one person did not respond to a brainstorming session invitation. Following an invitation to perform the prioritising and clustering tasks, 6 people withdrew for the following reasons: not returning an answer sheet with data for the two tasks, not attending a scheduled session, time commitments, personal reasons, and loss of interest in the study. One person did not give any reason. One person from this group withdrew after completing the prioritising task, finding the instructions to the clustering task too difficult.

Figure 3: Recruitment flowchart for family and friends

```
┌─────────────────────────────┐
│ Requested more information  │
│ (n=31)                      │
└─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐
│ Were sent information sheets│
│ (n=31)                      │
└─────────────────────────────┘
              │
              │         ┌──────────────────────────────────────┐
              ├────────▶│ Did not express interest to take part│
              │         │ (n=9); cancelled a meeting due to time│
              │         │ constraints (n=1)                    │
              ▼         └──────────────────────────────────────┘
┌─────────────────────────────┐
│ Consented (n=21)            │
└─────────────────────────────┘
              │
              │         ┌──────────────────────────────────────┐
              ├────────▶│ Did not respond to invitation to a   │
              │         │ brainstorming session (n=1)          │
              ▼         └──────────────────────────────────────┘
┌─────────────────────────────┐
│ Took part in the brainstorming│
│ phase (n=20)                │
└─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐
│ Invited to take part in the │
│ prioritising and clustering │
│ phase (n=21)                │
└─────────────────────────────┘
```

Withdrew (n=6)

-Did not return answer sheets (n=1)

-Did not attend a scheduled session (n=1)

-Did not provide any reason (n=1)

-Not interested in the study any more (n =1)

-Time commitments at work (n=1)

-Personal reasons (split up with his partner) (n=1)

```
┌─────────────────────────────┐
│ Performed the prioritising task│
│ (n=14)                      │
└─────────────────────────────┘
              │
              │         ┌──────────────────────────────────────┐
              ├────────▶│ Withdrew: found the clustering       │
              │         │ task too difficult (n=1)             │
              ▼         └──────────────────────────────────────┘
┌─────────────────────────────┐
│ Performed the clustering task│
│ (n=13)                      │
└─────────────────────────────┘
```

6.3.3 Healthcare workers

The numbers of healthcare workers informed about the study, withdrawing in different stages, and taking part are shown in Figure 4. Of the 142 workers who were given information about the study, 95 did not express an interest in the study and did not request further information. Of those who did, 5 did not respond to invitations to attend any of the data collection sessions. A total number of 45 healthcare workers consented to take part in the study. Forty-two people took part in brainstorming, and 19 of them completed the prioritising and clustering phase. The remaining 23 workers did not perform the second phase of the study, mainly due to not responding to invitations. One person withdrew due to going on maternity leave, and one due to health reasons. Three healthcare workers only took part in the prioritising and clustering phase due to being recruited at a later stage in the study. Two of them withdrew after completing the first task, having found the instructions for the clustering task too difficult.

Figure 4: Recruitment flowchart for healthcare workers

Total contacted and given information about study (n=142)

Did not express an interest in the study (reasons unknown, n=95)

Requested more information (n=47)

Did not respond to invitation to a session (n=5)

Consented (n=45)

Took part in the brainstorming phase (n=42)

Only took part in the prioritising and clustering phase (due to being recruited at a later stage, n=3)

Withdrew (n=23)

-Did not respond to invitations (no reasons provided, n=21)

-Went on maternity leave (n=1)

-Health reasons (n=1)

Withdrew: found the clustering task too difficult (n=2)

Completed the prioritising and clustering tasks (n=19)

Completed the prioritising and clustering tasks (n=1)

6.4 Description of participants

6.4.1 People with depression

6.4.1.1 Demographic characteristics

Demographic characteristics of the people with depression taking part in the two phases of the study are shown in Table 3, together with the characteristics of the general population of England and Wales collected in the national census in 2011 (Office of National Statistics, 2011). No significant differences were identified between the whole group of people with depression who took part in brainstorming (n=36), and the part of the group who continued to participate in the clustering and prioritising phase (n=28). Almost two thirds of the sample were female, and almost all people described themselves as White British or White Irish. This is more than in the general population of England and Wales in 2011. Almost twice as many people in the study sample had achieved a University degree or higher, compared to the general population. There were also differences in employment status between the general and study populations. Just over a half of our participants were people currently employed, compared to almost 90% of the general population in economically productive age (16-74), based on the census (Office of National Statistics, 2011). There were also approximately twice as many unemployed participants and students in the study, compared to the general population.

Table 3: Demographic characteristics of people with depression

	Brainstorming (n=36)	Prioritising and clustering (n=28)	P-value (based on Chi-Square, unless * then based on t-test)	Norfolk population (Census 2011) (%)[2]	Norfolk population (Census 2011) (%)[2]
	N (%), unless * then Mean (SD; min-max)				
Female	23 (64%)	18 (64%)	NS[1]	51%	51%
Age in years*	47 (16.5; 18-79)	46 (16; 18-79)	NS	-	-
White British or White Irish	34 (94%)	27 (96%)	NS	92.9%	80.9%
Highest achieved qualification					
Secondary education	16 (44%)	12 (43%)	NS	46.5%	44.5%
University Degree or higher	20 (56%)	16 (57%)	NS	21.9%	27.4%
Marital status					
Single	15 (42%)	11 (39%)	NS	29.5%	34.6
Married/co-habiting	16 (44%)	14 (50%)	NS	50.2%	46.8
Divorced/separated	5 (14%)	3 (11%)	NS	10.1%	11.7
Employment status					
Employed	19 (52%)	15 (54%)	NS	61.5%	62.1%
Not employed	5 (14%)	3 (11%)	NS	13.8%[2]	15%[2]
Student	4 (11%)	4 (14%)	NS	6.9%	9.2%
Retired	8 (22%)	6 (21%)	NS	17.9%	13.7%

[1] NS – not significant

[2] Not employed include those looking after home or family, long-term sick or disabled and 'other' according to Census 2011

6.4.1.2 Clinical characteristics

Table 4 shows the reported history of depression by participants in the study. The sub-sample who took part in the prioritising phase did not significantly differ from the whole study sample in the reported number of depressive episodes, or the number of years that they reported that they had lived with depression.

Table 4: Clinical characteristics of people with depression: history of depressive episodes

	Brainstorming phase (n=36)	Prioritising and clustering phase (n=28)	P-value
	(Mean, SD, min-max)		
Number of depressive episodes	5.4 (5.3; 1-25)[1]	5.8 (5.6; 1-25)[2]	NS[5]
Years with depression	20 (15.3; 1-62)[3]	22 (15.9; 1-62)[4]	NS

[1] Data for 9 people was not included in calculation: 1person reported having had more than 150 episodes, 5 people reported having had one constant episode, and 3 did not know the number of episodes they had experienced

[2] Data for 6 people was not included in the calculation: 1 person reported having had more than 150 episodes, 3 reported having had one constant episode, and 2 people did not know how many episodes they had experienced

[3] Data for 3 people was missing – not provided.

[4] Data for 1 person was missing – not provided.

[5]Not significant

Table 5 shows the different types of treatment participants reported to have been prescribed most recently, and the treatment they said they were taking at the time of study. Almost half of all people with depression were prescribed antidepressant medication alone, and almost 40% said they had been given medication in combination with psychological therapy. Two people had been prescribed psychological therapy alone.

Table 5: Clinical characteristics of people with depression: treatment history

	Were prescribed			Reported that they took		
Treatment	Brainstorming phase	Prioritising and clustering phase	P-value	Brainstorming phase	Prioritising and clustering phase	P-value
	N (%)			N (%)		
Antidepressant medication alone	18 (50%)	12 (43%)	NS[6]	14 (39%)	12 (43%)	NS[6]
Psychological therapy alone	2 (6%)	2 (7%)	-	0	0	-
Combination of medication and psychological treatment	14 (39%)	12 (43%)	NS	4 (11%)	3 (11%)	NS
Combination of medication and self-initiated therapy[1]	N/A	N/A	NS	8 (22%)	6 (21%)	NS
Other	2 (6%)[2]	2 (7%)[3]	NS	10 (28%)[4]	7 (25%)[5]	NS
Total	**36 (100%)**	**28 (100%)**		**36 (100%)**	**28 (100%)**	

[1] Self-initiated treatment included psychological therapy accessed privately, self-help and mindfulness-based therapy or books, and complementary therapies, such as blu-light box, reflexology, emotional regulation therapy.

[2,3] One person did not seek medical help and was therefore not prescribed any treatment, and one person was recommended mindfulness-based therapy

[4] One person was recommended and reported receiving mindfulness-based therapy, two people had only alternative or self-initiated psychological workshop, and 7 people (19%) reported taking no treatment at all

[5] One person was recommended and reported receiving mindfulness-based therapy and 6 people (21%) reported taking no treatment at all.

[6] Not significant

Table 6 shows a summary of participants' reported adherence to the type of treatment they had been prescribed. Over one third of the whole sample of people with depression reported that they undertook the treatment they had been prescribed or recommended. Approximately a third of people with depression said they either took no treatment or only a part of what they had been prescribed (e.g. was prescribed medication and CBT workshop, but only took the medication). Just over a quarter of the participants said they initiated psychological or alternative therapy on their own, in addition to their prescribed treatment (or to replace a part of it). There were no significant differences between the whole sample and the sub-sample who also took part in the second phase of the study.

Table 6: Clinical characteristics of people with depression: treatment history, reported adherence to prescribed treatment options

Type of treatment reported to have taken:	Brainstorming phase N (%)	Prioritising and clustering phase N (%)	P-value
As prescribed	13 (36%)	10 (36%)	NS[3]
Discontinued one or more of the prescribed treatment options	12 (33%)	11 (39%)	NS
Reported taking one or more self-initiated treatment options in addition[1]	6 (17%)	4 (14%)	NS
One or more prescribed treatment options replaced by a different type of treatment[2]	4 (11%)	2 (7%)	NS
Total	**36 (100%)**	**28 (100%)**	

[1] Self-initiated treatment options participants reported to have been taking included privately accessed psychological therapy, as well as self-help books, emotional regulation therapy, mindfulness-based therapy, and alternative treatments, for example, reflexology, blu-light box,

[2] For example, when prescribed medication and CBT course, but reported taking medication and having private counselling, or when prescribed medication but reported having reflexology instead.

[3] Not significant

6.4.2 Family and friends

Demographic characteristics of family and friends are shown in Table 7. The whole sample did not significantly differ across any of the variables from the sub-group who also took part in the prioritising and clustering phase of the study. Two thirds of all family and friends were female, and all said they were of either the White British or White Irish ethnic group. The study sample included a higher proportion of people holding a University degree or higher, when compared to the general population. More than two thirds of the sample reported that they were married or co-habiting, and just over a half reported being employed.

Table 7: Demographic characteristics of family and friends

	Brainstorming phase (n=36) N (%), unless * then Mean (SD; min-max)	Prioritising and clustering phase (n=28)	P-value calculated using Chi-Square unless *, then p-value calculated using t-test	Usual residents of Norfolk, Census 2011, (%)[2]	Usual residents of England, Census 2011 (%)[2]
Female	13 (65%)	10 (71%)	NS[1]	51%	51%
Age in years*	58 (14; 32-80)	60 (13; 41-80)	NS	-	-
White British or White Irish	20 (100%)	14 (100%)	-	92.9%	80.9%
Highest achieved qualification					
Secondary education	8 (40%)	6 (42%)	NS	46.5%	44.5%
University Degree or higher	9 (45%)	7 (50%)	NS	21.9%	27.4%
Marital status					
Single	2 (10%)	2 (14%)	NS	29.5%	34.6
Married/co-habiting	13 (65%)	9 (64%)	NS	50.2%	46.8
Divorced/separated	1 (5%)	0	NS	10.1%	11.7
Widowed	3 (15%)	3 (21%)	NS	7.9%	6.9%
Employment status					
Employed	11 (55%)	8 (57%)	NS	61.5%	62.1%
Retired	8 (40%)	6 (43%)	NS	17.9%	13.7%

[1] Not significant

[2] Based on usual population aged 16 and over

6.4.3 Healthcare workers

Demographic characteristics of the healthcare workers taking part in the two phases of the study are shown in Table 8. The subgroup did not differ from the whole sample of healthcare workers across any of the variables. More than one fifth of the groups were female, all were employed, and the average age was approximately 40 years old. One third of the sample consisted of healthcare professionals such as doctors, nurses and psychologists.

Table 8: Demographic and professional characteristics of healthcare workers

	Brainstorming phase (n=42) N (%), unless * then Mean (SD; min-max)	Prioritising and clustering phase (n=22) N (%), unless * then Mean (SD; min-max)	P value
Female	34 (81%)	18 (82%)	NS[3]
Mean age in years (SD; min-max)	41 (11; 24-61)	43 (12; 24-61)	NS
Employed	42 (100%)	22 (100%)	-
Profession			
Healthcare professionals[1]	14 (33%)	7 (32%)	NS
Unqualified staff[2]	27 (64%)	14 (64%)	NS
Experience in years*	9 (8.5; 1-35)	10 (9; 2-35)	NS

[1]Healthcare professionals included General Practitioners, psychiatric consultants, psychologists, occupational therapists and mental health nurses

[2] Unqualified staff included psychological therapists, wellbeing practitioners, counsellors, CBT practitioners and alternative medicine practitioners.

[3] Not significant

6.5.1 Contrasting the stakeholder groups' demographic characteristics

Demographic characteristics of people with depression, family and friends, and healthcare workers, are shown in Table 3, Table 7 and Table 8, respectively. All three groups included a higher proportion of women than in the general population, and this trend was the strongest in the group of healthcare workers. Among the participants, family and friends had the highest average age of 58. People with depression were on average 11 years younger, and the healthcare workers 17 years younger than family and friends. Data for the remaining demographic characteristics was only collected for people with depression and family and friends. Both groups were characterised by over-representation of the White ethnic group, and University educated people when compared with the general population.

The two groups differed in their reported marital and employment statuses. The proportion of retired participants was twice as high in the group of family and friends as in people with depression, while the numbers of employed people were similar in the two groups. More people with depression than family and friends were therefore unemployed. Also, more people with depression were single or divorced than family and friends. On the other hand, more family and friends reported being married or co-habiting, and more of them said they had lost their partner, compared to the group of people with depression.

6.6 Description of the study phases

6.6.1 Brainstorming sessions

A total of 98 participants were involved in generating statements about the factors influencing treatment decisions made by people with depression. Table 9 shows that the majority of participants in all stakeholder groups took part in group sessions. Altogether we held 80 group sessions and 17 individual meetings (face to face with researcher or phone conversations) across the three groups in order to facilitate brainstorming about the focus question. An average number of attendees was 5 for groups with healthcare workers (ranged from 2-13; SD=4.5) and 4 for both people with depression and family and friends (range from 3-8; SD=1.7 and range from 3-5; SD=1, respectively).

Table 9: Types of brainstorming sessions.

	People with depression (n=36)	Family and friends (n=20)	Healthcare workers (n=42)	Total
Type of session	N of attendees (% of the stakeholder group)			
Group sessions	34 (94%)	15 (75%)	31 (74%)	80 (82%)
Individual conversation with researcher	1 (3%)	3 (15%)	7 (17%)	11 (11%)
Email	0	1 (5%)	0	1 (1%)
Phone conversation	1 (3%)	1 (5%)	4 (10%)	6 (6%)
Total	**36 (100%)**	**20 (100%)**	**42 (100%)**	**98 (100%)**

6.6.2 Statements

During the brainstorming phase participants generated a total of 1,400 statements related to the factors affecting treatment decisions that people with depression make. In the review process I categorised the items into 6 main groups and separated those that seemed too specific, too vague or not clearly understandable. Those items were excluded from the further review process.

Table 10 shows the six main categories with the numbers of statements in the set of original statements and the final set. The table shows that the proportions of three categories were similar in the two sets (i.e. personal factors and depression, culture and other people, and practical issues). Two categories differed by 5 percent (patients' personal characteristics and treatment related issues) and one differed by 7 percent (healthcare professionals).

The largest proportion, one third of all statements, was related to the personal factors of people with depression, and their own experience of depression. This group included ideas such as desperation to try anything that could help relieve depressive symptoms, feelings of responsibility and guilt for the depression, being ready to take treatment, desire to get to the root of the depression, understanding that depression affects other people as well, and various negative effects of depression on one's decision-making about treatment options.

The second largest group of statements was related to treatment, and included a quarter of all statements. They covered topics such as positive and negative past experiences with various treatments, awareness of different treatment options and having been given a choice, concerns about the effects of medications, statements related to specific expectations of treatment (such as, wanting an easy or fast-acting treatment), and weighing up the risks and benefits of the different options. The four remaining categories contained more homogenous statements. Culture and other people included a total of 15% of the concepts generated, which were related to positive and negative beliefs, views and attitudes of one's family and friends and

the wider social circle, social isolation and other people's experiences with depression. Statements associated with a person's healthcare professional made another 15% of all concepts, and included their beliefs, attitudes, knowledge, and patients' perceptions of the professionals, including for example relationship, experience and expectations from them.

Table 10: Main categories of statements generated in the brainstorming phase

Main category of statements	Original statements	Revised statements (final set)
	N (%)	N (%)
Personal factors and depression	441 (32%)	19 (32%)
Treatment related issues	351 (25%)	12 (20%)
Culture and other people	214 (15%)	8 (14%)
Healthcare workers	217 (15%)	13 (22%)
Practical issues, such as financial problems and access to treatment	102 (7%)	3 (5%)
Patients' personal characteristics	24 (2%)	4 (7%)
Vague statements not included in further review	51 (4%)	0
Total	1,400 (100%)	59 (100%)

6.6.3 Prioritising and clustering phase

Table 11 shows that the majority of participants in the prioritising and clustering phase of the study performed the two tasks during group sessions with a researcher and other participants.

Table 11: Types of prioritising and clustering sessions.

Type of session	People with depression (n=28)	Family and friends (n=14)	Healthcare workers (n=22)
	N of attendees (% of the stakeholder group)		
Group session	20 (71%)	9 (64%)	10 (45%)
Individual session	2 (7%)	1 (7%)	1 (5%)
Remotely (answer sheets submitted by post)	6 (21%)	4 (29%)	11 (50%)

Table 12 shows the average numbers of clusters participants generated when performing the clustering task. The stakeholder groups did not differ.

Table 12: Average number of clusters generated by participants in each stakeholder group

Total (n=64)	People with depression (n=28)	Family and friends (n=14)	Healthcare workers (n=22)	P value
		Number of clusters (Mean, SD)		
7.5 (2.6)	7.5 (2.2)	6.4 (2.5)	5.1 (3)	NS[1]

[1] Not significant

6.6.3.1 Missing data

Table 13 shows the number of missing entries which occurred in each stakeholder group for each of the two tasks. Some participants omitted more than one statement.

Table 13: Numbers of missing entries in each stakeholder group

Missing entries of statements	Whole sample (n=64)	People with depression (n=28)	Family and friends (n=14)	Healthcare workers (n=22)
		N (%)		
Prioritising	23 (0.6%)	7 (0.4%)	3 (0.4%)	13 (1%)
Clustering	22 (0.6%)	5 (0.3%)	3 (0.4%)	14 (1.1%)

Chapter 7 Clustering

7.1 Final set of statements

The original statements were reviewed and we generated a final set of 59 items, which were used in the prioritising and clustering tasks (study phase 2). The whole set of items is listed in Table 14.

Table 14: The final set of statements

Number	Statement
1	Financial costs related to the particular treatment option
2	Practical issues related to starting treatment
3	Being given a choice of treatments
4	Recognizing I have a problem I need help with
5	Playing an active role in getting better
6	Desperation to try anything that could help
7	Information about depression and its treatment
8	Having my view about what is the best treatment confirmed
9	Inability to make a choice because of my depression
10	Beliefs of family and friends about depression
11	Weighing up the risks and benefits of treatments
12	Wanting a treatment that works quickly
13	My past experiences of treatment
14	Feeling it's my fault for having depression
15	Worries about the side effects of medication
16	My knowledge and understanding of the effects of treatment
17	Wanting to share my experiences with depression with others
18	Healthcare professionals' beliefs about depression and its treatment
19	Healthcare professionals' knowledge and understanding about depression and its treatment
20	My relationship with the healthcare professional
21	My personal characteristics (age, being male or female, ethnicity - being black, white or other)
22	Culture (my background as well as my current culture)
23	My religion
24	Continuity of care (seeing the same healthcare professional)

Table 14 (continued)

25	Personal characteristics of the healthcare professional (age, being male or female, ethnicity - being black, white or other)
26	My understanding of the side effects of treatment
27	My experiences with healthcare professionals
28	My expectations from healthcare professionals
29	Wanting to escape from the situation
30	My past experience with depression (knowing whether I can feel better or not)
31	How I feel right now
32	Fear of dealing with problems
33	Desire to get to the root (the bottom) of depression
34	Not wanting to have depression listed in health records
35	A desire to get better for people I care about
36	Isolation, and not having the support network close
37	My belief that depression is a chemical imbalance
38	Understanding it is normal to have depression and I am not alone
39	Thinking that nothing can help me
40	Having an introverted or extroverted personality
41	Wanting to please the doctor (to be a good patient)
42	Realizing all people's experiences with depression are different
43	Being ready to accept treatment
44	Being ready to engage with treatment
45	Healthcare professionals being ready to discuss depression and its treatment with family and friends
46	Worries about becoming dependent on medication
47	Realizing there is no quick fix
48	Views about depression in society
49	Not wanting to be a burden on others
50	Wanting the easiest treatment
51	My upbringing
52	The healthcare professionals' personality
53	Healthcare professionals discussing depression and its treatment openly
54	Wanting a 'natural' treatment
55	Other people's experiences with depression and its treatment
56	Being given a clear diagnosis
57	Communication between different healthcare professionals
58	Wanting what doctors say is the most effective treatment
59	Wanting a treatment that is provided with no time limitations

7.2 Principal component analysis

Results of the Principal component analysis (PCA) were the statements' scores on five dimensions and their eigenvalues, all listed in Appendix 38.

7.3 Statements on concept maps and the 5 dimensions

7.3.1 Dimensions 1 and 2

Figure 5 shows a concept map where the x-axis is dimension 1 identified in the PCA, and the y-axis is dimension 2. The map is divided into four parts by the two axes in the approximate centre. Values on dimension 1 range from -0.3 to 0.2, and the range of statements' scores on dimension 2 is from -0.3 to 0.3.

7.3.1.1 Dimension 1

At the left end of dimension 1 several statements are placed close to each other. There are 13 items in this part of the map, and all are related to healthcare professionals as a factor affecting treatment decisions. They include, for example, trust and relationship with the professional, healthcare professionals' beliefs, attitudes and experiences.

Statements on the right hand side of axis 1 are spread across a wider area. Focusing on those located at the most distant areas from the zero point, a common theme is a patient's personal approach to depression and treatment. Immediately below the zero line, there are items related to patients' emotions and feeling that one does not have control over the situation, for example, how I feel right now, wanting to escape from the situation, feeling it's my fault for depression. Above the zero line (which also represents dimension 2), statements relate to a patient's own insight into their situation. Examples are, recognising I have a problem I need help with, wanting to play an active role in treatment, realising there is no quick fix.

Statements at the left and right ends of axis 1 convey different themes, i.e. the impact of health professionals (left) and the effects of a patient's personal view on depression treatment. The dimension could therefore be viewed as a continuum between the effect and reliance on the professionals, and a person's own approach to depression, and the impacts of their cognition and emotion. Consequently, the left end is labelled 'professionals' and right end is 'a patient'.

7.3.1.2 Dimension 2

Dimension 2 is the vertical axis on the map shown in Figure 5. Statements placed at the top end of this axis all refer to making a rational decision by understanding and evaluating the available information about depression and treatment. This includes: weighing up the risks and benefits of treatment, being given a choice, information about depression treatment, one's knowledge and understanding of the effects of treatment. A common theme these items share is an emphasis on an individual's control over treatment choice, and one's personal involvement in decision-making.

The items at the opposite side of dimension 2, at the bottom of the map, are mostly related to the influence of other people and their opinions. This is demonstrated by statements such as upbringing, beliefs of family and friends about depression, one's culture and the views about depression in society. These statements refer to the external factors and emphasise the effects of one's cultural background and social environment on their depression treatment decisions.

Dimension 2 could therefore be considered as a continuum between one's perception of having control over treatment decisions (internal) and viewing other people and their views as highly influential (external).

Figure 5: A concept map with dimensions 1 and 2

Internal – an individual

3-being given a choice 11-risks and benefits
8-my view confirmed   16-understand treatment effect
7-info about depression 26-understand tr effect

46-worry dependent on meds
15-worries about side effects
56-a clear diagnosis   59-no time limits 54-natural treatment
58-what the doc says   44-ready to engage with tr
                              2-practical 12-quick treatment
                              37-depre chemical
                              50-easy treatment 43-ready to accept trea
24-care continuation   47-no quick fix
19-hcw knowledge 53-hcw discuss openly   13-past experience of tr
18-hcw beliefs,   38-I'm not alone 33-get to the root
20-hcw relationship 28-expectation of hc 27-experience of hcw 30-experience with depre 4-problem recognition
52-hcw personality 45-hcw discuss depre with FF
                                             1-financial 42-experiences differ 5-active role
41-please the doctor

External - health professionals   Internal – a patient

25-hcw demographic
                              17-share my experience 31-how I feel now
                              35-get better for ff 6-desperate to try anythin
                              34-health records   29-escape from situation
                              9-unable to decide 39-nothing can help
                              55-others' experience 49-not being a burden 32-fear of problems
                              36-isolation   14-guilt

48-society views
21-my demographic 10-beliefs of FF
22-culture 40-personality
51-upbringing
23-religion

External – society

Dimension 2

Dimension 1

-0.30   -0.20   -0.10   0.10   0.20

0.30   0.20   0.10   -0.10   -0.20   -0.30

7.3.2 Dimensions 3, 4 and 5

Figure 6 shows a concept map with statements placed on dimensions 3 (axis x) and 4 (axis y). Statement coordinates on dimension 3 range between -0.3 and 0.3, and they are between -0.4 and 0.2 on dimension 4. Unlike in the first concept map, statements on this graph are relatively evenly spread across the whole graph. Figure 7 shows a concept map with dimension 4 as axis x and dimension 5 as axis y. Dimension 5 is shown in a range between -0.4 and 0.2, but only two statements have a dimension value lower than -0.2.

7.3.2.1 Dimension 3

Statements which are located at greater distances from the zero point of axis x define dimension 3. Those placed around the left end of the map emphasise the effects of a patient's cultural and social background on their depression treatment decisions, for example, culture, upbringing, religion, a person's age, gender and ethnicity (i.e. demographic characteristics). These items relate to the external social and cultural influences relating to where a person might search for an explanation of their depression.

Statements located at the right end of the dimension 3 are linked to a patient's emotions, mostly negative depressive thoughts about own ability to deal with depression. These include how I feel right now, fear of problems, desperation to try anything that could help, wanting to escape from the situation, feeling that nothing can help and inability to make a decision due to depression.

The common theme of statements on the left is the influence of the cultural, i.e. external influences, while the items on the right emphasise a person's emotional, i.e. internal approach to the problem. The dimension 3 is therefore an individual's perceived source of support – own cultural identity versus focus on own emotional response to depression and a need for treatment.

7.3.2.2 Dimension 4

Items in the upper end of the map characterise the top part of dimension 4. These items are related to a person's perception of barriers and limitations when deciding about treatment, for example, wanting a quick treatment, wanting an easy treatment, not wanting to have depression listed in health records, wanting treatment with no time limitations.

Items located in the bottom part of the map all relate to appreciating and benefiting from own and others' experiences with depression and its treatment. These statements include: realising all people's experiences with depression are different, understanding it is normal to have depression and I am not alone, wanting to share my experience with others, past experience with treatment.

Considering the two areas of the map, dimension 4 could be interpreted as a continuum between making a treatment choice based on a sense of caution and fear of the unknown, and ability to benefit from experiences with depression and treatment.

Figure 6: A concept map with dimensions 3 and 4

Sense of caution

External - cultural identity

Internal – emotional response

Experiences

12-quick treatment
2-practical   34-health records 50-easy treatment
1-financial
15-worries about side effects
39-nothing can help
29-excape from situation
54-natural treatment
59-no time limits   36-isolation 9-unable to decide 6-desperate to try anything
46-worry dependent on meds   32-fear of problems
14-guilt
58-what the doc says
26-understand tr effect   41-please the doctor
3-being given a choice
49-not being a burden   31-how I feel now
57-hcw communication
23-religion   11-risks and benefits   25-hcw demographic   18-hcw beliefs   28-expectation of hc 45-hcw discuss depre with FF
22-culture   40-personality   8-my view confirmed   52-hcw personality   24-care continuation
51-upbringing   7-info about depression   16-understand treatment effect   19-hcw knowledge
21-my demographic   10-beliefs of FF   56-a clear diagnosis   27-experience of hcw
48-society views 37-depre chemical   20-hcw relationship
35-get better for ff
44-ready to engage with tr
43-ready to accept treatment   5-active role
33-get to the root
47-no quick fix   4-problem recognition
55-others' experience
13-past experience of tr   38-I'm not alone
17-share my experience
30-experience with depre
42-experiences differ

0.20

-0.20

-0.40

-0.30   -0.20   -0.10   0.10   0.20   0.30

Dimension 4

Dimension 3

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7.3.2.3 Dimension 5

The concept map in Figure 7 shows that the majority of statements are located in the central part of the graph. The statements placed at the top and bottom ends of the horizontal axis exhibit the most extreme values on dimension 5, and therefore define it. The items located in the top part of the map relate to a person's internal awareness and insight into their depression and a need for treatment, for example readiness to engage with treatment, readiness to accept treatment, personality, wanting to play an active role in treatment, religion.

Statements in the bottom part of the graph refer to a patient's communication with people in similar situations, and sharing experiences with depression, such as wanting to share my experiences of depression with others, and other people's experiences with depression. Contrasting the statements' themes in the top and bottom parts of the graph, the dimension 5 could be described as a continuum between an individual focusing on their own awareness of depression, and an individual's focus on what they can learn from sharing experiences with others. The dimension is therefore labelled as 'internal – personal awareness' (top part) and 'external – sharing experiences (bottom part).

Figure 7: A concept map with dimensions 4 and 5

Internal – personal awareness

44-ready to engage with tr

43-ready to accept treatment   40-personality
21-my demographic
5-active role
23-religion
4-problem recognition
33-get to the root
47-no quick fix   51-upbringing
22-culture

25-hcw demographic

54-natural treatment
31-how I feel now   59-no time limits
52-hcw personality   50-easy treatment
8-my view confirmed 3-being given a choice   1-financial
20-hcw relationship 19-hcw knowledge   2-practical 12-quick treatment

Experiences   38-I'm not alone   56-a clear diagnosis   58-what the doc says   29-escape from situation   Sense of caution
18-hcw beliefs 11-risks and benefits   6-desperate to try anything
35-get better for ff   27-experience of hcw 41-please the doctor 9-unable to decide
7-info about depression 16-understand treatment effect 32-fear of problems
37-depre chemical   39-nothing can help
26-understand tr effect   34-health records
30-experience with depre
10-beliefs of FF   14-guilt
49-not being a burden
42-experiences differ 13-past experience of tr   46-worry dependent on meds
48-society views   36-isolation 15-worries about side effects

-0.20

17-share my experience

55-others' experience

Dimension 5

-0.40

-0.40   -0.20   0.20

External – sharing
experiences

Dimension 4

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7.3.3 The 5 dimensions from another perspective

The five dimensions have been described and labelled, and several of them share a contrast between the internal and external factors affecting patients' treatment decisions. In the first dimension, it is a patient's emotionally based approach to treatment decisions versus a focus on the health professional as a source of advice. In the second dimension, the internal aspect of treatment decision-making is characterised by a person's focus on information and making an informed choice, as opposed to an external approach, i.e. an emphasis on the cultural influences and other people's views.

The third, fourth and fifth dimensions also represent the internal versus external approaches. They also demonstrate that concepts which are close and similar to each other on the first two dimensions are relatively distinct and at considerably greater distances when inspected from a different point of view, i.e. adding another dimension to the picture.

Similarly to the dimension 2, the third dimension represents the external aspect as a person's social and cultural context, i.e. a person's background which is out of one's control. The internal aspect is an individual's emotional response and attempt to avoid a problem, i.e. a person's individual emotional response. The fourth dimension, unlike the others, does not involve the internal and external aspects of decision-making. Instead, it shows a distinction between a person's concerns about treatment and their comprehension of depression, which is based on experience and awareness of the problem. The fifth dimension adds another perspective on a concept which defines one end of the dimension 4, i.e. experience and awareness of depression as a problem. Dimension 5 is then a continuum between an external aspect of depression awareness, i.e. sharing experiences with others in similar situations, and an internal recognition of a need for help with depression.

7.4 Cluster analysis

The scores for all five dimensions were used as input in the k-means cluster analysis. I ran the cluster analysis 15 times, in order to obtain information for solutions with 2 to 16 clusters. Results of each time the analysis was run consisted of the information about cluster membership for each statement, and the statements' distances from their cluster centres. From the distances, I calculated the Sums of squared distances (entropy values) for each cluster solution. Table 15 shows the entropy values and Figure 8 shows an elbow plot depicting the entropies.

Table 15: Sums of square distances for 15 cluster solutions

N of clusters	Sum of square distances	Difference between the Sum of squared distances
2	4.10	
3	3.33	0.77
4	2.59	0.74
5	1.78	0.81
6	0.94	0.84
7	0.80	0.14
8	0.61	0.19
9	0.55	0.06
10	0.49	0.06
11	0.43	0.05
12	0.38	0.06
13	0.36	0.01
14	0.31	0.05
15	0.25	0.06
16	0.25	-0.01

Figure 8: An elbow graph of sums of squared distances plotted for each cluster solution
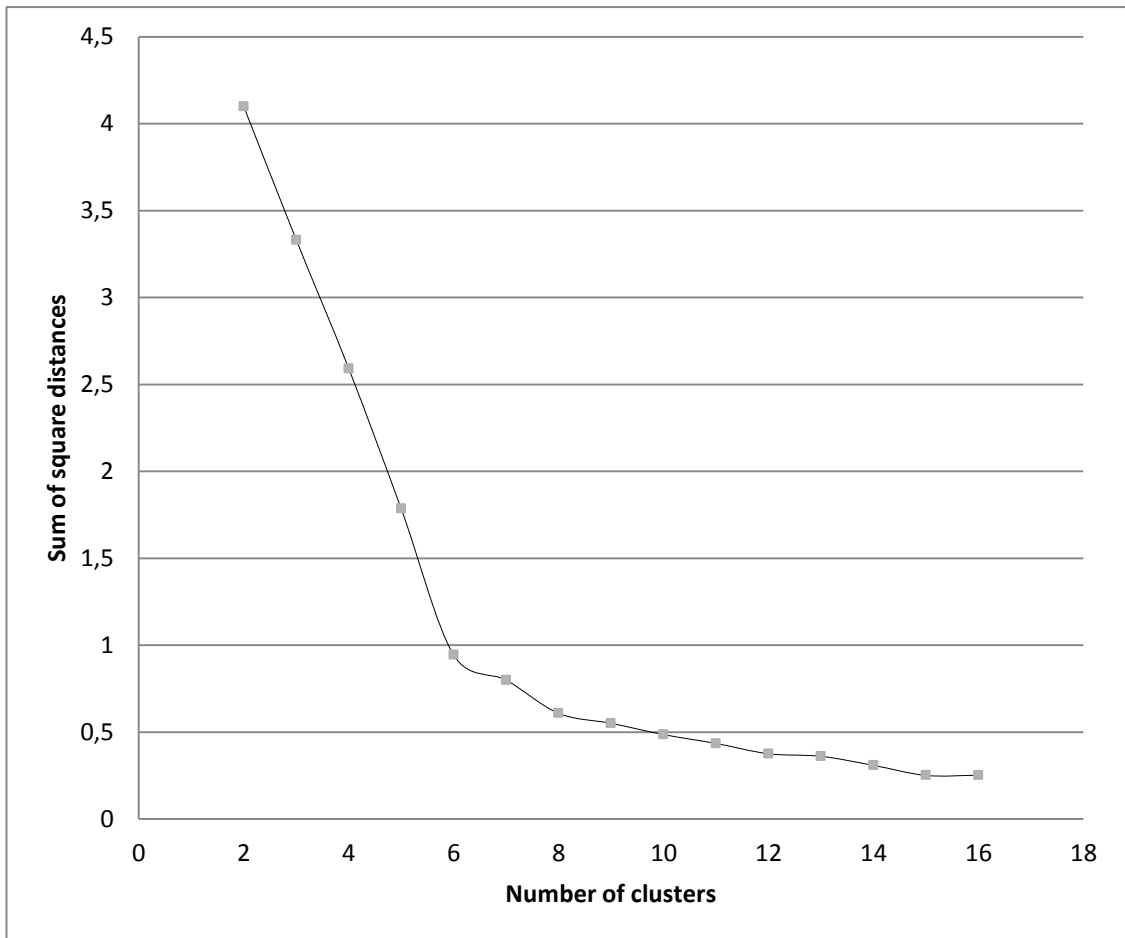
7.4.1 The number of clusters

Based on the entropy values for each cluster arrangement, I identified an 'end of a jump' on the graph's line of best fit at the number of clusters 6, which should be the best number of clusters for this dataset. The next acceptable solutions are at 8 and at 12 clusters. With the research team we evaluated each arrangement's clusters and their abilities to represent the themes conveyed by their statements. We selected the 12 cluster solution as the most appropriate, and this decision is justified in the section describing the final cluster arrangement. The three sets of clusters are described and contrasted in the following sections.

7.4.2 Six cluster solution

Table 16 shows a solution with 6 clusters in the set of 59 final statements. The clusters are graphically depicted on a concept map with the first two dimensions in Figure 9.

Table 16: Statements in 6 clusters

Cluster number	Statement number	Statement
1	1	Financial costs related to the particular treatment option
1	2	Practical issues related to starting treatment
1	3	Being given a choice of treatments
1	7	Information about depression and its treatment
1	8	Having my view about what is the best treatment confirmed
1	11	Weighing up the risks and benefits of treatments
1	12	Wanting a treatment that works quickly
1	15	Worries about the side effects of medication
1	16	My knowledge and understanding of the effects of treatment
1	26	My understanding of the side effects of treatment
1	37	My belief that depression is a chemical imbalance
1	46	Worries about becoming dependent on medication
1	50	Wanting the easiest treatment
1	54	Wanting a 'natural' treatment
1	59	Wanting a treatment that is provided with no time limitations
2	10	Beliefs of family and friends about depression
2	13	My past experiences of treatment
2	17	Wanting to share my experiences with depression with others
2	30	My past experience with depression (knowing whether I can feel better or not)
2	42	Realizing all people's experiences with depression are different
2	48	Views about depression in society
2	55	Other people's experiences with depression and its treatment
3	18	Healthcare professionals' beliefs about depression and its treatment
3	19	Healthcare professionals' knowledge and understanding about depression and its treatment
3	20	My relationship with the healthcare professional
3	24	Continuity of care (seeing the same healthcare professional)
3	25	Personal characteristics of the healthcare professional (age, being male or female, ethnicity - being black, white or other)
3	27	My experiences with healthcare professionals
3	28	My expectations from healthcare professionals
3	41	Wanting to please the doctor (to be a good patient)
3	45	Healthcare professionals being ready to discuss depression and its treatment with family and friends
3	52	The healthcare professionals' personality

Table 16 (continued)

3	53	Healthcare professionals discussing depression and its treatment openly
3	56	Being given a clear diagnosis
3	57	Communication between different healthcare professionals
3	58	Wanting what doctors say is the most effective treatment
4	4	Recognizing I have a problem I need help with
4	5	Playing an active role in getting better
4	33	Desire to get to the root (the bottom) of depression
4	38	Understanding it is normal to have depression and I am not alone
4	43	Being ready to accept treatment
4	44	Being ready to engage with treatment
4	47	Realizing there is no quick fix
5	21	My personal characteristics (age, being male or female, ethnicity - being black, white or other)
5	22	Culture (my background as well as my current culture)
5	23	My religion
5	40	Having an introverted or extroverted personality
5	51	My upbringing
6	6	Desperation to try anything that could help
6	9	Inability to make a choice because of my depression
6	14	Feeling it's my fault for having depression
6	29	Wanting to escape from the situation
6	31	How I feel right now
6	32	Fear of dealing with problems
6	34	Not wanting to have depression listed in health records
6	35	A desire to get better for people I care about
6	36	Isolation, and not having the support network close
6	39	Thinking that nothing can help me
6	49	Not wanting to be a burden on others

Figure 9: A concept map with 6 clusters

Internal – an individual

Cluster 1

3-being given a choice   11-risks and benefits
8-my view confirmed   16-understand treatment effect
7-info about depression 26-understand tr effect

46-worry dependent on meds
15-worries about side effects
59-no time limits   54-natural treatment

Cluster 3

56-a clear diagnosis
58-what the doc says

2-practical
12-quick treatment
37-depre chemical
50-easy treatment 43-ready to accept trea

44-ready to engage with tr

47-no quick fix
13-past experience of tr
38-I'm not alone 33-get to the root

Cluster 4

24-care continuation
19-hcw knowledge 53-hcw discuss openly
18-hcw beliefs   27-experience of hcw
20-hcw relationship 28-expectation of hc
52-hcw personality 45-hcw discuss depre with FF
41-please the doctor

30-experience with depre   4-problem recognition
1-financial 42-experiences differ   5-active role

External - health professionals

Internal – a patient

25-hcw demographic

17-share my experience
31-how I feel now

35-get better for fr 6-desperate to try anythin
29-escape from situation
34-health records
9-unable to decide.   39-nothing can help

55-others' experience 49-not being a burden 32-fear of problems

Cluster 2

36-isolation   14-guilt

Cluster 6

48-society views
21-my demographic 10-beliefs of FF
22-culture   40-personality
51-upbringing
23-religion

Cluster 5

Dimension 2

-0.30

-0.20

-0.10

0.10

0.20

-0.30   -0.20   -0.10   0.10   0.20

0.30

0.20

0.10

-0.10

-0.20

-0.30

External – society

Dimension 1

7.4.2.1 Description of the 6 cluster solution

Cluster 1 contains 15 statements and is the largest in this set. It is located in the upper part of a concept map showing dimensions 1 and 2, relevant to the internal aspect of dimension 2. Statements in this group are broadly related to a person's thoughts about treatment and their expectations of it. Further inspection of this cluster's items reveals that most are related to two main themes. One theme, making an informed and considered decision about depression treatment, describes a part of dimension 2. The other theme, wanting to avoid the problem and have an easy solution, is relevant for dimension 4. Both themes describe internal factors, but they differ in the perspectives they emphasise, information driven approach, versus an attitude based on avoiding the situation and wanting a quick fix.

Cluster 2 contains seven statements and is located in the central area of a graph with dimensions 1 and 2. Because it stretches across the central and bottom part of dimension 2, it contains statements related to personal and internal aspects of depression treatment decision-making (relating to the individual's own experiences), as well as more external issues, including other people's experiences, others' beliefs about depression and views about depression in society.

Cluster 3 groups 14 statements located at the left hand side of the concept map. The majority of these items are located at small distances to each other and the whole cluster is visibly separate from all other statements on a graph with dimensions 1 and 2. The statements characterise the external aspect of the dimension 1, and they refer to a range of issues associated with doctors and health professionals, such as professionals' personal characteristics, their knowledge and beliefs, relationship and ability to discuss depression with the patient and their family in an open manner.

Cluster 4 contains seven statements located at the right hand side part of the concept map, which is characterised by the internal aspect of patient treatment decision-making. It is located adjacent to some of the items in cluster 1, which are

related to concerns and worries about treatment. The cluster 4 also emphasises a patient's focus on their internal factors. Specifically, it groups the items linked to a person recognising they have a problem, and feeling ready to seek help for their problem. These statements refer to an insightful approach to own depression, and were highlighted on dimension 5.

Cluster 5 groups 5 statements positioned at small distances to each other at the bottom end of dimension 2, which represents external aspects of the dimension 2 (and the dimension 3), including cultural background. The statements are related to a person's social and cultural context, such as the social environment in which they were brought up and which influenced their current attitudes.

Cluster 6 is positioned in the central part of the dimensions 1 and 2, extending to the right end of dimension 1, the internal aspect which was labelled 'a patient'. It contains 11 statements associated with a patient's emotions and emotional response to depression. These statements refer to a patient's own and highly individual understanding of their situation and their acceptance of having depression and a need for treatment. The items are mostly related to emotions specific for depressive symptoms: how I feel right now, fear of dealing with the situation, feelings of guilt for depression, low self-confidence, feeling unable to make a decision due to depression.

Some clusters in this solution contain statements, which are related to rather different themes. For example, some items in cluster 1 are associated with making an informed decision, but others are related to perceived barriers and wanting an easy treatment, rather than the most appropriate and effective option. Cluster 2 contains statements related to stigma, as well as personal encounters with depression, and experiences of other people. I believe this cluster solution does not allow the best possible representation of the concepts that participants had raised. I therefore searched for an arrangement that would provide a more detailed distinction between the themes.

7.4.3 Eight cluster solution

Table 17 shows a solution with statements being grouped into 8 clusters. Figure 10 shows a spatial configuration of the 8 clusters on a concept map. The graph shows the statements as points labelled as individual numbers.

Table 17: Statements in 8 clusters

Cluster number	Statement number	Statement
1	1	Financial costs related to the particular treatment option
1	2	Practical issues related to starting treatment
1	12	Wanting a treatment that works quickly
1	34	Not wanting to have depression listed in health records
1	50	Wanting the easiest treatment
1	54	Wanting a 'natural' treatment
1	59	Wanting a treatment that is provided with no time limitations
2	3	Being given a choice of treatments
2	7	Information about depression and its treatment
2	8	Having my view about what is the best treatment confirmed
2	11	Weighing up the risks and benefits of treatments
2	15	Worries about the side effects of medication
2	16	My knowledge and understanding of the effects of treatment
2	26	My understanding of the side effects of treatment
2	37	My belief that depression is a chemical imbalance
2	46	Worries about becoming dependent on medication
3	21	My personal characteristics (age, being male or female, ethnicity - being black, white or other)
3	22	Culture (my background as well as my current culture)
3	23	My religion
3	40	Having an introverted or extroverted personality
3	51	My upbringing
4	4	Recognizing I have a problem I need help with
4	5	Playing an active role in getting better
4	33	Desire to get to the root (the bottom) of depression
4	43	Being ready to accept treatment
4	44	Being ready to engage with treatment
4	47	Realizing there is no quick fix
5	10	Beliefs of family and friends about depression
5	48	Views about depression in society

Table 17 (continued)

5	55	Other people's experiences with depression and its treatment
6	6	Desperation to try anything that could help
6	9	Inability to make a choice because of my depression
6	14	Feeling it's my fault for having depression
6	29	Wanting to escape from the situation
6	31	How I feel right now
6	32	Fear of dealing with problems
6	35	A desire to get better for people I care about
6	36	Isolation, and not having the support network close
6	39	Thinking that nothing can help me
6	49	Not wanting to be a burden on others
7	13	My past experiences of treatment
7	17	Wanting to share my experiences with depression with others
7	30	My past experience with depression (knowing whether I can feel better or not)
7	38	Understanding it is normal to have depression and I am not alone
7	42	Realizing all people's experiences with depression are different
8	18	Healthcare professionals' beliefs about depression and its treatment
8	19	Healthcare professionals' knowledge and understanding about depression and its treatment
8	20	My relationship with the healthcare professional
8	24	Continuity of care (seeing the same healthcare professional)
8	25	Personal characteristics of the healthcare professional (age, being male or female, ethnicity - being black, white or other)
8	27	My experiences with healthcare professionals
8	28	My expectations from healthcare professionals
8	41	Wanting to please the doctor (to be a good patient)
8	45	Healthcare professionals being ready to discuss depression and its treatment with family and friends
8	52	The healthcare professionals' personality
8	53	Healthcare professionals discussing depression and its treatment openly
8	56	Being given a clear diagnosis
8	57	Communication between different healthcare professionals
8	58	Wanting what doctors say is the most effective treatment

Figure 10: A concept map with 8 clusters

Internal – an individual

Cluster 2

3-being given a choice 11-risks and benefits
8-my view confirmed   16-understand treatment effect
7-info about depression 26-understand tr effect

Cluster 8

46-worry dependent on meds
15-worries about side effects

Cluster 4

59-no time limits   54-natural treatment
56-a clear diagnosis
58-what the doc says
2-practical
44-ready to engage with tr
37-depre chemical   12-quick treatment
50-easy treatment 43-ready to accept tre

24-care continuation
47-no quick fix
19-hcw knowledge 53-hcw discuss openly
Cluster 1
13-past experience of tr
18-hcw beliefs.   27-experience of hcw
38-I'm not alone 33-get to the root
28-expectation of hc
30-experience with depre
20-hcw relationship
4-problem recognition
52-hcw personality 45-hcw discuss depre with FF
External - health
1-financial 42-experiences differ 5-active role
professionals
41-please the doctor
Cluster 7
Internal – a patient
25-hcw demographic
31-how I feel now
17-share
6-desperate to try anythi
35-get better for fr
29-escape from situation
34-health records
9-unable to decide. 39-nothing can hel
Cluster 5
55-others' experience 49-not being a burden 32-fear of problems
36-isolation   14-guilt
Cluster 6
48-society views
21-my demographic 0-beliefs of FF
22-culture 40-personality
51-upbringing   Cluster 3
23-religion

External – society

Dimension 2

Dimension 1

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7.4.3.1 Description of the 8 cluster solution

Some of the 8 clusters in this arrangement are identical with those identified in the 6-cluster arrangement. For example, cluster 8 is related to health professionals and their influence on a patient's depression treatment decisions, and contains the same statements as cluster 3 in the previous solution. The new cluster 3, which refers to a person's cultural and social context, is also identical with the relevant group, the former cluster 5 in the previous solution.

Other clusters in the new arrangement are similar to their preceding versions, and most of the differences between the versions of clusters were caused by minor changes to the allocation of some statements to groups. Two larger clusters in the previous arrangement have been divided into two separate groups, and in several instances one or two statements have been removed from their original cluster, in order to form a new group.

For example, statements in the former cluster 1 are grouped into two separate clusters (1 and 2) in the current cluster solution. The new group 1 contains 7 statements, one of which (no.34) has been removed from its original clusters and placed in this group. The new cluster 2 contains 9 statements related to making an informed choice based on understanding of treatment options. All of these were part of the original cluster.

The former cluster 2 has also been divided into smaller groups, the new clusters 5 and 7. Cluster 5 contains three statements related to the external factors that emphasise the influence of other people's views, and is located at the bottom part of the dimension 2, i.e. its external aspect described as society.

Cluster 7 contains 5 statements located in the central part of the dimensions 1 and 2. Statements in this cluster are related to a person's appreciation of their own experiences with depression. Four out of the 5 statements in this cluster were

already grouped together in the previous cluster solution, except for item 38 which was originally placed in another group. Thematically, statement 38 relates to the items in this cluster as it refers to an understanding that depression also affects other people.

The new cluster 4 refers to a patient's insight into their situation, and realising they need treatment to deal with depression. It contains the same statements as its first version in the previous solution, except for statement 38 (i.e. understanding it is normal to have depression and I am not alone), which has been moved to the new cluster 7.

Cluster 6 refers to a patient's emotions and depressive thoughts as factors influencing their treatment choices and decision-making, and is located at the right hand side of dimension 1. It contains all but one statement which formed this cluster in the previous solution. The removed statement is number 34, not wanting to have depression listed in health records, which is now part of cluster 1.

The eight cluster solution provides a better categorisation of the statements into groups, compared to the six cluster solution. This is shown by separating the clusters 1 and 2. Some of the groups still appear to contain items that are related to different themes. For example, the statements in clusters 5 and 7 have been re-grouped but the themes they contain could be further divided for an improved reflection of the concepts. This arrangement of statements in clusters has therefore been rejected.

7.4.4 Twelve cluster solution

Table 18 shows how the statements were grouped into 12 clusters. Figure 11 shows a concept map with the 12 clusters portrayed in the space of the first two dimensions. The final 12 clusters are placed at approximate locations of the map, emphasising the concepts represented and the relationships between them.

Table 18: Statements in 12 clusters

Cluster number	Statement number	Statement
1	4	Recognizing I have a problem I need help with
1	5	Playing an active role in getting better
1	33	Desire to get to the root (the bottom) of depression
1	43	Being ready to accept treatment
1	44	Being ready to engage with treatment
1	47	Realizing there is no quick fix
2	31	How I feel right now
2	35	A desire to get better for people I care about
3	13	My past experiences of treatment
3	30	My past experience with depression (knowing whether I can feel better or not)
3	38	Understanding it is normal to have depression and I am not alone
3	42	Realizing all people's experiences with depression are different
4	3	Being given a choice of treatments
4	7	Information about depression and its treatment
4	8	Having my view about what is the best treatment confirmed
4	11	Weighing up the risks and benefits of treatments
4	15	Worries about the side effects of medication
4	16	My knowledge and understanding of the effects of treatment
4	26	My understanding of the side effects of treatment
4	37	My belief that depression is a chemical imbalance
4	46	Worries about becoming dependent on medication
5	6	Desperation to try anything that could help
5	9	Inability to make a choice because of my depression
5	14	Feeling it's my fault for having depression
5	29	Wanting to escape from the situation
5	32	Fear of dealing with problems
5	36	Isolation, and not having the support network close
5	39	Thinking that nothing can help me
5	49	Not wanting to be a burden on others
6	56	Being given a clear diagnosis
6	58	Wanting what doctors say is the most effective treatment
7	18	Healthcare professionals' beliefs about depression and its treatment
7	19	Healthcare professionals' knowledge and understanding about depression and its treatment
7	20	My relationship with the healthcare professional
7	24	Continuity of care (seeing the same healthcare professional)

Table 18 (continued)

7	25	Personal characteristics of the healthcare professional (age, being male or female, ethnicity - being black, white or other)
7	27	My experiences with healthcare professionals
7	28	My expectations from healthcare professionals
7	41	Wanting to please the doctor (to be a good patient)
7	45	Healthcare professionals being ready to discuss depression and its treatment with family and friends
7	52	The healthcare professionals' personality
7	53	Healthcare professionals discussing depression and its treatment openly
7	57	Communication between different healthcare professionals
8	1	Financial costs related to the particular treatment option
8	2	Practical issues related to starting treatment
8	12	Wanting a treatment that works quickly
8	50	Wanting the easiest treatment
8	54	Wanting a 'natural' treatment
8	59	Wanting a treatment that is provided with no time limitations
9	17	Wanting to share my experiences with depression with others
9	55	Other people's experiences with depression and its treatment
10	10	Beliefs of family and friends about depression
10	48	Views about depression in society
11	21	My personal characteristics (age, being male or female, ethnicity - being black, white or other)
11	22	Culture (my background as well as my current culture)
11	23	My religion
11	40	Having an introverted or extroverted personality
11	51	My upbringing
12	34	Not wanting to have depression listed in health records

Figure 11: A concept map with 12 clusters

Figure 12: Final concept map

Internal – an individual

(4) Making an informed choice

(7) Doctors' advice

(8) Seeking an effortless treatment

(1) Personal insight

(3) Experiences with depression

(6) Health professionals

External – health professionals

Internal – a patient

(9) Sharing experiences with others

(2) Emotional states

(12) Depression in health records

(5) Depressive symptoms

(10) External views about depression

(11) My social context

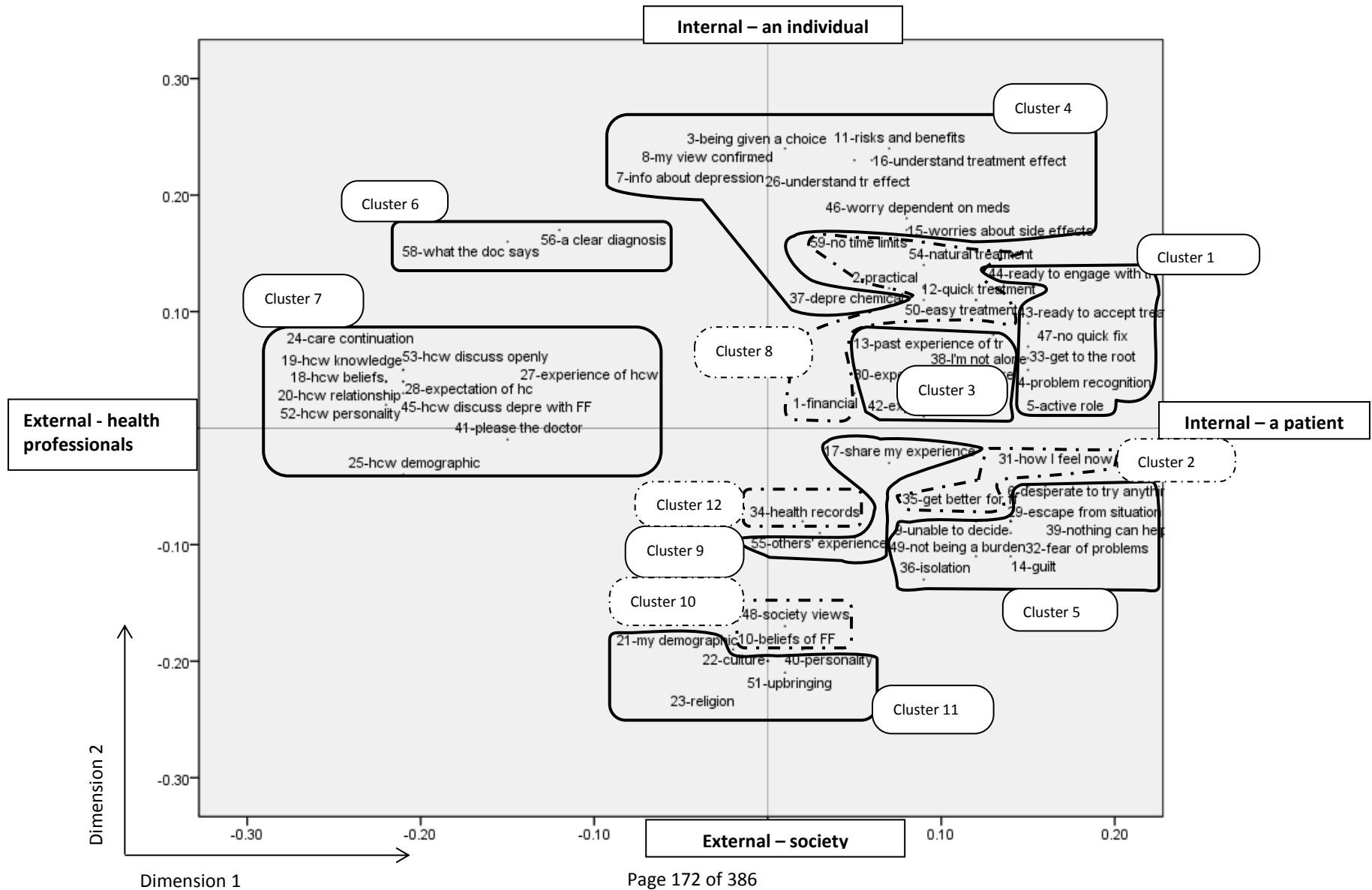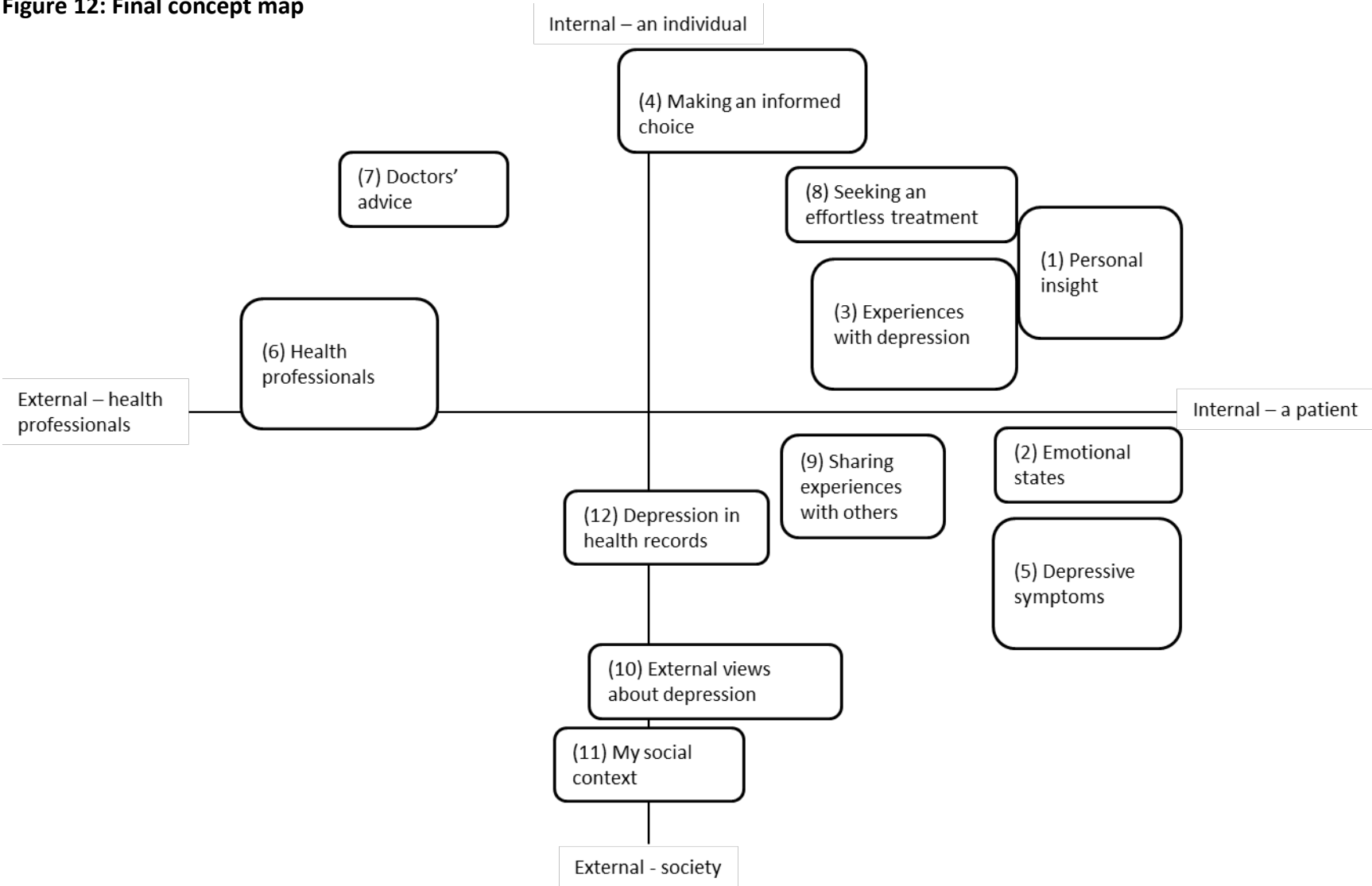External - society

7.4.4.1 Description of the 12 cluster solution

In this arrangement the statements are divided into 12 groups. Most statements have been grouped together with the same statements as in the previous solution with 8 clusters. Several minor modifications in the ways the statements are grouped in this arrangement have allowed conceptualising the issues independently from the larger groups of other items. As a result, this cluster solution has been selected as final.

Of the 12 clusters, 3 are identical with their previous versions (new clusters 1, 4 and 11). Three pairs of clusters were created by dividing three of the clusters' former versions into two: group 8 from the previous solution has been divided into new clusters 6 and 7; the previous cluster 1 is now separated into clusters 8 and 12; and clusters 2 and 5 have been created by dividing group number 6 from the previous solution. Statements in the three remaining clusters of this solution (clusters 3, 9 and 10) were previously grouped as two clusters. In their current formation two statements, located at the neighbouring ends of their original groups (nos. 17 and 55), have been put together into a new cluster.

The 12 clusters are factors that affect people's treatment decision-making, and statements are their components. The statements provide particular details of the factors, and define their nature. In the following sections I describe the clusters based on the statements' themes, positions on the map and relationships with their neighbours.

7.4.4.2 Cluster 4: Making an informed choice

This cluster is located at the top of the concept map, and characterises the internal aspect of dimension 2. It contains nine statements, which are related to a person's evaluation of the depression treatment options from different perspectives, i.e. an attempt to make a considered and informed decision. Six statements located in the top area of the cluster (numbers 3, 7, 8, 11, 16 and 26) refer to being given a choice of treatments and information and understanding about different options and their

effects, as well as side effects. The six items emphasise an information-focused approach to decision-making, which is based on understanding the effects and side effects of options, and weighing up the positive and negative aspects of different options.

One statement, number 37, is thematically different from the other items, referring to a person's belief about the origin of depression (i.e. chemical imbalance in brain), rather than their approach to information about treatment. This is the only statement in the set, that refers to a person's conceptualisation of the cause of depression, and based on the participants' views about the statements' relationships it is related to other items in this cluster.

Two statements at the bottom right hand side of the cluster, numbers 15 and 46, relate to a patients' worries and concerns about treatment. One is related to treatment in general, i.e. worries about the side effects of treatment, while the other is specific to medication, such as worries about becoming dependent on medication. Considering these items in relation to the other statements in the cluster, its information-focused atmosphere could be viewed from the perspective of a person who wants to be given a choice of treatment options due to being worried about the possible side effects. They want to evaluate the different options and the relevant information, in order to find the best treatment for their own needs. Based on this relationship I labelled this cluster as 'Making an informed choice'.

7.4.4.3 Cluster 8: Seeking effortless treatment

Cluster 8 contains 6 statements related to a person's thoughts about treatment. Its main subject and location on the concept map indicate a thematic relationship with its close neighbour, cluster 4.

Items 12, 50, 54 and 59 reflect patients' specific desires from their treatment, for example wanting a treatment that works quickly, wanting the easiest treatment,

natural treatment, or wanting a treatment that is provided with no time limitations. Statements 1 and 2, concerning financial and practical issues, relate to a person's wish to avoid or overcome practical difficulties and barriers, such as physical and geographical access to a therapist or a place where the treatment is provided. A theme that links the statements in this cluster is a wish to avoid problems with treatment provision, and wanting to avoid any effort necessary to face their negative thinking patterns and depressive cognitions. As a result, rather than emphasising the information-seeking approach which is characteristic for cluster 4, cluster 8 focuses on wanting a treatment with little or no barriers, and minimal effort needed. Based on this observation, I labelled it 'seeking effortless treatment'.

7.4.4.4 Cluster 1: Personal insight

This cluster is bordering with clusters 8 and 3, and is located at the right hand side of the concept map with dimensions 1 and 2. It groups 6 statements about a person's insight into their depression and gaining a personal awareness of having a problem that needs to be dealt with. For example, statement 4 refers to a person realising their depressive feelings are symptoms of an illness and that they might need help to deal with it. Statements 5 and 33 share a theme of an individual being pro-active in improving their symptoms. In particular, these statements reflect a person's desire to take control over the situation, and to find out the cause of their current state in order to enable them to deal with it effectively. Statement 47 contributes with an idea that depression cannot be treated quickly and without a patient's active involvement in the process. The remaining items 43 and 44 refer to a person's readiness to accept treatment and engage with it.

The theme in this cluster relates to a person internally acknowledging having a problem (depression), which warrants treatment, and the individual statements each add a specific feature to this concept. For instance, a patient's feeling of readiness for a change, recognition of a need for help, feeling determined to face the problem, rather than avoid it. Based on these themes the cluster is labelled as patient's 'personal insight'.

The six items in this cluster had also been put into a single group in previous cluster solutions, and the only modification occurred between 6 and 8 cluster arrangements, when statement 38 was moved away from this cluster. This suggests that the six statements form a stable group. The six statements, together with statements about personality, demographic characteristics and religion, also characterised the internal aspect of dimension 4, one's personal attentiveness to, and recognition of their depression.

7.4.4.5 Cluster 3: Experiences with depression

Cluster 3 contains four statements and is located in the top right quadrant of the concept map, between its adjacent clusters 8 and 1. Two of the items in this group, numbers 13 and 30, are related to a person's own past experiences with a depressive illness. Two other statements reflect a person's recognition of depression as a common illness which affects people differently (numbers 38 and 42). Together they emphasise a person learning from their own experience, that depression is an illness affecting various people in various ways, rather than a personal weakness. Although not specifically mentioning people's own experience(s) with depression, these items refer to personal familiarity with depression, and conceptualisation of the condition from a viewpoint of a person with knowledge or experience with it. I labelled the cluster 'experiences with depression' to reflect its character oriented to practice and learning from personal encounters of the illness.

7.4.4.6 Cluster2: Emotional state

Cluster 2 is located next to cluster 5, and both are at the right hand side of the concept map, together characterising the internal aspect of dimension 1. This cluster contains two statements related to patients' personal issues as factors influencing depression treatment choices, for example number 31: how I feel right now, and 35: a desire to get better for people I care about. These two items relate to a patient's emotions, an issue which is reflected in general terms by one of the

statements. The other statement relates to a person's sense of responsibility towards important people in their life, and a wish to get treatment for depression. These are highly subjective issues, and may be largely dependent on a person's mood in a given situation. The two statements emphasise one's mood and emotions in general terms, rather than focusing on specific, either negative or positive valence of the feeling. To articulate the theme of this cluster I labelled it 'emotional states'.

7.4.4.7 Cluster 5: Depressive symptoms

Cluster 5 contains eight statements located next to cluster 2 but distinct from other groups. Statements in cluster 5 relate to several aspects of treatment decision-making. For example, items 36 (isolation, and not having the support network nearby) and 49 (not wanting to be a burden on others) focus on a patient's consideration of other people in relation to own depression. Items 9, 14, 32 and 39 convey a negative attitude and a concept of being prevented from facing the problem and effectively dealing with it by own depressive emotions. These statements share a pessimistic, apprehensive and avoidance-oriented approach to the reality of having depression, including feeling unable to make a choice due to depressive symptoms, feeling guilty for depression, thinking that nothing can help and a wish to escape from the situation. From this perspective, item 6 (desperation to try anything that could help) is different from the others in this cluster, since it demonstrates an approach based on hope and one's openness to search for new treatment possibilities.

From another point of view, the 8 statements in this cluster are very similar. They all reflect some of the characteristic features of a depressive illness and its effect on a patient, that is symptoms of depression. The cluster is, therefore, labelled 'depressive symptoms'. It emphasises how depression as an illness can directly influence people's decision-making, specifically related in this instance to the selection of treatment for depression.

7.4.4.8 Cluster 9: Sharing experiences of depression with others

Cluster 9 is located near the central part of the concept map with dimensions 1 and 2, not directly characterising either of the dimensions. It contains two statements, number 17 – 'wanting to share my experiences with depression with others' and number 55 – 'other people's experiences with depression and its treatment'. The themes represented by the two items are related to experiences with depression, specifically focusing on a person's own experience in relation to the experience of other people. Wanting to share one's own, and to know about others' encounters with depression are two aspects of a communication channel, of giving and receiving information about personal experiences with the illness, and strategies for dealing with it. Based on the subject of this cluster, I labelled it 'sharing experiences of depression with others'.

7.4.4.9 Cluster 10: External views about depression

Cluster 10 is located in the bottom area of the concept map, and together with cluster 11 it characterises an external aspect of dimension 2, society. The cluster contains two statements which reflect beliefs about depression held by a patient's family and friends and their wider social environment. The statements are formulated in a neutral way, and in relation to patients' treatment choices they could include others' negative and stigmatising attitudes to depression and treatment, as well as positive and supporting views. I labelled the cluster 'external views about depression', to reflect its core concept that patients with depression might modify their treatment decisions according to the supporting or stigmatising views held by other people.

7.4.4.10 Cluster 11: My social context

The five statements in cluster 11 are located at the bottom of the concept map and on the concept map they are around the statements in cluster 10. These items can be described as the features and attributes of a person with depression, that place them in their current social environment – demographic characteristics (age, gender, and ethnicity), personality, upbringing, religion and cultural background.

Unlike cluster 10 which emphasises the effects of others' views on one's treatment choices, the focus of cluster 11 is on a patient's social and cultural identity. Whilst this is partly influenced by other people (in terms of such aspects as upbringing, religion and culture), in this cluster an individual's perception of external views is secondary. Instead, the emphasis is on an interaction of different aspects of a person's social identity. Acknowledging the cluster's focus on a patient's personal characteristics and their social environment, I labelled it 'my social context'.

7.4.4.11 Cluster 12: Depression in health records

Cluster 12 is the only cluster containing a single statement. It is located in the central part of the concept map, neighbouring with cluster 9 (sharing experiences of depression with others). This statement (not wanting to have depression listed in health records) represents a person's fear of disclosing the diagnosis to others, for example potential future employers. It could also be described as a fear of being discriminated against and stigmatised based on the illness.

The statement in this cluster was the only item belonging to different clusters in each of the three solutions. It was first put together with statements regarding depressive symptoms' influence on decisions (in the 6-cluster solution), and then with the statements about effortless treatment in the 8-cluster solution. In the final arrangement it is a cluster on its own, suggesting that the participants did not think that keeping the diagnosis of depression a secret was closely related to other statements in the set.

7.4.4.12 Cluster 7: Healthcare professionals

Clusters 7 and 6 are the only two clusters located on the left hand side of the concept map. Together, they characterise the external aspect of dimension 1, i.e. health professionals as a factor influencing patients' treatment decision-making. In the previous solutions these two groups formed one large cluster and in this final arrangement they are considered as two separate factors.

Cluster 7 is the largest in this set, and it contains 12 statements related to health professionals, viewing them from several perspectives. These include, for example, a patient's subjective perceptions of the professional (such as patients' experiences, expectations and relationships with the professional), professionals' personal characteristics (including demographic and personality factors) and provision of healthcare (for example continuity of care). Several statements, in addition, reflect the healthcare workers' communication skills (such as professionals openly discussing depression and its treatment with the patient and their family and friends) and the doctors' personal views about depression (including their beliefs, knowledge and understanding about this mental illness).

All of the 12 statements are located at small distances from each other, reflecting the participants' perception of the similar themes they represent, a person's reliance on their health professional as a major pillar when selecting depression treatment. Based on this observation, I labelled the cluster 'health professionals'.

7.4.4.13 Cluster 6: needing the doctor's advice

Cluster 6 is the only close neighbour to cluster 7, but its two statements are placed approximately halfway between clusters 7 and 4 (making an informed choice). Based on these items' position on the map and their subject, they can be viewed as a connecting link between clusters 7 and 4. They refer to a patient relying on the doctor's advice and needing the professional's confirming their treatment choices (for instance a need for a clear diagnosis and wanting treatment recommended by the doctor). Whilst this theme is related to health professionals, the cluster also places an emphasis on the patient's desire to be involved in treatment choice and using the expert advice of a doctor to inform their decision. This cluster was therefore labelled 'needing the doctor's advice'.

7.4.5 Meta-clusters

Based on descriptions and positions of the 12 individual clusters, it is apparent that some are related to each other more than others. These groups of related clusters

can be considered as meta-clusters for the purposes of interpreting their shared focus on decision-making about treatment.

7.4.5.1 An informed and perceptive approach

Clusters 4 (an informed choice), 8 (seeking effortless treatment), 1 (personal insight) and 3 (experiences) are closely adjacent to each other on the concept map. All are related to a decision that is based on information and understanding of a variety of issues, including the effects of depression as an illness on a person's life, and the effects and side effects of different treatment options. Whilst some statements can be viewed as having an emotional character (for example worries about becoming dependent on medication), in general they emphasise problem solving and can be viewed as concerns related to a lack of information. From this perspective, the four clusters all refer to factors based on an informed and perceptive approach to decision-making, demonstrating themselves as a person's internal locus of control over improving the depressive symptoms.

7.4.5.2 Depressive emotions

The three clusters related to relatively subjective and sentiment-driven factors are clusters 2 (emotions), 5 (depressive symptoms) and 12 (depression in health records). In the 6-cluster solution they formed a single cluster, and most of them describe patients' negative feelings about themselves from various perspectives. When regarded as a factor influencing patients' treatment decisions, the effect of emotional states in particular situations is closely related to a persons' depressive symptoms, including feeling guilt about depression, fear of facing their problem, or wanting to avoid the situation. The clusters' close positions on the map suggest that participants viewed them as related, and together they form a meta-cluster 'depressive emotions'.

7.4.5.3 External factors

Three clusters are related to the external factors, such as views of other people about depression (cluster 10), a person's social and cultural context (cluster 11) and

sharing experiences with depression with other people (cluster 9). The shared theme here is a person emphasising the influence of factors which are not directly related to their subjective living with depression. Instead, the focus is on the factors related to a person's environment, and the opinions and advice of other people, such as a need for an input from other people.

7.4.5.4 Health professionals

Two clusters (numbers 6 and 7) in this set are directly related to health professionals as an influence on patients' decision-making. Their location on the map (close to each other but distinct from other clusters), and their common focus on healthcare practitioners indicate that they can be regarded as one meta-group, health professionals. The theme of this meta-cluster is a person's attention and hope being projected onto the doctor as an expert with an authority, rather than a person's sense of confidence in their own judgement.

Chapter 8 Prioritising

8.1 Relative importance of clusters

Table 19 (key to table on separate page) shows the relative importance rankings of the final 12 clusters for the whole sample and for each stakeholder group separately. The group as a whole ranked patients' personal insight, emotional states and needing the doctor's opinion (expert advice) as the three most important factors affecting patients' treatment choices. The factors viewed as the least important were sharing experiences of depression with others, patient's social context and not wanting to have depression listed in health records. The three stakeholder groups differed significantly in their perceptions of the relative importance of 5 clusters, marked by asterisks in the table.

8.1.1 People with depression

Table 19 shows that people with depression emphasised the importance of the internal factors. They ranked personal insight into depression, their current emotional states and their own experiences with depression as the most influential factors on their decision-making about treatment. This group pointed to health professionals and expert advice as moderately important, and reported that external factors, such as external views about depression, social context, and depression in health records were the least influential factors.

8.1.2 Family and friends

Family and friends thought that people with depression are most influenced by the doctors' expert advice. They also felt that patients' personal insight and their desire to make informed choices were important for their treatment decisions. The group reported external factors, such as depression in health records, patient's social context, and their desire to share experiences of depression with other people, as the least influential.

8.1.3 Healthcare workers

The group of healthcare workers thought that people with depression make their treatment decisions mostly influenced by external views about depression (the opinions and beliefs of their family and friends or generally within society). The patients' need for doctors' expert advice about depression and treatment, and patients' own insight into their condition and symptoms were also thought to be important. Similarly to the two other groups, healthcare workers felt that the least important factors were patients' social contexts, sharing experiences with other people, and a desire to avoid having depression listed in health records.

Table 19: Clusters' importance rankings by stakeholder groups

Cluster	Whole group (N = 63)		People with depression (N = 28)		Family and friends (N = 14)		Healthcare workers (N = 21)		Post-hoc test
Label	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)	
(1) Personal insight	1	3.7 (.7; 3.5-3.9)	1	4.0 (.6; 3.8-4.3)	2	3.5 (.8; 3.0-3.9)	3	3.4 (.7; 3.1-3.7)	PWD→HCW** PWD→FF*
(2) Emotional states	2	3.6 (1.0; 3.3-3.8)	2	4.0 (.8; 3.7-4.3)	5	3.2 (1.1; 2.6-3.8)	4	3.3 (1.0; 2.8-3.7)	PWD→HCW* PWD→FF*
(3) Experiences with depression	4	3.3 (.8; 3.2-3.5)	3	3.5 (.8; 3.2-3.8)	4	3.3 (.6; 3.0-3.7)	5	3.2 (.7; 2.8-3.5)	
(4) Making an informed choice	5	3.2 (.7; 3.0-3.4)	4	3.2 (.6; 2.9-3.4)	3	3.4 (.7; 3.1-3.8)	6	3.1 (.9; 2.7-3.5)	
(5) Depressive symptoms	6	3.1 (.7; 2.9-3.2)	5	3.2 (.7; 2.9-3.4)	6	3.1 (.6; 2.8-3.4)	8	2.9 (.7; 2.6-3.2)	
(6) Needing the doctor's opinion	3	3.4 (1.0; 3.2-3.6)	6	3.1 (1.0; 2.7-3.5)	1	4.0 (.8; 3.5-4.4)	2	3.4 (.9; 3.0-3.8)	FF→PWD*
(7) Healthcare professionals	8	2.8 (.6; 2.7-3.0)	7	2.8 (.7; 2.5-3.1)	7	2.9 (.5; 2.6-3.2)	9	2.8 (.5; 2.6-3.1)	
(8) Seeking effortless treatment	9	2.8 (.7; 2.6-3.0)	8	2.7 (.7; 2.5-3.0)	8	2.6 (.6; 2.3-3.0)	7	3.0 (.8; 2.6-3.3)	
(9) Sharing experiences of depression with others	10	2.5 (.9; 2.3-2.7)	9	2.6 (1.0; 2.2-3.0)	12	2.1 (.9; 1.6-2.7)	12	2.6 (.8; 2.2-2.9)	
(10) External views about depression	7	2.9 (1.0; 2.6-3.1)	10	2.5 (.8; 2.2-2.8)	9	2.6 (1.1; 2.0-3.2)	1	3.5 (.8; 3.1-3.9)	HCW→PWD** HCW→FF**
(11) My social context	11	2.3 (.9; 2.1-2.6)	11	2.0 (.6; 1.8-2.2)	11	2.3 (1.3; 1.6-3.1)	10	2.8 (.9; 2.4-3.2)	HCW→PWD***
(12) Depression in health records	12	2.2 (1.3; 1.9-2.5)	12	1.8 (1.1; 1.4-2.3)	10	2.4 (1.5; 1.5-3.2)	11	2.7 (1.3; 2.1-3.3)	

* p<.05 using Tukey's post-hoc test

** p<.01 using Tukey's post-hoc test

*** p<.01 using Welch's test and Tamhane's T2 post-hoc test, as the Levene's test was significant, which violated assumption of Anova and indicated need for alternative test.

8.2 Relative importance of the individual statements

Table 20 shows the perceived relative importance rankings of all statements for each stakeholder group and for the participants as a whole. The groups significantly differed in their rankings of 12 statements, which are marked by an asterisk.

8.2.1 Whole group perspectives

According to the group as a whole, the top ten most important issues affecting patients' choices included several statements related to a person's insight, including patients' ability to recognise their illness, readiness to accept treatment and engage with it, and wanting to get to the root of their depressive illness. Participants also valued patient's current emotional state (how I feel right now), and their past experience with depression and treatment. Other highly ranked items included patients' information about depression and treatment, professionals' knowledge about depression, and people's feeling of desperation to try any treatment option that could help them.

The 10 least important statements all belonged to clusters rated as less influential by people with depression, i.e. clusters 7-12. These statements relate to a person wishing to have a 'quick fix' treatment and avoid a more in-depth dealing with depression (for instance wanting the easiest treatment), patient's social contexts (including personality, religion, personal characteristics) and external factors (such as sharing experiences with others) and depressive emotions, (i.e. not wanting to have depression listed in health records). Several of the least important statements related to health professionals (such as professionals' readiness to discuss depression with the family and friends, communication between different health professionals, and patients wishing to please their doctor).

8.2.2 People with depression

The top ten most important statements for this group include mostly internally focused items, such as recognising that they have a problem they need help with, and feeling ready to accept treatment. People with depression thought that their treatment decision-making is greatly affected by their past experience, including knowing whether one can feel better, and the current emotional states. Overall, the group also emphasised the importance of being actively involved in treatment and getting to the root of their depressive illness when selecting treatment for depression. Whilst several of the top ten most influential statements are related to people's insightful approach and making informed decisions, patients also felt that their treatment choices are shaped by their depressive emotions, such as wanting to avoid dealing with the situation and feeling desperate to try anything that might help.

The ten statements ranked as the least influential on patients' own treatment choices were mostly external factors, such as religion, culture, beliefs of family and friends about depression. Patients did not consider that they made decisions in an attempt to please their doctor, or that they wanted to avoid having depression listed in health records. A wish to have a 'natural' treatment was not regarded as highly influential. Additionally, patients did not think that their own or their health professional's personality or demographic characteristics had a significant influence on their decisions.

8.2.3 Family and friends

Family and friends emphasised the need for patients to see the same health professionals during the course of their illness, and the need to be given a clear diagnosis, in order to make informed decisions. They also considered that people's depressive illness significantly affected their ability to make treatment decisions, but that it was important for patients to recognise their problem and that they are not alone with the illness. Other important items, according to the family and friends, are patients' information and understanding about depression and their

readiness to engage with treatment. The group thought that patients want to feel in control by being given a choice of treatment, but want to have treatment which is recommended by their health professional.

This group thought that the least influential factors related to the age, gender and ethnicity of health professional, the patient's social context (including religion, culture), and wanting to please the doctor. Family and friends did not think that sharing experiences with others was important for people with depression, or that it was relevant for them to realise that depression affects people differently. Similarly to people with depression, this group did not find a wish for a 'natural' treatment to be highly significant for patients' decisions.

8.2.4 Healthcare workers

Healthcare workers, similarly to people with depression, thought that patients' recognition of their illness was the most important statement of all. They also suggested that patients' past experiences were highly influential, together with their personal readiness to accept treatment. The group attributed significance to people's need for information about depression and its treatment, and thought that patients want treatment that works quickly. This is supported by the group's low relative ranking of the importance of patients' realisation that there is no quick fix for depression. Other highly rated items include patients' reliance on the doctor's recommendation, and their experience with the professional.

Statements that were not considered to be as important include the patients' realisation that people's experiences with depression are different and feeling guilty about depression. Healthcare workers agreed with the other stakeholder groups' low rankings of the professionals' personal characteristics, and the patients' wish for a 'natural' treatment and to please the doctor.

Table 20: The relative importance of statements

cluster	ID	Statement	Whole sample (n=64) rank	Mean (SD)	People with depression (n=28) rank	Mean (SD)	Family and friends (n=14) rank	Mean (SD)	Healthcare workers (n=22) rank	Mean (SD)
1	4	Recognizing I have a problem I need help with	1	4.3 (1.1)	1	4.5 (0.9)	4	3.9 (1.2)	1	4.2 (1.2)
1	43	Being ready to accept treatment	2	4.1 (1.1)	2	4.4 (0.8)	13	3.6 (1.2)	4	4 (1.2)
3	30	My past experience with depression (knowing whether I can feel better or not)	3	3.9 (1.2)	3	4.1 (1.3)	14	3.6 (1.1)	3	4 (1.2)
2	31	How I feel right now	8	3.6 (1.3)	4	4.1 (1)**	31	3 (1.4)	16	3.4 (1.3)
1	33	Desire to get to the root (the bottom) of depression	9	3.6 (1.3)	5	4 (1.2)	20	3.4 (1.4)	22	3.3 (1.3)
1	5	Playing an active role in getting better	15	3.4 (1.4)	6	4 (1.1)*	33	2.9 (1.6)	39	2.9 (1.2)
5	29	Wanting to escape from the situation	11	3.5 (1.5)	7	3.9 (1.5)	23	3.4 (1.3)	36	2.9 (1.4)
5	6	Desperation to try anything that could help	10	3.6 (1.5)	8	3.9 (1.4)	21	3.4 (1.3)	19	3.3 (1.6)
4	16	My knowledge and understanding of the effects of treatment	12	3.5 (1.4)	9	3.9 (1.2)*	10	3.6 (1.5)	35	2.9 (1.6)
2	35	A desire to get better for people I care about	14	3.5 (1.3)	10	3.9 (1.2)	17	3.4 (1.6)	24	3.2 (1.3)
1	44	Being ready to engage with treatment	4	3.8 (1.2)	11	3.9 (1)	7	3.8 (1.2)	10	3.7 (1.3)
7	19	Healthcare professionals' knowledge and understanding about depression and its treatment	7	3.7 (1.1)	12	3.7 (1.2)	11	3.6 (1.5)	7	3.8 (0.9)
3	13	My past experiences of treatment	5	3.7 (1.3)	13	3.6 (1.3)	16	3.5 (1.2)	2	4 (1.2)
7	24	Continuity of care (seeing the same healthcare professional)	13	3.5 (1.3)	14	3.6 (1.3)	1	4.1 (1.1)*	31	3 (1.3)
5	49	Not wanting to be a burden on others	23	3.3 (1.3)	15	3.6 (1.2)	18	3.4 (1.6)	44	2.7 (1.2)
8	59	Wanting a treatment that is provided with no time limitations	30	3 (1.5)	16	3.4 (1.5)*	19	3.4 (1.6)	53	2.2 (1.3)
4	7	Information about depression and its treatment	6	3.7 (1.2)	17	3.4 (1.3)	6	3.9 (0.8)	5	3.9 (1.2)

Table 20 (continued)

6	56	Being given a clear diagnosis	16	3.4 (1.4)	18	3.3 (1.4)	2	4 (1.2)	28	3.1 (1.4)
7	27	My experiences with healthcare professionals	19	3.4 (1)	19	3.3 (1.2)	26	3.4 (0.8)	6	3.8 (1)
1	47	Realizing there is no quick fix	35	2.9 (1.3)	20	3.3 (1.2)**	27	3.3 (1.3)**	56	2 (1.1)
8	12	Wanting a treatment that works quickly	20	3.3 (1.4)	21	3.2 (1.3)	34	2.9 (1.5)	8	3.7 (1.5)
7	20	My relationship with the healthcare professional	21	3.3 (1.3)	22	3.2 (1.3)	22	3.4 (1.3)	21	3.3 (1.3)
3	42	Realizing all people's experiences with depression are different	47	2.5 (1.2)	23	3.2 (1)***	50	2.4 (1)	58	1.7 (0.8)
4	15	Worries about the side effects of medication	18	3.4 (1.3)	24	3.1 (1.4)	12	3.6 (1.2)	11	3.6 (1.2)
3	38	Understanding it is normal to have depression and I am not alone	26	3.2 (1.3)	25	3.1 (1.4)	5	3.9 (1.2)	33	3 (1.3)
5	36	Isolation, and not having the support network close	28	3.1 (1.3)	26	3.1 (1.3)	25	3.4 (1)	37	2.9 (1.4)
4	11	Weighing up the risks and benefits of treatments	42	2.8 (1.2)	27	3.1 (1)	32	3 (1)	46	2.4 (1.4)
4	3	Being given a choice of treatments	25	3.2 (1.4)	28	3 (1.5)	9	3.7 (1.3)	26	3.1 (1.5)
7	53	Healthcare professionals discussing depression and its treatment openly	29	3 (1.5)	29	3 (1.4)	37	2.8 (1.4)	30	3 (1.6)
4	26	My understanding of the side effects of treatment	27	3.1 (1.3)	30	3 (1.3)	24	3.4 (1.1)	38	2.9 (1.3)
4	46	Worries about becoming dependent on medication	22	3.3 (1.3)	31	3 (1.3)	15	3.5 (1.3)	18	3.4 (1.1)
7	28	My expectations from healthcare professionals	40	2.8 (1.3)	32	3 (1.2)	45	2.5 (0.9)	40	2.8 (1.5)
4	37	My belief that depression is a chemical imbalance	31	3 (1.3)	33	3 (1.2)	28	3.2 (1.6)	32	3 (1.3)
5	9	Inability to make a choice because of my depression	24	3.2 (1.5)	34	2.9 (1.6)	3	3.9 (1.3)	25	3.1 (1.6)
6	58	Wanting what doctors say is the most effective treatment	17	3.4 (1.4)	35	2.9 (1.4)	8	3.8 (1.1)	9	3.7 (1.4)
7	52	The healthcare professionals' personality	39	2.8 (1.4)	36	2.9 (1.3)	35	2.9 (1.5)	43	2.7 (1.5)
5	32	Fear of dealing with problems	44	2.7 (1.4)	37	2.8 (1.4)	44	2.5 (1)	41	2.8 (1.5)

Table 20 (continued)

4	8	Having my view about what is the best treatment confirmed	32	3 (1.1)	38	2.8 (0.9)	29	3.1 (1.3)	23	3.2 (1.3)
5	14	Feeling it's my fault for having depression	46	2.5 (1.4)	39	2.7 (1.4)	49	2.4 (1.2)	50	2.3 (1.5)
8	1	Financial costs related to the particular treatment option	33	2.9 (1.5)	40	2.6 (1.5)	40	2.6 (1.7)	15	3.4 (1.4)
11	51	My upbringing	34	2.9 (1.5)	41	2.6 (1.4)	39	2.6 (1.8)	13	3.5 (1.3)
8	2	Practical issues related to starting treatment	38	2.8 (1.4)	42	2.6 (1.3)	48	2.4 (1.3)	20	3.3 (1.5)
9	17	Wanting to share my experiences with depression with others	54	2.2 (1.8)	43	2.6 (1.3)**	54	2.2 (1.1)	59	1.6 (0.8)
9	55	Other people's experiences with depression and its treatment	43	2.8 (1.2)	44	2.6 (1.2)	56	2.1 (1.1)	14	3.5 (1)****
7	18	Healthcare professionals' beliefs about depression and its treatment	37	2.9 (1.1)	45	2.6 (0.9)	30	3.1 (1)	29	3.1 (1.2)
10	48	Views about depression in society	41	2.8 (1.3)	46	2.5 (1.2)	47	2.4 (1.5)	17	3.4 (1.3)
7	45	Healthcare professionals being ready to discuss depression and its treatment with family and friends	52	2.3 (1.4)	47	2.4 (1.5)	42	2.5 (1.6)	57	1.9 (0.8)
5	39	Thinking that nothing can help me	45	2.6 (1.3)	48	2.4 (1.3)	43	2.5 (1.4)	34	3 (1)
11	40	Having an introverted or extroverted personality	51	2.4 (1.3)	49	2.4 (1.2)	41	2.6 (1.5)	47	2.4 (1.4)
10	10	Beliefs of family and friends about depression	36	2.9 (1.2)	50	2.4 (1.1)	36	2.8 (1.4)	12	3.6 (0.9)**
8	54	Wanting a 'natural' treatment	53	2.3 (1.3)	51	2.3 (1.4)	52	2.3 (1.1)	51	2.3 (1.3)
7	57	Communication between different healthcare professionals	50	2.4 (1.4)	52	2.3 (1.4)	38	2.8 (1.3)	52	2.2 (1.4)
8	50	Wanting the easiest treatment	49	2.4 (1.4)	53	2.2 (1.3)	55	2.1 (1.3)	42	2.8 (1.5)
11	21	My personal characteristics (age, being male or female, ethnicity - being black, white or other)	55	2.2 (1.3)	54	1.9 (1.3)	53	2.2 (1.7)	49	2.4 (1.1)
11	22	Culture (my background as well as my current culture)	48	2.4 (1.4)	55	1.9 (1.1)	51	2.3 (1.5)	27	3.1 (1.4)**

Table 20 (continued)										
7	25	Personal characteristics of the healthcare professional (age, being male or female, ethnicity - being black, white or other)	58	1.8 (1.2)	56	1.8 (1.2)	59	1.6 (1.2)	54	2 (1.3)
12	34	Not wanting to have depression listed in health records	56	2.2 (1.3)	57	1.8 (1.1)	46	2.4 (1.5)	45	2.6 (1.3)
7	41	Wanting to please the doctor (to be a good patient)	59	1.8 (1.2)	58	1.6 (1.1)	58	1.9 (1.1)	55	2 (1.2)
11	23	My religion	57	1.8 (1.2)	59	1.1 (0.4)	57	2 (1.4)*	48	2.4 (1.3)**

*p<.05

**p<.01

***people with depression ranked the statement as significantly more important than family and friends at p<.05, and more important than healthcare workers at p<.01

****healthcare workers ranked the statement as significantly more important than people with depression at p<.05, and more important than family and friends at p<.01

8.3 Conclusion

The three stakeholder groups differed significantly in their views about how people with depression make treatment choices. Whilst people with depression emphasised the importance of understanding their own situation, feeling ready to seek help and deal with emotions, the other two groups thought that the factors external to the person were more influential than their insight or emotions. Healthcare workers ranked the insight and emotions factors as significantly less important than people with depression did, and focused on the role of views about depression held by people's family and within their social circles. Family and friends, on the other hand, appeared to be mostly concerned about a need to tell people what is wrong (to give a diagnosis), and to provide suggestions how to treat the illness. The two latter groups focused on the influence of stigma and expert advice on people's treatment decisions. Patients' inner understanding of their depression, and their emotions, are recognised as important by themselves, but not by the family or professionals. This observation was made, despite the professionals and patients assigning high importance rankings to two insight-related statements, namely recognising I have a problem I need help with, and being ready to accept treatment. Overall, the two groups' views about the role of several factors differed significantly.

Chapter 9 Types of stakeholder groups

9.1 Clustering of participants

The dimension scores for each stakeholder group separately were used in k-means cluster analysis to compute several cluster solutions.
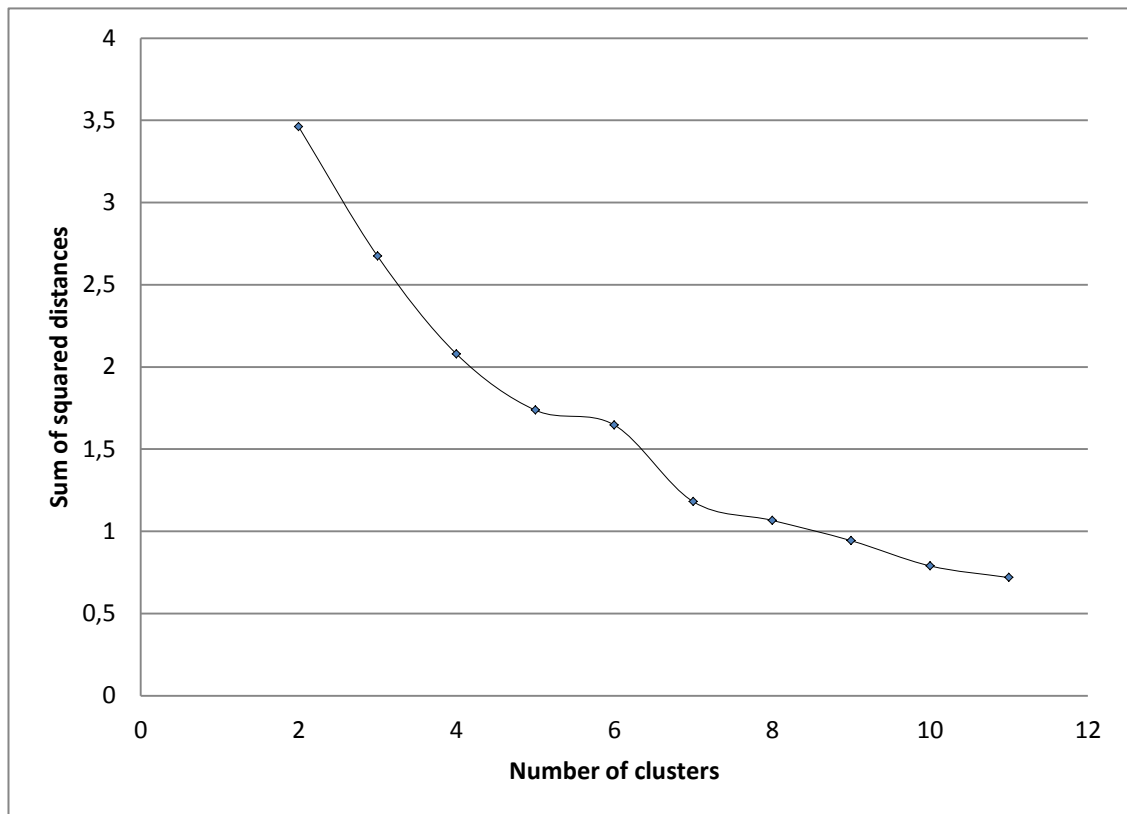
9.2 People with depression

9.2.1 Types of people with depression

Table 21 shows the sums of squared distances for 10 different cluster solutions for people with depression. These values are plotted on an elbow graph in Figure 13. The most appropriate cluster solution is marked by a point located at the bottom of a steady 'jump' of the line of best fit. Such point is typically followed by another point at a very similar value, i.e. shown as a flat line and indicating a non-significant improvement in the values. Such point on the elbow graph in Figure 13 represents a solution with 5 clusters, i.e. 5 types of patients.

Table 21: Sums of squared distances for clusters of people with depression

N of clusters	Sum of square distances	Difference between the Sum of squared distances
2	3.46	
3	2.67	0.79
4	2.08	0.60
5	1.74	0.34
6	1.65	0.09
7	1.18	0.47
8	1.07	0.11
9	0.94	0.12
10	0.79	0.15
11	0.72	0.07

Figure 13: An elbow plot of sums of squared distances for different numbers of clusters of people with depression

9.2.2 Types of patients described

9.2.2.1 Demographic characteristics

Table 22 shows the demographic characteristics of the 5 types of people with depression. Two of the types contain 7 participants, one has 2 patients, one includes 4 people and one has 8 participants. The five types did not differ in most of the demographic characteristics, except for gender. Three out of four people in Type 5 were males, whilst two other types only included between 0-43% of males. Average age among the types ranged between 36-59, all people described themselves being of the White ethnic group and approximately half of the patients were married or co-habiting. Just over a half of the patients in most types said they had a University degree or higher education. Approximately half of the people were employed and one in five was retired.

Table 22: Demographic characteristics of the 5 patient types

	Type 1 (n=7)	Type 2 (n=4)	Type 3 (n=2)	Type 4 (n=7)	Type 5 (n=8)	PWD total (n=28)
	N (%), unless *, then Mean (SD)					
Female	6 (86)	4 (100)	2 (100)	4 (57)	2 (25)	18 (64)
Age in years*	46.3 (18.4)	35.8 (18.2)	59 (24)	44.3 (13)	48.8 (15.9)	46 (16; 18-79)
White British or White Irish	7 (100)	3 (75)	2 (100)	7 (100)	8 (100)	27 (96)
Highest achieved qualification						
Secondary education	3 (43)	2 (50)	1 (50)	3 (43)	3 (38)	12 (43)
University Degree or higher	4 (57)	2 (50)	1 (50)	4 (57)	5 (63)	16 (57)
Marital status						
Single	2 (29)	2 (50)	1 (50)	3 (43)	3 (38)	11 (39)
Married/co-habiting	4 (57)	1 (25)	1 (50)	4 (57)	4 (50)	14 (50)
Divorced/separated	1 (14)	1 (25)	0	0	1 (13)	3 (11)
Employment status						
Employed	2 (29)	2 (50)	1 (50)	6 (86)	4 (50)	15 (54)
Unemployed	1 (14)	0	0	1 (14)	1 (13)	3 (11)
Student	1 (14)	2 (50)	0	0	1 (14)	4 (14)
Retired	3 (43)	0	1 (50)	0	2 (25)	6 (21)

9.2.2.2 Clinical characteristics

Participants in the 5 types reported having experienced an average of 3-9 depressive episodes, and had suffered from their symptoms for 13-35 years on average.

Table 23 shows treatment patients said they had been prescribed or recommended. Based on self-reports, the most commonly prescribed treatment was a combination of antidepressant medication and psychological therapy (50-57% of types 1, 2 and 4). Patients in type 3 (n=2) did not report that they had been prescribed any treatment, since they either did not seek medical help or were recommended other therapies (such as mindfulness). Seventy-five percent of type 5 patients said they had only been prescribed medication (compared to 30-50% of other types), and 25% were given a combination of antidepressants and psychological therapy.

Table 23: Clinical characteristics of the 5 patient types: treatment prescribed

	Type 1 (n=7)	Type 2 (n=4)	Type 3 (n=2)	Type 4 (n=7)	Type 5 (n=8)	PWD total (n=28)
	N (%)					
Antidepressant medication alone	2 (29)	2 (50)	0	2 (29)	6 (75)	12 (43)
Psychological therapy alone	1 (14)	0	0	1 (14)	0	2 (7)
Combination of medication and psychological treatment	4 (57)	2 (50)	0	4 (57)	2 (25)	12 (43)
Other	0	0	2 (100)[1]	0	0	2 (7)[1]
Total	**7 (100)**	**4 (100)**	**2 (100)**	**7 (100)**	**8 (100)**	**28 (100)**

[1] One person did not seek medical help and was therefore not prescribed any treatment, and one person was recommended mindfulness-based therapy

Table 24 shows that 25-50% of patients in most types reported taking the treatment they had been prescribed. Between 25-38% of patients in most types decided to take only a proportion of their prescribed treatment options, or no treatment at all. This was true for almost 3 out of 4 people in the type 4. Approximately half of the patients in types 1 and 2 initiated a therapy to complement or replace one of their prescribed treatment options (for example, signed up for private counselling in addition to taking medication). No participants in types 3 or 4, and 1 person in type 5 reported taking anything other than prescribed treatment.

Table 24: Clinical characteristics of the 5 subgroups of patients: reported adherence to prescribed treatment options

Type of treatment reported to have taken:	Type 1 (n=7)	Type 2 (n=4)	Type 3 (n=2)	Type 4 (n=7)	Type 5 (n=8)	PWD total (n=28)
N (%)						
As prescribed	2 (29)	1 (25)	1 (50)	2 (29)	4 (50)	10 (36)
Discontinued one or more of the prescribed treatment options	2 (29)	1 (25)	0	5 (71)	3 (38)	11 (39)
One or more self-initiated treatment options were taken in addition, or instead of a prescribed treatment option[1]	3 (43)	2 (50)	0	0	1 (13)	4 (21)
Total	**7 (100)**	**4 (100)**	**2 (100)[3]**	**7 (100)**	**8 (100)**	**28 (100)[3]**

[1] Self-initiated treatment options participants reported to have been taking included privately accessed psychological therapy, as well as self-help books, emotional regulation therapy, mindfulness-based therapy, and alternative treatments, such as reflexology, blu-light box, for example, when prescribed medication and CBT course, but reported taking medication and having private counselling, or when prescribed medication but reported having reflexology instead.

[3] Data for one person was not provided

9.2.3 Patient types: importance rankings of 12 factors

Table 25 (key to table on a separate page) shows the importance rankings of the 12 factors for each of the five patient types. Their average scores were compared using a one-way ANOVA and Welch's test where appropriate, followed by a Tukey's and Tamhane's Post Hoc tests (respectively). I identified significant differences in the subgroups' views about the following 5 factors, i.e. Making an informed choice, Depressive symptoms, Health professionals, Wanting to share experiences and My social context. The views about the remaining 7 factors were similar across the five patient types.

Table 25: Patient subgroups' importance rankings of the 12 factors that affect treatment choices

Cluster	Type 1: Needing experts (n=7)		Type 2: Irrational emotional (n=4)		Type 3: Stigma driven (n=2)		Type 4: Not trusting experts (n=7)		Type 5: Externally driven (n=8)	
	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)
(1) Personal insight	2	3.6 (0.8; 2.9-4.4)	3	3.7 (0.7; 2.5-4.8)	2	4.2 (0.5; -0.1-8.4)	2	4.3 (0.2; 4.1-4.5)	1	4.2 (0.6; 3.8-4.7)
(2) Emotional states	1	3.9 (1.0; 2.9-4.8)	2	3.9 (0.8; 2.7-5.1)	4	3.8 (1.8; -12.1-19.6)	1	4.3 (0.5; 3.8-4.7)	2	4.0 (0.9; 3.3-4.7)
(3) Experiences with depression	7	2.9 (1.1; 1.9-3.8)	6	3.2 (0.7; 2.1-4.3)	3	3.9 (0.2; 2.3-5.5)	3	3.7 (0.7; 3.0-4.3)	3	4.0 (0.4; 3.7-4.4)
(4) Making an informed choice	6	3.1 (1.1; 2.6-3.5)	8	2.8 (0.7; 2-3.6)	5	3.7 (0.2; 1.2-6.2)	4	3.7 (0.7; 3.2-4.1)[1]*5*	6	2.8 (0.4; 2.4-3.2)[1]*4*
(5) Depressive symptoms	4	3.4 (0.3; 3.2-3.6)[4]*5*	1	4.2 (0.3; 3.7-4.7)[3]*4,5*	11	1.8 (0.9; -6.2-9.7)	6	3.3 (0.5; 2.9-3.7)[3]*2*	7	2.7 (0.3; 2.4-2.9)[4]*1,2*
(6) Needing the doctor's opinion	3	3.4 (1.3; 2.2-4.5)	4	3.6 (1.2; 1.7-5.5)	6	3.5 (0.7; -2.9-9.9)	8	2.5 (0.8; 1.8-3.2)	5	3.0 (1.0; 2.2-3.8)
(7) Healthcare professionals	5	3.3 (0.3; 3-3.6)[2]*2,4*	9	2.4 (0.6; 1.5-3.2)[2]*1,5*	10	2.4 (0.7; -3.4-8.2)	10	2.1 (0.3; 1.9-2.4)[2]*1,5*	4	3.3 (0.5; 2.9-3.6)[2]*2,4*
(8) Seeking effortless treatment	9	2.7 (0.6; 2.2-3.2)	5	3.4 (0.7; 2.3-4.6)	9	2.8 (0.2; 0.7-5.0)	7	2.6 (0.6; 2.1-3.1)	9	2.4 (0.7; 1.8-3.0)
(9) Sharing experiences of depression	10	2.0 (0.7; 1.4-2.6)[1]*4*	10	2.1 (0.9; 0.8-3.5)	8	2.8 (0.4; -0.4-5.9)	5	3.6 (1.1; 2.7-4.6)[1]*1*	8	2.5 (0.9; 1.7-3.3)
(10) External views	8	2.8 (0.8; 2.1-3.5)	7	2.8 (1.3; 0.6-4.9)		3.0*	9	2.4 (0.7; 1.7-3.0)	11	2.1 (0.6; 1.6-2.7)
(11) My social context	11	1.7 (0.5; 1.2-2.1)[1]*3,5*	11	1.9 (0.4; 1.2-2.5)[1]*3*	7	3.1 (0.4; -0.7-6.9)[1]*1,2,4*	12	1.7 (0.4; 1.4-2.0)[1]*3,5*	10	2.4 (0.4; 2.0-2.7)[1]*1,4*
(12) Depression in health records	12	1.4 (0.5; 0.9-1.9)	12	1.0 (0; 1-1)	1	4.5 (0.7; -1.9-10.9)	11	1.7 (0.8; 1-2.4.0)	12	2.0 (1.2; 1.0-3.0)

*Based on response of one participant due to missing data for the other participant.

[1]p<.05, based on Tukey's Post Hoc test

[2]p<.01, based on Tukey's Post Hoc test

[3]p<.05, based on Tamhane's Post Hoc test

[4]p<.01, based on Tamhane's Post Hoc test

Note: number(s) after superscripted number in the table indicate the patient type(s) which had ranked the particular cluster as significantly different.

9.2.4 Types of patients compared

9.2.4.1 Type 1: Depressed and relying on experts

Type 1 patients ranked four factors differently to some of the other types. Together with type 5, they found health professionals as significantly more influential than types 2 and 4 did. Type 1 patients thought their depressive symptoms affected their choices more than type 5 people did, and found sharing experiences with other people to be less important than type 4. Patients in type 1 ranked the impact of their social environment as smaller than types 3 and 5.

Based on the differences in the perceived importance of the factors, type 1 patients are described as influenced by depressive symptoms and an increased need for the input of health professionals. They are not affected by their social context, and do not find exchanging knowledge and experiences with others to be highly influential of their decisions. The type was therefore described as Depressed and relying on experts.

9.2.4.2 Type 2: Emotion driven

Type 2 patients emphasised the role of the depressive symptoms and emotions on their treatment decisions, and ranked the factor significantly more influential than types 4 and 5. Unlike type 1, type 2 patients did not consider health professionals to have a large impact on their choices, and found them as significantly less important than types 1 and 5. They also differed from type 3 by ranking their social context as less influential.

Type 2 patients are distinctive in their focus on the effect of depressive symptoms and emotions over the external factors, such as health professionals or their social environment and background. They are therefore described as Emotion driven.

9.2.4.3 Type 3: Fearing stigma

Type 3 patients found their social context to be significantly more influential than types 1, 2 and 4 did. In addition, this type of participants was the only type who viewed any of the external factors as more influential than the internal factors, i.e. not wanting to have depression listed in health records was the most important of all factors for this type. The views of the type 3 patients also emphasised the importance of having personal insight and benefiting from their personal experiences over the role of depressive emotions and worries. Based on their distinctive focus on social and cultural background, and a wish to avoid having an 'official' or formal diagnosis of depression, the type is labelled as Fearing stigma.

9.2.4.4 Type 4: Independent from experts

Type 4 patients ranked their depressive symptoms as moderately important, but significantly less influential than type 2. Type 4 found it significantly more important to make informed decisions than type 5 did, and significantly more important to share experiences than type 1 did. Similar to type 1, type 4 patients did not find their social context to have a high impact on their choices, and ranked it less important than types 3 and 5.

Overall, type 4 can be characterised as wanting to make informed decisions based on the effects of their depressive symptoms and the anecdotal evidence coming from people with similar experiences. Based on their cluster rankings, type 4 patients did not find the health professionals to be very influential. Consequently, I labelled the type as 'Independent from experts' in order to reflect their reliance on themselves in treatment decision-making.

9.2.4.5 Type 5: Externally driven

Type 5 patients ranked their depressive symptoms as significantly less influential than types 1 and 2, and found it less important in order to make informed treatment decisions than type 4. These patients reported that health professionals

influenced their choices significantly more than types 2 and 4. They also attributed more importance to their social context and background than types 1 and 4 did.

In contrast to other types of patients, type 5 emphasised the role of professionals and their own social and cultural backgrounds. Although the most important factors for this type were personal insight and emotional states (ranked similarly to other types), these patients did not find their symptoms to be highly influential and did not find it highly important to make informed decisions. Reflecting their relative emphasis of professionals and the cultural aspects and lower rankings of making informed choices, I labelled this type of patients as Externally driven.

9.3 Types of patients based on self-report of treatment taken

In order to explore the differences between depressed people further, I performed a second subgroup analysis based on patients' self-reported adherence to their prescribed treatment. Specifically, I aimed to compare people who reported taking treatment as prescribed, those saying that they had discontinued one or more of prescribed treatment options and those who took one or more other options in addition to their prescribed treatment.

9.3.1 Three types of patients described

Table 26 shows the demographic characteristics of the three types of depressed people. Type 1 patients (n=10) reported taking treatment as prescribed, type 2 patients (n=11) said that they had discontinued one or more of prescribed treatment options, and type 3 patients (n=6) said that they had taken one or more other options in addition to their prescribed treatment. The three types were similar in most of the characteristics. The mean age of all groups was between 42 and 48 years and the majority of all types described themselves being of the White ethnic group. The groups differed in the highest achieved education. While most patients in type 1 and 2 had a University degree, 83% of type 3 patients reported having secondary education as the highest.

Table 26: Demographic characteristics of the three patient types

	Type 1 (as prescribed) (n=10)	Type 2 (discontinued one or more) (n=11)	Type 3 (added one or more) (n=6)	PWD total (n=28)
	N (%), unless *, then Mean (SD)			
Female	5 (50)	7 (64)	5 (84)	18 (64)
Age in years*	48 (17.5)	42 (13.4)	44 (17.2)	46 (16; 18-79)
White British or White Irish	10 (100)	10 (91)	6 (100)	27 (96)
Highest achieved qualification				
Secondary education	2 (20)	4 (36)	5 (83)	12 (43)
University Degree or higher	8 (80)	7 (64)	1 (17)	16 (57)
Marital status				
Single	3 (30)	4 (36)	3 (50)	11 (39)
Married/co-habiting	5 (50)	7 (64)	2 (33)	14 (50)
Divorced/separated	2 (20)	0 (0)	1 (17)	3 (11)
Employment status				
Employed	6 (60)	6 (55)	3 (50)	15 (54)
Unemployed	0 (0)	3 (27)	0 (0)	3 (11)
Student	1 (10)	2 (18)	1 (17)	4 (14)
Retired	3 (30)	0 (0)	2 (33)	6 (21)

9.3.2 Three types of patients: comparison of the cluster importance rankings

Table 27 shows the results of a one-way ANOVA and a Tukey's post-hoc (Tamhane's in cluster 10) test comparing the three types of patients in how they ranked the importance of the 12 clusters. There were no significant differences between the three groups' rankings.

Table 27: Importance rankings of 12 clusters for patients based on reported adherence

Cluster	Type 1: As prescribed (n=10)		Type 2: Discontinued one or more of the prescribed treatment options (n=11)		Type 3: One or more self-initiated treatment taken in addition or instead of prescribed treatment[1] (n=6)		Post-hoc test[3]
Label	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)	P value
(1) Personal insight	1	4.1 (0.6; 3.7-4.5)	1	4.1 (0.7; 3.6-4.6)	2	3.7 (0.7; 3.0-4.4)	NS[2]
(2) Emotional states	2	3.9 (0.9; 3.2-4.5)	2	4.1 (0.8; 3.6-4.6)	1	3.9 (0.9; 3.0-4.9)	NS
(3) Experiences with depression	3	3.5 (0.7; 3.0-4.1)	3	3.7 (1.0; 3.0-4.3)	6	3.1 (0.8; 2.2-4.0)	NS
(4) Making an informed choice	4	3.2 (0.5; 2.8-3.5)	5	3.2 (0.8; 2.7-3.7)	7	3.0 (0.3; 2.6-3.3)	NS
(5) Depressive symptoms	6	3.0 (0.7; 2.5-3.5)	4	3.3 (0.4; 3.0-3.6)	3	3.5 (0.6; 2.8-4.2)	NS
(6) Needing the doctor's opinion	5	3.2 (1.2; 2.1-3.9)	6/7	2.9 (1.0; 2.3-3.6)	4	3.4 (1.0; 2.4-4.4)	NS
(7) Healthcare professionals	8	2.8 (0.7; 2.3-3.3)	8	2.6 (0.5; 2.2-2.9)	5	3.2 (0.9; 2.3-4.1)	NS
(8) Seeking effortless treatment	7	2.9 (0.6; 2.4-3.3)	9	2.6 (0.7; 2.2-3.1)	10	2.5 (0.7; 1.7-3.3)	NS
(9) Sharing experiences of depression with others	10	2.3 (1.3; 1.3-3.3)	6/7	2.9 (1.0; 2.3-3.6)	9	2.6 (0.5; 2.1-3.1)	NS
(10) External views about depression	9	2.6 (0.4; 2.3-2.9)	10	2.3 (0.8; 1.8-2.8)	8	2.8 (1.2; 1.5-4.0)	NS[4]
(11) My social context	11	2.1 (0.5; 1.7-2.5)	11	1.9 (0.6; 1.5-2.3)	11	1.7 (0.4; 1.3-2.1)	NS
(12) Depression in health records	12	1.8 (1.2; 0.9-2.7)	12	1.8 (1.1; 1.1-2.5)	12	1.5 (0.8; 0.6-2.4)	NS

[1] Self-initiated treatment options participants reported to have been taking included privately accessed psychological therapy, as well as self-help books, emotional regulation therapy, mindfulness-based therapy, and alternative treatments, such as reflexology, blu-light box, for example, when prescribed medication and CBT course, but reported taking medication and having private counselling, or when prescribed medication but reported having reflexology instead.

[2] Not significant

[3] Tukey's post-hoc test unless [4]

[4] Tamhane's post-hoc test

9.4 Family and friends

Table 28 shows the Sums of squared distances for 10 cluster solutions for family and friends. These values are plotted on an elbow graph in Figure 14. A point, after which the following point does not provide a significant improvement in the entropy value, represents an arrangement with 5 types of participants, i.e. types of family and friends. Two of these types include one participant each, two contain two participants each, and one types includes 8 members of the family and friend stakeholder group. Due to the small numbers of participants and a relatively large number of types in this stakeholder group, it is not possible to compare all groups' characteristics and importance rankings of the 12 factors.

Table 28: Sums of squared distances for clusters of family and friends

N of clusters	Sum of square distances	Difference between the Sum of squared distances
2	1.61	
3	1.29	0.32
4	1.03	0.26
5	0.70	0.33
6	0.60	0.10
7	0.41	0.18
8	0.32	0.10
9	0.24	0.08
10	0.16	0.09
11	0.08	0.08

Figure 14: An elbow plot of sums of squared distances for different clustering options for family and friends
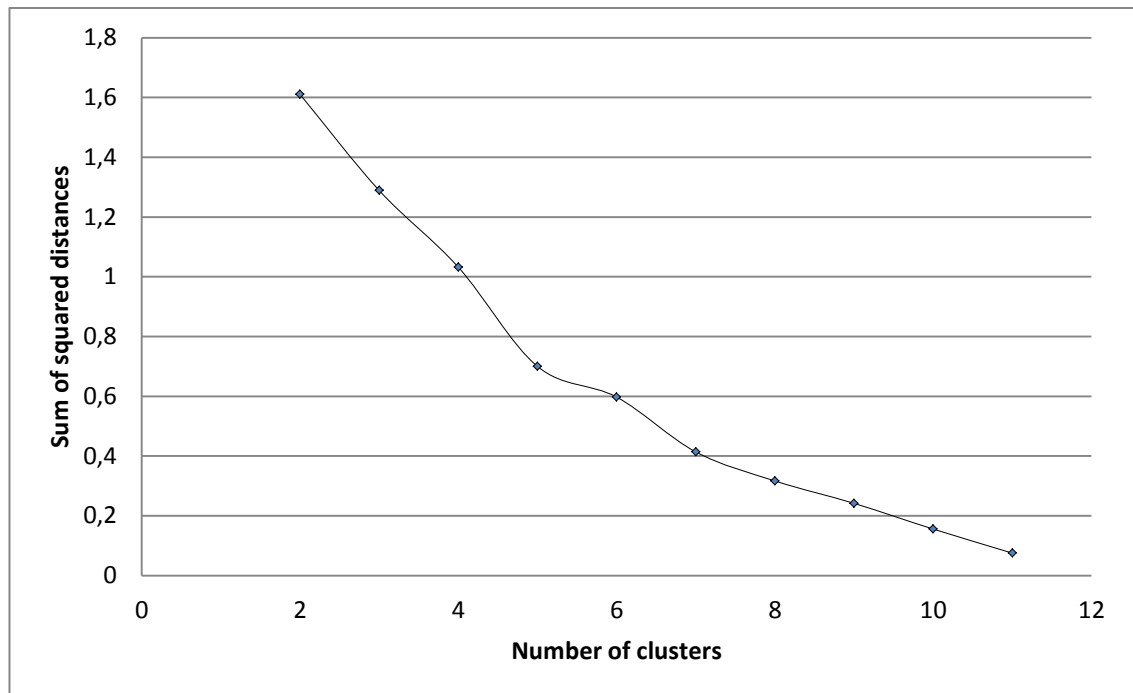
9.4.1 Description of the largest type of family and friends

9.4.1.1 Demographic characteristics

Table 29 shows the demographic characteristics of the largest out of the 5 types of family and friends, which included 8 participants. The mean age of this sub-group was 62.4 years, ranging between 46 and 76 years. Most of these participants were women and all of them reported being of White British or White Irish ethnic group. Half of these participants reported that they had achieved a University Degree or higher level of education, 50% were married and 50% were employed. The table shows that this sub-group of family and friends was similar to the whole group of family and friends in terms of their demographic characteristics.

Table 29: Largest type of family and friends: demographic characteristics

	Type 1 (n=8)	Whole group (n=14)
	N (%) unless *, then mean (SD; min-max)	
Female	5 (63%)	10 (71%)
Age in years*	62.4 (11.4; 46-76)	60 (13; 41-80)
White British or White Irish	8 (100%)	14 (100%)
Highest achieved qualification		
Secondary education	4 (50%)	6 (42%)
University Degree or higher	4 (50%)	7 (50%)
Marital status		
Single	1 (13%)	2 (14%)
Married/co-habiting	4 (50%)	9 (64%)
Widowed	3 (38%)	3 (21%)
Employment status		
Employed	4 (50%)	8 (57%)
Retired	4 (50%)	6 (43%)

9.4.1.2 Perceived importance of the 12 clusters

Table 30 shows the perceived importance rankings of the 12 factors, as assigned by the 8 members of the largest type of family and friends. This sub-group of participants found the experts' advice to be the most important factor, followed by the patients' need to make informed treatment choices, and their depressive symptoms. The least influential were thought to be the factors related to external views about depression, people's social context and their wish to share experiences with depression with other people. The relative importance rankings of the sub-group were similar to those of the whole group, but the individual ranks differed in several factors. For example, the sub-group thought the depressive symptoms were the third most important, whilst the whole group of family and friends put it to a sixth place. Conversely, the sub-group ranked personal insight as the 5th most important factor, whilst the group as a whole thought it was the second most influential factor.

Table 30: Largest type of family and friends: relative importance of the 12 factors

	Type 1 (n=8)		Whole group (n=14)	
	Rank	Mean (SD; 95% CI)	Rank	Mean (SD; 95% CI)
(6) Needing the doctor's opinion	1	4.1 (.7; 3.5-4.7)	1	4.0 (0.8; 3.5-4.4)
(4) Making an informed choice	2	3.7 (.4; 3.4-3.9)	3	3.4 (0.7; 3.1-3.8)
(5) Depressive symptoms	3	3.4 (.2; 3.2-3.6)	6	3.1 (0.6; 2.8-3.4)
(3) Experiences with depression	4	3.3 (.5; 2.9-3.7)	4	3.3 (0.6; 3.0-3.7)
(1) Personal insight	5	3.1 (.6; 2.6-3.6)	2	3.5 (0.8; 3.0-3.9)
(7) Healthcare professionals	6	3.0 (.4; 2.7-3.6)	7	2.9 (0.5; 2.6-3.2)
(2) Emotional states	7	3.0 (.9; 2.3-3.7)	5	3.2 (1.1; 2.6-3.8)
(8) Seeking effortless treatment	8	2.6 (.5; 2.2-3.0)	8	2.6 (0.6; 2.3-3.0)
(12) Depression in health records	9	2.6 (1.5; 1.4-3.9)	10	2.4 (1.5; 1.5-3.2)
(10) External views about depression	10	2.3 (.8; 1.6-3.0)	9	2.6 (1.1; 2.0-3.2)
(11) My social context	11	1.8 (.9; 1.0-2.5)	11	2.3 (1.3; 1.6-3.1)
(9) Sharing experiences of depression with others	12	1.7 (.6; 1.2-2.2)	12	2.1 (0.9; 1.6-2.7)

9.5 Healthcare workers

Table 31 shows Sums of squared distances for 10 clustering solutions of healthcare workers. In Figure 15 the values are plotted on an elbow graph. Based on the differences in these values, the most appropriate number of types of healthcare workers is 8, since the corresponding point on the map is followed by a considerably worse cluster solution (i.e. the value for 9 clusters is larger than that for 8 clusters).

Out of the eight types of healthcare workers, three contain 2 participants, four have three participants each, and one has 4 people. Comparison of professional types with too few participants does not yield meaningful and generalisable results. I therefore decided to abandon further analyses of the 8 types of healthcare workers.

Table 31: Sums of squared distances for clusters of healthcare workers

N of clusters	Sum of square distances	Difference between the Sum of squared distances
2	3.01	
3	2.49	0.52
4	1.97	0.52
5	1.66	0.31
6	1.42	0.25
7	1.19	0.23
8	1.02	0.17
9	1.09	-0.07
10	0.74	0.35
11	0.69	0.05

Figure 15: An elbow plot of sums of squared distances for different clustering options for healthcare workers
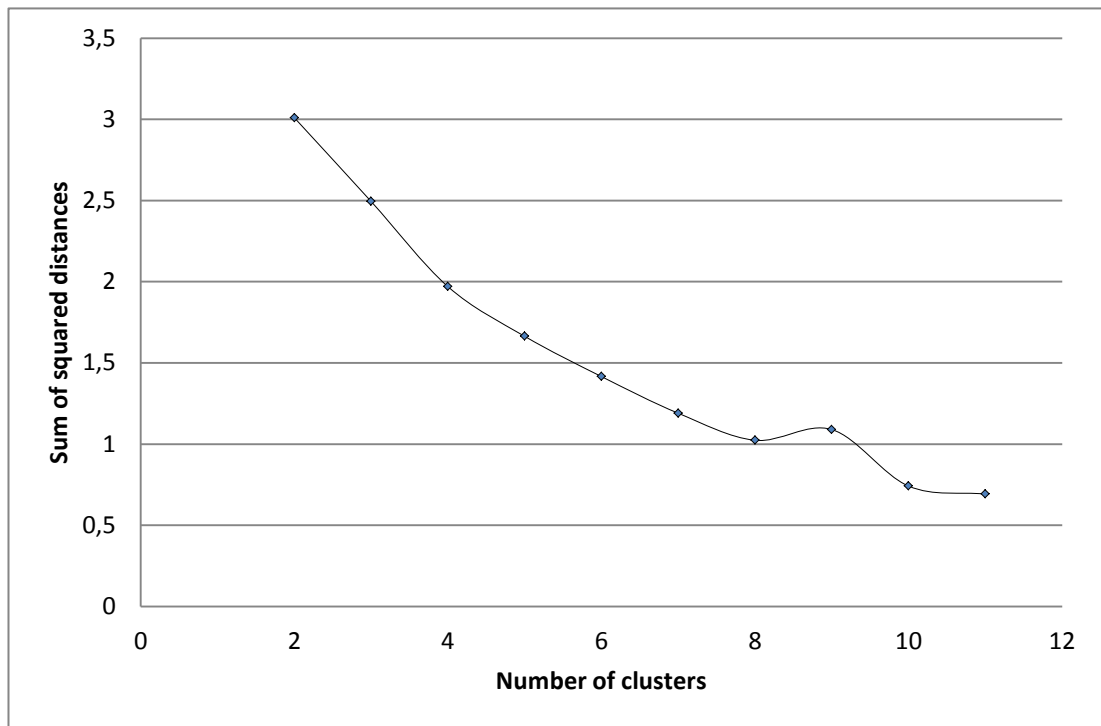
9.6 Conclusion

In this chapter, I presented a typology of stakeholder groups, attempting to explore the possibility of describing patients, family and friends and healthcare workers according to their views about treatment decision-making. The results suggested a potential for typology especially in the group of people with depression but the sample size in all three groups are not sufficient for meaningful conclusions.

Chapter 10 Discussion

10.1 Summary of aims and findings

In this study, I aimed to understand how people with depression make treatment choices. To explore this issue, I conducted a concept mapping study. Firstly, I asked participants to brainstorm about the factors they thought influence depressed patients' decisions. Participants were then asked to rank the relative importance of each factor and to put the factors that seemed to be related together. From this data I generated a final list of 12 factors and calculated their relative importance based on the individual items' rankings. I found that participants across categories thought that decisions made by people with depression are largely influenced by doctors' recommendations, but mostly based on their internal understanding and emotional states. The different stakeholder groups did not agree about the perceived relative importance of stigma, personal insight, emotional states and advice from doctors.

10.2 Views of the entire group

Overall, the most important factors were thought to be insight, emotional states and doctors' advice, whilst the least influential was stigma. This observation is consistent with public and patient surveys demonstrating that peoples' recognition of their mental illness is related to a positive attitude to seeking medical help (Meltzer et al., 2003, Verhaak et al., 2009). The group's views are not consistent with research suggesting that patients consider healthcare professionals and relationships with them among the most important aspects of healthcare for depression (Cooper et al., 2000, Deledda et al., 2013). Moreover, the limited perceived influence of stigma and side effects on patients' choices contradict commonly held views about the role of these factors (Thornicroft, 2006). Participants' emphasis on the role of insight and emotions suggests that they viewed patients as in need of developing a personal interpretation of depression in order to make treatment decisions. On the other hand, the high importance

attributed to doctors' advice appears to contradict their perception about the role of insight. This in turn suggests that participants viewed patients as in need of seeking health professionals' recommendations, as opposed to seeking active engagement in treatment choice. Alternatively, it could suggest that patients are thought to be in an urgent need of physician's direct instructions and recommendations about diagnosis and treatment and that their personal insight is viewed mainly as a first step to help-seeking.

Participants' high rankings of doctors' advice contrast with research showing that patients prefer an active engagement in treatment choices (Patel and Bakken, 2010). In addition, Stacey et al (2008) suggested that fewer than one in ten patients wanted to allow the professional to make the treatment decisions. A wish for active involvement in treatment choices does not automatically imply a lack of appreciation of professionals' recommendations. On the contrary, this advice can be helpful for patients' involvement in shared decision-making. After gaining insight about their own depressive symptoms, patients might wish to receive confirmation that their symptoms are treatable. In addition, due to the emotional burden of depression, patients might also want to hand over the weight of treatment decision-making to the doctor and follow their advice. I suggest that participants across groups viewed patients as trusting the professionals' recommendations, which has been shown as important for people with mental illness (Verhaak et al., 2009).

10.3 Differences between the stakeholder groups

The observed disparity between the views of the three stakeholder groups suggests that patients' decision-making about treatment for depression is not clearly understood by their health professionals and close family and friends. Consequently, people who are emotionally vulnerable might not be adequately supported in the decisions they make to improve their condition. Their different perspectives also retrospectively support our decision to involve all three stakeholder groups in the study. By recognising their misunderstanding, health

professionals might be better able to develop understanding of patients' decision-making needs and facilitate a person-centred approach.

Identification of group differences is consistent with evidence that patients and professionals disagree about various aspects of health care, including adherence in schizophrenia, selection of antidepressant medication and general preferences for treatment of physical illnesses (Kikkert et al., 2006, Gardner et al., 2007). The views about the factors affecting patients' treatment choices in depression have not yet been studied from the perspectives of patients, professionals and close family and friends, although the latter is often considered as an important part of patients' support system. My findings therefore provide a novel characterisation of decisions about treatment for depression.

10.3.1 Stigma

External views about depression were considered to be the most important factor by healthcare workers, but not by the other groups. Together with patients' social context, external views were ranked as significantly more influential by the healthcare workers than by people with depression. I categorised these factors as stigma because some of the main concepts they contain correspond with the dimensions described in stigma.

Stigma has been described as negative attitudes, emotions or behaviours towards people who belong to a certain subgroup, for example, having a specific illness or displaying certain behaviour, based on that characteristic (Link and Phelan, 2001). Corrigan and Watson (2002) described two main ways in which stigma affects people. The commonly recognised concept is public stigma, i.e. attitudes and behaviours of other people. Internalised negative attitudes by the stigmatised person were referred to as self-stigma, or personal stigma, and the two types influence people in different ways (Corrigan et al., 2005).

The four factors that were conceptually related to stigma referred to its effect on the public level, including the views about depression held in society and beliefs of family and friends about depression among others. Participants did not explore the concept of personal stigma, although some of the self-stigmatising attitudes and beliefs resemble the factor insight. For example, thinking that no-one can help and that people should be able to deal with the problems alone (Coppens et al., 2013), relates to the more positively-charged attitudes such as recognition of the need for help and readiness to accept treatment, that is to say insight. Participants in this study, however, viewed insight and stigma as conceptually unrelated factors, which were positioned in different parts of the concept map.

10.3.1.1 Stigma: external views about depression

Healthcare workers' views about the importance of stigma in patients' treatment choices reflect commonly held perceptions about the strong impact of stigma on patients' help-seeking and other decisions (Jorm and Reavley, 2013, Thornicroft, 2006). Stigma towards and discrimination of people with mental illnesses is very common in society across different countries (Lasalvia et al., 2013) and negatively impacts on people's self-esteem (Link and Phelan, 2001). There is, nevertheless, mixed evidence of the effect of perceived or anticipated public stigma on people's treatment decisions.

Professionals' views are consistent with reports that readiness to seek treatment is negatively influenced by anticipated discrimination, although it was as important as patients' attitudes and knowledge (Schomerus and Angermeyer, 2008). The effect of perceived stigma was shown to be mainly as a consequence of increasing patients' personal stigma, which in turn impacted upon help-seeking (Vogel et al., 2007). One study also suggested that stigma negatively influenced adherence (Sirey et al., 2001), which supports professionals' views but contradicts those of patients. Personal stigma has been found to predict patients' preference for dealing with depression alone (Griffiths et al., 2011) and to perceptions that professional treatment was unhelpful (Coppens et al., 2013). This does not correspond with the

views of healthcare workers observed in this study, which underscore the role of external views, i.e. perceived stigma.

There isconflicting evidence about the impact of stigma. Health professionals' views suggest that any stigma is highly influential, but their opinion is not consistent with the findings of previous studies. For example, Roeloffs et al. (2003) showed that perceiving stigma among close family had a negative impact on help-seeking and adherence, but patients' anticipated stigma had little effect on the behaviour. Anticipated stigma and discrimination were also found to have limited effect on patients' help-seeking intentions (Schomerus et al., 2009b). These studies, on the other hand, support the views of people with depression in this study. Patients' low ranking of stigma is also consistent with the findings of a systematic review suggesting that treatment barriers related to stigma and embarrassment were less important than practical barriers (Prins et al., 2008). My observation suggests that people with depression do not consider the views and beliefs held by people in their social environment to be very influential of the treatment decisions they make.

10.3.1.2 Stigma: Social context

The views of professionals and patients also differed regarding the role of social context. Whilst both groups thought it was one of the least important factors, professionals ranked it significantly higher than patients ranked it. This observation is difficult to compare with previous research, since participants' perspectives about their views about the role of their age, gender or culture have seldom been explored. Instead, researchers have used socio-demographic factors to detect differences between particular subgroups of the population. For example, gender and age appear to be related to different treatment preferences (Winter and Barber, 2013) and members of ethnic and cultural minorities are less likely to seek medical help (Prins et al., 2008). In addition, studies show that attitudes towards help-seeking for mental illnesses are related to gender, age and level of education (Coppens et al., 2013, Griffiths et al., 2011). Some characteristics, for example, younger age, were also found to predict adherence to treatment for mood disorders (Pompili et al., 2013). My findings regarding professionals' views about

social context are therefore consistent with previous research about the effects of personal characteristics. Whilst all groups attributed relatively little importance to social context, healthcare workers appeared to think that some of patients' decisions are due to this factor. Based on their exposure to patients from various backgrounds, I suggest that professionals might have greater awareness of the effects of different individual characteristics than patients or close family. Alternatively, their views might be an additional sign of healthcare workers' over-emphasis on the impact of stigma and external views.

10.3.1.3 Stigma: overall

Patients' lower ranking of stigma despite evidence that it is common suggests that it might not affect people's treatment choices directly and that other factors are more influential than stigma. Consequently, strategies intended to support involvement in decision-making by addressing stigma might not be effective. Currently, there is limited evidence about the impact of such interventions on patients' attitudes or help-seeking behaviour (Gulliver et al., 2012).

Understanding patients is an important part of professionals' practice and is seen as underpinning professional practice (Joseph-Williams et al., 2013, Gray, 2014). Whilst healthcare workers often think that they understand patients, my findings challenge this view. By overestimating the importance of stigma professionals demonstrate reliance on assumptions about patients' decision-making, rather than on their clinical observations. This supports previous research about professionals' willingness to involve patients in shared decision-making as a result of a belief that many would not appreciate being actively engaged in their treatment choices (Legare et al., 2008). Based on my observation, I suggest that health professionals and researchers should regard patients as individuals, rather than focus on stigma which is currently viewed as a priority (Jorm and Reavley, 2013, Thornicroft, 2006). Instead, I suggest that professionals should develop a better understanding of the patients' views and explore what stigma means to individual patients.

10.3.2 Insight

People with depression considered their personal insight about experiencing symptoms to be the most important factor affecting their treatment decisions. Although healthcare workers and family and friends ranked the factor as the third and second most important respectively, there were significant differences between the views of patients and the other two groups. To my knowledge, the role of insight in patients' treatment decisions has not been explored from the perspectives of patients, family and friends and healthcare workers before. Insight has mostly been studied in relation to severe mental illness and there has been limited focus on the impact of insight on treatment choices made by people with depression.

Insight is a complex concept that describes the patients' ability to reflect on their own experiences and to recognise some of these as symptoms of an illness. It has been described as a continuous construct consisting of several overlapping dimensions: awareness of having a mental illness, ability to recognise own symptoms, and recognition of a need for treatment (David, 1990). Two more aspects, awareness of social consequences of the illness and attribution of symptoms to the illness were added to the concept (Amador and David, 1998).

I describe insight into depression based on ideas extracted from what participants said influences patients' treatment decisions. The factor that was labelled as insight is consistent with the main dimensions of a person's awareness of symptoms and a need for treatment, as described originally (David, 1990). In addition to these, the concept of insight used in this study also includes an ability to be pro-active in the treatment and a wish to understand the root of depression. Contrary to our observation, these aspects have not been considered as part of patients' insight into illness, although research shows that people often try to explain their illness and have theories about what caused their depression (Fu and Parahoo, 2009, Hansson et al., 2010) and that these beliefs might influence treatment decisions and help-seeking behaviour (Prins et al., 2008). My findings suggest that awareness of the

causes of low mood or depressive episodes might be an important aspect of patients' insight into their mental illness.

Lack of insight has typically been investigated in relation to schizophrenia-spectrum and bipolar disorders and has been shown to affect between 50 and 80% of patients (Crumlish et al., 2005, Varga et al., 2006). Improved insight into these disorders has been associated with better adherence and treatment outcomes (Kampman et al., 2002, Depp et al., 2014), but also with an increase in depressive symptoms (Crumlish et al., 2005). Approximately 40% of people with unipolar depression have been shown to have impaired insight (Yen et al., 2005).

Overall, there is a paucity of literature about the role of insight on the treatment decisions made by people with depression. Research shows that patients and professionals differ in how they perceive the severity of patients' symptoms (Enns et al., 2000, Rane et al., 2010), although the effects on decision-making are unclear. Other authors have suggested that depressed people commonly experience avoidance and somatisation of symptoms, failure to determine a need for help and defensiveness (Farmer et al., 2012, Goldman et al., 1999, Meltzer et al., 2003). Failure to recognise the symptoms as sign of a depressive illness has been associated with delayed help-seeking (Farmer et al., 2012, Thompson et al., 2008). This evidence supports my findings that patients' insight may strongly impact on their treatment choices.

My observation disagrees with research suggesting that lack of insight is not an important issue for people with non-psychotic depression (Dell'Osso et al., 2002, Peralta and Cuesta, 1998). In addition, Lee et al (2010) found that insight did not predict adherence, although people with more severe depression had greater insight. This evidence indicates that the role of insight has not yet been fully understood and that its influence might be different in people with depression compared to schizophrenia. The differences in effect might be explained by variations in understanding of the concept between different illnesses. Whilst in

psychotic disorders lack of insight is viewed as a cognitive syndrome and symptom of the illness (Chakraborty and Basu, 2010), in affective disorders insight appears to be more related to psychological denial or avoidance of an unpleasant situation, i.e. illness. This interpretation is consistent with evidence that patients with depression feel a need for help with knowing, naming and explaining their symptoms (Epstein et al., 2010).

Depressed people's focus on the role of insight suggests that in order to engage in treatment decision-making, they first expect to be aware of the problem and feel ready to engage actively with their treatment. This finding supports the results of several surveys of the opinions of the public and people with mental illness, which all concluded that people's recognition of their mental illness is crucial for having a positive attitude towards seeking medical help (Lauber et al., 2005, Meltzer et al., 2003, Verhaak et al., 2009).

Some authors recommend that psycho-education and improving public's mental health literacy is required in order to address the general lack of recognition of mental problems (Riedel-Heller et al., 2005). My findings, on the other hand, demonstrate that patients' insight into their depression and need for help are conceptually a separate factor from their knowledge about depression and treatment options. Having information was viewed as part of 'making informed decisions' and was considered only moderately important. This suggests that rather than general information, participants valued patients' ability to recognise and accept their depressive symptoms and a need for treatment. The patients' views are consistent with reports that in addition to receiving a diagnosis, people felt a need to link their own experiences with what their doctor described as depression (Wittink et al., 2008). I suggest that patients' personal insight into depression is recognised as a central part of treatment decision-making. Helping patients to improve insight might therefore be empowering, and might facilitate their engagement in better informed treatment choices.

In contrast, depressed people's views were not shared with the other two stakeholder groups, who appear to under-estimate the role of insight in affecting patients' treatment choices. Whilst patients' and professionals' perceptions about insight in depression have not been directly compared, my observation is consistent with evidence that the two groups disagree about various aspects of health care (Kikkert et al., 2006, Lester et al., 2005). Alternatively, professionals might be aware of patients' need for insight, but not necessarily believe it is important, especially if it directly challenges their own understanding of patients' decision and treatment needs. Over-reliance on their training might then prevent them from having an empathetic understanding of people with depression. This is consistent with evidence that, despite training and improved skills in facilitating shared decision-making, physicians still subjectively decide which patients might be suitable for the approach (Elwyn et al., 2012, Edwards et al., 2005). Consequently, training clinicians to understand their patients and facilitate gaining insight might not be effective.

An alternative strategy to help patients develop recognition and insight is contact with peer support workers, i.e. people with experience with mental illness who do not have extensive professional training and could be more able to empathise with patients and understand their perspectives (Lloyd-Evans et al., 2014). Peer support workers can help reduce hospital admissions and engagement with the service (Repper and Carter, 2011) and positively impact on patients' sense of hope, control, ability to make changes and self-awareness (Proudfoot et al., 2012, Jones et al., 2013). Peer support workers might help people with depression improve insight to facilitate engagement in making informed treatment decisions.

My observation suggests that the person and the internal resources are more important than external views when dealing with depression. I propose that professionals should not focus on stigma, but address people's subjective views and understanding about their depression. My findings show that it is imperative that they should view patients as equal partners in the decision-making process, and take their views seriously, rather than wanting to change them.

10.3.3 Emotions and depressive symptoms

Unlike insight, patients' emotional states have rarely been studied in relation to their treatment decision-making. Cognitive research, on the other hand, shows that emotional states play a considerable role in judgement and decision-making (Blanchette and Richards, 2010). Whilst often viewed as a source of irrational decisions, emotions can positively influence decision-making due to their increase in reliance on heuristics and cognitive shortcuts in reaching judgements (Reyna, 2008). My observation supports this evidence, although the extent of the data does not allow the determination of the effect of specific emotions on decision-making. Differences I found between the stakeholder groups regarding the perceived importance of emotions suggest that patients might be relying on how they feel in a given situation to inform their healthcare choices, but professionals undermine the impact of emotions.

10.3.3.1 Depressive symptoms

Relative positions of emotions and depressive symptoms on the concept map suggest that the factors are distinct yet closely related. This is consistent with the definition of depression and its effect on mood (WHO, 2010, APA, 2013). By emphasising the role of emotions whilst ranking depressive symptoms as only moderately important, participants highlighted the effect of patients' current mood over generally negative thinking styles associated with depression. I suggest that these concepts might have separate effects on patients' treatment decisions.

The groups' perceptions about the role of patients' depressive symptoms support previous research suggesting that the nature and severity of mental illness affect patients' selection of professional (Mojtabai et al., 2002). My results are also in line with the suggestion that people with depression perceive more barriers to psychotherapy than healthy people (Mohr et al., 2006). Severity of symptoms has also been related to a perceived need for treatment (Beljouw et al., 2010, Farmer et al., 2012) and more perceived barriers to visiting a doctor (Bell et al., 2011).

10.3.3.2 Emotions

Emotions have been described in terms of valence (type of emotions ranging from positive to negative) and arousal, i.e. intensity (Winkielman et al., 2007). Research shows that emotions influence people's decisions and judgement and that the effects differ between emotions with the same valence. For example, sad mood but not anxiety has been linked to high-risk/high-reward behaviour (Raghunathan and Pham, 1999). Sad mood can also increase the systematic information processing and a more elaborate evaluation of the situation than positive mood (Blanchette and Richards, 2010). Patients' views about the role of emotions are in line with the evidence that affective states impact on judgement and decision-making. My findings are consistent with the evidence that people with depression rely on emotional processing more than healthy people (Harle et al., 2010). This suggests that patients' mood might have a stronger effect on their treatment decisions than previously thought.

The results of this study are not consistent with previous research about patients' self-reported decision-making needs in which patients did not mention addressing their emotional states (Stacey et al., 2008, Cooper-Patrick et al., 1997b). Emotions might therefore be a factor that is identified only in response to certain research questions, since it is not easy to address and might not be an issue patients typically consider in relation to treatment choices. This reflects evidence that the influence of emotions is considered to be subconscious and that people are either generally unaware of how they make decisions, or they might rationalise past decisions to justify their behaviour (Andrade and Ariely, 2009).

Unlike patients, healthcare workers viewed emotions as only moderately important, suggesting that they view patients' decisions as more rational. It is surprising that mental health professionals did not consider emotions to have a strong impact on decisions made by people with mood disorders. This observation suggests that professionals might not realise that patients' emotional states are a fundamental part of their internal states (Paulus and Yu, 2012) and that emotions are tightly linked to their judgements and reasoning about behaviour (Blanchette and

Richards, 2010). As a consequence, they might undermine patients' emotions and fail to effectively meet their decision-making needs.

On the other hand, by ranking the factor as the fourth most important, professionals demonstrated some awareness about the relevance of patients' emotions on treatment decisions. My observation might suggest that professionals do not feel able to influence patients' emotions during consultations, and therefore fail to resolve this problem. Ignoring a factor that patients consider to be highly important might, however, have negative impact on the professional-patient communication and relationship.

10.3.3.3 Emotions as information

Participants' views support the theory of mood acting as information for decision-making (Schwartz, 1990, Schwartz, 2012), proposing that experienced emotions might be an indicator of the situation and possible problems. As a result, sad mood might cause people to process information in a more detail-oriented manner and with reduced creativity and playfulness (Schwartz, 2012). The mechanism in people with depression might be more complex than in healthy people, since their performance in cognitive tasks involving judgements has been found to be different (Cella et al., 2010, van Randenborgh et al., 2010). I wonder if the different emotions in people with depression might cause them to use different decision-making mechanisms in relation to their treatment. Consequently, in addition to understanding of their problem, patients' emotional states might also directly influence their treatment choices.

My findings suggest that emotions play a significant role in patients' decision-making about treatment for depression. Patients' awareness of the importance of their emotions, highlights the need for professionals to acknowledge and explore the issue in practice. I suggest that paying more attention to patients' emotional states might be empowering for depressed people. Addressing patients' emotions

directly during consultations could therefore help them engage in making more considered treatment choices.

10.3.4 Doctors' advice and healthcare professionals

Doctors' advice is another factor that was perceived differently by the stakeholder groups. Patients considered it as only moderately influential, but family and friends and healthcare workers ranked it among the two most important factors. Difference in views was significant between patients and family and friends. 'Doctors' advice' was viewed as conceptually distinct from the factor 'healthcare professionals' relating to doctor-patient relationship and communication, among other aspects and was considered as moderately important by all groups. There is a dearth of literature about the perceived influence of healthcare professionals on patients' decisions in relation to other factors affecting their choices. This study provides novel evidence about the influence of doctors' advice on patients' treatment choices as perceived by the three groups.

Participants' moderate ranking of health professionals as care providers is consistent with the findings of a large European survey suggesting that a third of the public does not think that mental health professionals would be helpful for serious mental conditions (ten Have et al., 2010). My findings contrast with previous evidence that the therapeutic relationship is an important predictor of adherence (Pompili et al., 2013) and that helping alliance and relationship with clinicians are the most important aspects of psychiatric care (Johansson and Eklund, 2003). My findings suggest that, within the context of all factors affecting patients' choices, professionals' personal characteristics and relationships with patients might not play as important a role as previously thought. Alternatively, professionals might have a strong influence on patients' treatment choices depending on the patients' perception of their relationship. For example, negative experiences and lack of trust in physicians might discourage patients from contacting them, and instead motivate them to seek other means of help.

10.3.4.1 Views of people with depression

Patients' views suggest that they do not strongly rely on expert advice. My findings are consistent with the results of a recent systematic review (Deledda et al., 2013), which showed that, although patients want to openly discuss the illness and treatment with physicians, they do not generally expect to be given a prescription or direct advice (Little et al., 2001). Other studies have also shown that the most common barrier to help-seeking was a fear of having unwanted medication prescribed (Bell et al., 2011). I suggest that patients' views might be a reflection of their previous dissatisfaction or disappointment with professionals, possibly resulting from being given less than helpful advice in the past. This interpretation corresponds with evidence that professionals sometimes do not meet patients' decision-making needs (Kravitz et al., 2011). Alternatively, people with depression might not want to defer the treatment decisions to physicians. Instead, they might view professionals as a reference or a supporting factor in the process of making decisions.

10.3.4.2 Views of healthcare workers and family and friends

The two groups prioritised the role of expert advice over patients' engagement in informed choices and this view is further supported by their lower rankings of factors related to patients' informed choice, understanding and the doctor-patient relationship. Their perspectives correspond to a common view that the doctor knows best and their advice is most important for patients. Professionals have been found to consider their opinions as dominant to the patients' (Elwyn et al., 2012), be reticent to involve patients in treatment choices (Young et al., 2008) and to overestimate patients' expectation to receive advice (Lado et al., 2008). This corresponds with evidence that the NHS maintains the paternalistic approach (Doherty and Doherty, 2005), despite patients' preferences and clinical guidelines that recommend patients' active involvement (Annunziato et al., 2009). The two groups' views might therefore be reflecting their knowledge about the opportunities patients really have to actively engage in the treatment decision-making process during consultations with their doctors. Alternatively, the two groups might be overrating the need for giving advice and instructions and might

think that paternalistic approach is preferable. Such view disagrees with the evidence that patients' active engagement in decisions helps improve adherence and treatment outcomes (Hack et al., 2006, Loh et al., 2007a).

Family and friends' emphasis on the role of doctors' advice might suggest that they care about the patient, and that they wish to ensure that they are receiving the needed treatment. Due to being in a close relationship with the patient, they might be negatively affected by the depressive and decision-making problems the person faces, and even struggle to recognise their signs and symptoms (Highet et al., 2005). Family and friends' focus on advice and diagnosis might therefore reflect their own wish for the person to receive recommendations from their doctor. Alternatively, this finding might also suggest that family and friends, like professionals, endorse a more directive approach to patients.

Disagreement and conflict between a patient and their close family can put strain on interpersonal relationships and act as a source of additional stress for patients, possibly negatively impacting on their wellbeing. Feelings of being criticised and blamed by family members have been shown to worsen symptoms and treatment outcomes in people with bipolar disorder (Barrowclough and Hooley, 2003, Scott et al., 2012) and adherence in depression (Pompili et al., 2013). Interpersonal conflicts have not yet been demonstrated to directly influence treatment decisions made by people with depression, but the effect might be similar to that in serious mental illness and have detrimental effects on their symptoms and wellbeing.

Based on all these findings, I suggest that mental health professionals should adopt an approach that helps patients address or deal with the interpersonal problems with their family and friends. Rather than automatically assuming that all patients struggle with interpersonal conflicts, professionals should be vigilant to patients' personal views and needs in relation to decision-making support.

How professionals perceive the views and needs of their patients can have a large impact on their consultation style (Legare et al., 2008) and treatment recommendations. For example, Cockburn and Pit (1997) found that professionals' understanding of what patients expect from them influenced medication prescription more than patients' actual preferences or expectations. Our observation about professionals overestimating the influence of doctors' advice on patients' treatment choices is therefore very important. Since providing information and advice is what professionals tend to do most of the time (Loh et al., 2006), thinking that patients want and need advice might be natural for professionals and further encourage such approach. This is in contrast with evidence, which shows that more than receive advice, patients want to be understood and treated as equal. For example, Schout et al (2010) found that people who previously avoided care mostly appreciated professionals' qualities such as compassion, loyalty, patience and diplomacy, i.e. empathy (Schout et al., 2010).

Health professionals often talk about patient-centred care and shared decision-making, but thinking that the second most influential factor for patients' choices is receiving an advice does not correspond with principles of these approaches. I suggest that professionals should be more attentive to the patients' individual expectations from the consultations, and to their personal decision-making needs. Rather than assuming that giving patients an advice has the most impact on their decisions, they should initiate and engage in more discussions about patients' individual perspectives and expectations of the consultation.

10.4 Other factors

Stakeholder groups did not differ significantly in their views about the role of past experiences, wanting to make informed choices and a wish for effortless treatment, but they considered these factors as moderately important. The groups' views are consistent with research about the impact of past experiences on help-seeking and adherence (Pompili et al., 2013), and the evidence that involvement in treatment choices can improve adherence (Loh et al., 2007a). Barriers to treatment were thought to be less influential than most other factors, contradicting the findings of a

systematic review about the factors related to a perceived need for care (Prins et al., 2008). This suggests that participants might have emphasised the importance of the enabling, rather than inhibiting factors.

The fact that these factors were located adjacent to each other on the concept map suggests that they were perceived as closely interrelated and affecting each other. This might suggest, for example, that based on experiences with depressive symptoms people are better able to recognise their need for help and adjust their approach to treatment decision-making and perceived barriers. This interpretation is consistent with the evidence that experiences influence treatment preferences, although it is unclear whether people are more likely to prefer treatment they had taken before (Churchill et al., 2000) or a different option (Dwight-Johnson et al., 2000). My observation about the factors' relationships suggests that helping people recognise and address one of the aspects might facilitate their awareness about the others, and eventually support better informed treatment choices.

10.5 Types of people with depression

Another interesting finding in this study is identification of five different types of people with depression. The individual subgroups mostly differed in their perspectives about the importance of healthcare professionals, depression symptoms and stigma. This finding suggests that the same factors might influence different patients in different ways and emphasises the importance of professionals' individual approach to patients.

Only one identified previous study classified patients into groups based on their views about depression treatment decisions. Thacher et al (2005) used a latent-class analysis to identify subgroups of people with depression using a sample of 104 participants. The authors found that a three-group model best explained their data, and that the three subgroups of people with depression vary in their sensitivity to side effects, the cost of treatment and to treatment effectiveness, mostly based on their age and gender. Unlike Thacher et al (2005), I found no relationships between

patients' views and their socio-demographic factors. My observation also contrasts with research suggesting that gender, age and ethnicity influence patients' preferences for treatment and level of engagement in decisions (Say et al., 2006).

The findings of this study indicate that patients might vary in what decision factors they value the most when making treatment choices. The observation supports the findings of a scoping review of literature that emphasised the differences between patients in how they make decisions and that they should not be considered as a homogenous group making decisions in the same ways (Victoor et al., 2012). Health professionals should therefore consider the benefit of recognising patients' individual needs and preferences, in order to tailor their approach accordingly. However, the sample sizes of all stakeholder groups in this study were insufficient and further research is required to determine any typology of depressed people, family and friends or healthcare workers.

10.6 Strengths and limitations of the study

This study has important strengths and limitation that influence the interpretation and generalisability of the findings.

10.6.1 Concept mapping method

The use of concept mapping is a significant strength of this study. This method ensured data were collected and analysed in a highly structured way, whilst enabling the detailed exploration for a wide range of relevant concepts. Consequently, each of the ideas generated during the brainstorming phase could be evaluated and included in the analysis. In addition, the two-stage data collection and analysis allowed participants to focus fully on one task at a time and generate detailed information about the relative importance of factors and the perceived relationships between them.

10.6.1.1 Brainstorming sessions

Use of brainstorming sessions as a means of generating statements about factors affecting patients' treatment decisions had its strengths as well as limitations. An important strength of the data collection method was the flexibility offered to participants. Group brainstorming sessions were preferred mainly due to providing an opportunity for participants to interact with others and explore the details of treatment decision-making they might not have realised during individual discussions. Participants were also able to take part individually. Whilst this flexible approach caused more time-consuming data collection and more repetition in factors generated, it also allowed the inclusion of the people who did not feel comfortable to talk within a group setting. The quality of the sessions and the ideas generated was enhanced by involving a number of experienced facilitators.

The first limitation relating to the use of brainstorming sessions involves participants' potential recall bias due to relying on people's retrospective self-reports of factors they viewed as affecting their treatment decision-making, for example, inaccuracies in remembering how the decisions had been made, omitting of factors or providing more elaborate justifications for decisions. Consequently, the factors reported in this study might not be exhaustive and they are limited to concepts relevant to the focus question used in the study. Since the primary aim of this study was to understand the perceptions of the three stakeholder groups about patients' treatment decision-making, use of retrospective self-report was considered as an appropriate method for eliciting the participants' views.

10.6.1.2 Participatory approach

In combination with the participatory approach I adopted in the study, concept mapping proved to be an effective and useful tool in identifying a large number of factors and subsequently synthesising them to a relatively concise but an inclusive list of concepts. The study, therefore demonstrates that concept mapping can be used effectively to understand and relate perspectives of different groups about patients' decision-making.

The extent to which a study is participatory can vary. Whilst this study involved seeking stakeholders' advice and opinions about a number of study aspects, other research has shown that participants can be involved to a greater extent, for example to act as interviewers (Dodd et al., 2014) or take the lead in data analysis (van Bon-Martens et al., 2012). In the present project, I did not involve participants extensively due to time constraints and practical complications. In addition, the number of final clusters was decided based on complex data analysis and participants' involvement in this stage was not thought to be sufficiently productive in the process.

10.6.1.3 Data analysis: number of dimensions and clustering method

The specific data analysis used as part of the concept mapping method is another important strength of this study. The combination of multidimensional scaling techniques (for example, Principal Component Analysis) and a cluster analysis allowed me to analyse data from a unique perspective, using the perceived relationships between statements to identify underlying concepts. In addition, this is the first concept mapping study using data from five instead of two dimensions produced in the Principal Component Analysis. This allowed to utilise 76% of the variance rather than the 50% that is typically used in other concept mapping studies (Kikkert et al., 2006, Rosas and Kane, 2012). The present study is also the first to apply the K-means clustering, as opposed to one of the hierarchical methods, such as Ward's or Centroid methods. It has been argued that two dimensions sufficiently reflect the main relationships within the dataset, and that hierarchical clustering methods group the items together according to their relative closeness, i.e. similarity (Trochim, 1989). The findings of this study, on the other hand, suggest that the five dimensions can reflect sensitively even more subtle relationships between statements. Consequently, in order to identify the final set of clusters, I maximised the use of information about the data available. I suggest that this resulted in the generation of coherent final clusters that represented the original dataset more accurately than if the typical concept mapping analyses had been used.

Since the way the data were analysed largely depended on the number of dimensions, the clustering method and the number of clusters in the final set, the data could potentially have been interpreted differently. For example, another type of the clustering analysis could have been used, for example a hierarchical method instead of the K-means. Despite this, I suggest that the clusters strongly resemble the factors described in previous research, which supports their validity.

10.6.2 Study focus question

The focus questions used in the brainstorming stage in this study prompted participants to think about any type of treatment decisions for depression they had most recently been involved in. This study is the first to explore people's treatment decision-making while not focusing on a pre-defined type of decisions, such as help-seeking or adherence. An advantage of this approach is allowing participants to think about the most recent and relevant treatment decision they had been involved in. The decision is therefore most likely to be well-remembered and influenced by current factors.

A limitation of exploring all types of decisions altogether is a potential lack of focus and detail about any of them. Consequently, participants' responses might not be generalisable to other people's treatment decisions, since different patients might have discussed different types of choices. This limitation results in a need for further research to determine whether the different types of decisions can be studied together as one topic.

10.6.3 Multiple comparisons

Performing multiple comparisons as opposed to testing specific hypotheses is an important limitation of this study that increased the risk of Type one error (i.e. reporting a false-positive difference). This was necessary in order to explore the

differences between the views of three stakeholder groups. Since the final set of factors, the importance which participants would rank had not been known when the study was being planned, explicit hypotheses about group differences could not have been articulated before data collection was completed. In order to compare and contrast the groups' views about the factors I performed a total of 36 individual comparisons (12 factors times 3 groups). At a criterion alpha of $p<0.05$, two of the comparisons could have been found significant by chance alone. To address the elevated risk of Type one error, I first determined the significance of an F-test (ANOVA) for rankings of each cluster, and then computed Tukey's HSD (Honestly Significant Difference) post-hoc test to identify the particular group differences. This is a standard procedure for reducing the risk of error, and Tukey's post-hoc test is one of the most commonly used tests (Pallant, 2001).

The risk of bias due to multiple comparisons was also elevated when comparing the stakeholder groups' importance rankings attributed to the individual statements, and when comparing cluster rankings of the group subtypes, that is to say patient types. The risk was addressed by using the same method of an F-test, followed by a Tukey's post-hoc test. The results should, however, be interpreted with caution. Identifying a relatively few significant differences (n=12) between the groups' rankings of the individual statements might suggest that some or all of them were due to chance rather than a real difference in opinions. At $p<0.05$, the expected number of differences 'significant' by chance is 5% of 177 (i.e. 59 statements times 3 stakeholder groups), which equals 9. Since all reported differences between the groups were confirmed by an F-test and an appropriate post-hoc test, the risk of the Type one error was minimised.

The interpretation of the different views of five types of people with depression also carries risk of bias. The risk of Type one error was elevated, but addressed as described above. In addition, comparing five groups of unequal size carried an increased risk of Type two error due to violating one of the assumptions of ANOVA. Consequently, with larger and more equal groups, the non-significant differences could eventually be found significant.

The sizes of stakeholder groups limited the opportunity for performing effective subtype analyses. As a result, the identification of the five types of people with depression should be viewed as an indicator of potential differences among patients with the same illness, rather than as a confident description of patient types. The identification of the distinct types of patients highlights the need to consider them as individuals with various decision-making needs and preferences. To determine the predictive validity of the patient types a larger and more representative sample of people with depression would be required.

10.6.4 Number of participants

Considering the method used in the study, I recruited a good number of participants. A total of 98 people took part in the process of generating statements about how people with depression make treatment choices, and 64 took part in the ranking and clustering of the statements to final clusters. The numbers are similar to a study conducted in seven countries (Kikkert et al., 2006) and to other studies using concept mapping where average numbers of participants vary between 62 and 122 (Rosas and Kane, 2012). The authors also reported that number of participants is generally lower in the second stage of data collection, i.e. prioritising and clustering tasks and recommend having at least 20-30 participants. In my study, a total of 64 participants completed the second stage of data collection, which contributes to better quality of the study (Rosas and Kane, 2012), although I was unable to calculate the reliability of the analyses due to the type of concept mapping software chosen. Involving a relatively large number of participants allowed me to compare the stakeholder groups' views about the importance of the clusters and test for statistically significant differences between groups.

Whilst the overall number of participants was sufficient and added power and quality to the study considering the methodology used, it might enhance the generalisability of findings to involve more family and friends in future work. The number of family and friends taking part was less than optimal, which was the case

especially when comparing importance rankings of the three stakeholder groups. In several instances the groups' variances were unequal and a non-parametric alternative to Friedman's ANOVA was used. This addressed the possibility of bias in the comparisons, but involving a larger sample of family and friends would have been preferable. In addition, the number of family and friends recruited was considerably smaller compared to numbers in other stakeholder groups, limiting the validity of comparisons with the other groups, and elevated risk of Type two error. Their number also suggests specific problems with recruitment. One reason could be limited access to this stakeholder group via contact with people with depression, who often reported lack of close family and friends able to discuss their treatment decision-making. Inviting family and friends via published adverts was therefore the main recruitment strategy for this group and which was also limited by difficulties with the efficient wording of the adverts.

Recruitment of family and friends or carers has also been reported as problematic in other studies. Some authors, for example, suggested that this group of people might not want to engage in extensive discussions about the illness that caused them distress and difficulties, such as dementia (McCabe and Adams, 2013). Consequently, it is possible that only a few family and friends expressed an interest in taking part in the study as a result of their low motivation to spend time and effort discussing an illness that had already negatively affected their daily lives.

10.6.5 Selection bias

The selection bias might also have resulted from the dearth of the depressed people who had not sought help for depression or those who perceive their opinions as undesirable. Those people might have perceived additional barriers to taking part, despite my attempt to make the research appealing to all people with depression. Research shows that up to half of people with depression do not seek help for the condition and only half of them receive treatment (Kessler et al., 2003), whilst all but one person with depression in this study reported having sought help from a mental health professional or worker. This suggests that people who avoid

help-seeking and disclosing of depression were under-represented in the study and that the findings might not be generalisable to such groups of people.

The demographic characteristics of the sample also suggest that women, older people and those with higher educational achievement were over-represented in the study compared to the general population, both of Norfolk and of England as a whole (ONS, 2012). An important limitation of this study is also a limited number of participants from ethnic minorities, whose views could not be explored. Although people from other than White ethnic group were under-represented, the percentage of White British or Irish participants in the study was similar to that of the general population of Norfolk (ONS, 2012). The groups of people that were under-represented in this study are frequently found as most difficult to recruit (Patel et al., 2003), emphasising a need for their better involvement in research about depression treatment decisions.

The lack of objective information about the participants' depressive illness, such as diagnosis and severity, is another limitation of the study. These factors have been found to influence patients' treatment decisions (Bebbington et al., 2000, Farmer et al., 2012) although it is unclear whether the process of making treatment decisions is also different among people with various severity and duration of the depression. On the other hand, not requiring participants to undergo re-diagnosis of depression for purposes of this exploratory study, was expected to help maintain a comfortable and trusting atmosphere during data collection. As a result, participants might have been more honest and open in describing the factors affecting their treatment decision-making.

10.6.6 Recruitment strategies

Another limitation of this study is a possible sampling bias. A disadvantage of the recruitment strategies used in this study, was the reliance on the potential participants' self-selection to take part in the study. Whilst the use of a variety of methods was expected to inform as many people as possible about the study and to

minimise the overall selection bias, each of the methods had its limitations and carried a potential of bias. For example, no participants were recruited via the contact with their mental health practitioners, although this is one of the most common methods of recruitment in other studies. This might have been the result of the practitioners' lack of time during consultations, their possible doubts about the importance of the study, or another reason. Alternatively, it could have resulted from the lack of systematic identification of eligible patients from the health professionals' case lists.

Another strategy that yielded a small number of participants was the engagement of the local mental health charities, although charities are often supportive of research. Despite the willingness and support offered by the charity representatives (including the MIND and the Age UK), people with depression in these organisations expressed little interest in joining in this study. This could have been due to the charities focusing on people with other long term mental health conditions, such as bipolar disorder and dementia, and therefore involving a limited number of people meeting the inclusion criteria for this study. The charity organisations that provide support specifically to people with depression were not involved in this research.

The most successful recruitment strategies were publishing of information about the study on the University's website and in the local media, and the snowballing method. Using the website and the local newspapers to invite the potential participants corresponds with the recommendations to publicise the research widely in the target population (Brown et al., 1998). Similarly, the flyers distributed in the GP practices could be considered as widely publicising the study in the population, but unlike the newspaper articles, the flyers did not help me recruit any participants. The lack of effectiveness of the flyers is not surprising, since they were placed in the waiting rooms by the surgery staff with potentially no interest in the study. Such posters may be easy to miss if placed amidst a large number of other adverts and notices (Namageyo-Funa et al., 2014).

The success of the articles on the University's website and in the newspapers was, however, a surprise, although engaging the public is generally advised (Brown et al., 1998). People were unlikely to spot the newspaper articles immediately, as they were printed on either page 7, 17 or 25 in the individual newspapers. Despite this, the readers could have noticed them possibly due to reading the papers in their own time, as opposed to the time when waiting for a doctor's appointment. In addition, unlike the newspaper articles, the flyers could also be associated with feelings of embarrassment, since some people might not feel comfortable to pick up a leaflet about depression if others in the waiting room can see this. Combined with the article about the study, published on the University's website, the newspaper articles helped me to recruit participants with a variety of demographic characteristics, although the sample was not fully representative of the general population.

The snowballing method was also considered to be successful, although in some cases it was difficult to determine whether a person had read about the study or whether they had heard about it from their family members. Whilst snowballing is a recognised strategy (Sadler et al., 2010), it can also increase the risk of selection bias (Groger et al., 1999), since the process of spreading the information about the study is not random but specific to the individuals. For example, people might not share the information about the study if they do not find it appealing even if their friend might be interested. Moreover, people might be more willing to say interesting information to others who share their views and values, which further increases the bias. Despite its drawbacks, this strategy was crucial for the recruitment of family and friends of depressed people, since accessing this group would have proved to be considerably more difficult.

10.7 Conclusion

Despite the under-representation of some patient groups relative to the general population, my findings provide a detailed list of factors affecting patients' treatment decisions. Consequently, health professionals could use these factors to

explore and develop a better understanding of how different patients make their depression treatment decisions.

Chapter 11 Conclusion

11.1 Summary of thesis

In this thesis, I described and discussed an explorative study about the factors influencing treatment decisions made by people with depression, as perceived by members of three stakeholder groups: people with depression, their family and friends and healthcare workers. Using concept mapping, a mixed method designed for gathering and processing a large amount of information, I identified 59 statements representing factors affecting the patients' choices and grouped them into 12 distinct clusters of closely related items.

The findings of this study demonstrate that people with depression make their treatment decisions based on a number of different factors. These include internal factors related to their personal insight and understanding, emotional aspects that might be related to the illness. The treatment decisions are also influenced by the external factors, mostly associated with health professionals, family and friends and the person's wider social environment. The perspectives of depressed patients, their family and friends and healthcare workers about the relative importance of the individual factors suggest that these groups do not share the views about how patients make their treatment decisions patients.

11.2 Treatment decision-making

When experiencing low mood and other changes in emotional state, individuals might first think that the problems could be resolved by a simple and quick treatment that would provide an easy solution. Based on the results of the multidimensional scaling analysis, I suggest that such views could be informed and altered by the person's growing experience with living with depressive symptoms. There is evidence that people become less likely to seek professional help with the passing time of their illness (Thompson et al., 2008). Based on my observation, I suggest that this might be a result of the diminishing direct impact of insight on

help-seeking. Additionally, this may be due to another factor becoming more influential over time, such as people's current emotional states, which are closely related to the depressive symptoms people have. In line with the recent psychological theories of decision-making, this suggests that emotions have a large influence on how people decide in the critical situations. In relation to help-seeking, this effect might demonstrate as a sudden change in the person's decision to consult a professional based on a change in their emotional state. The other factors, then appear to play less prominent roles. For example, doctor's advice might be less influential on decisions made by a person who has not yet visited the physician to seek help. Although the anticipated views of the doctor might encourage or inhibit an individual's intention to consult the professional, their advice might still be most relevant once a person develops insight into their symptoms. On the other hand, perceived stigma and the beliefs of family and friends were previously found important in this stage of treatment decision-making. For example, research shows that some people might consider the members of their close social environment as a source of advice (Farmer et al., 2012). The family and friends' views could therefore be an important factor in a person's decision-making about treatment. The findings of this study, however, suggest that the external views about depression have a relatively small effect on patients' choices, when considered in the context of the people's internal representations of depression.

11.3 The findings in relation to particular treatment decisions

When conducting this study, a decision was made not to ask participants to differentiate between individual treatment decisions when discussing the factors affecting them. This was based on an assumption that people's treatment choices are influenced by the same set of factors, which reflects previous research demonstrating a number of similar factors found to predict the different types of decisions. Consequently, in this last section of the thesis, I attempt to relate the findings of this study to the individual types of decisions.

11.3.1 Help-seeking

My findings are consistent with the theoretical models suggesting that when people make the decision to consult a professional about depression, they had already developed some understanding of their symptoms. In relation to care-seeking, researchers have previously mentioned insight and some of its dimensions such as recognition of symptoms and ability to relate them to an illness. For example, Epstein et al (2010) specified that people go through a process of knowing, naming and explaining their experiences and symptoms, before they consult a GP. Farmer et al (2012) suggested that within the process of developing insight and awareness, people might become intimidated by their symptoms. Consequently, they may first need to come to terms with the thought that they are a depressed person. My findings provide additional detail into how depressed people might come to terms with the symptoms of their condition and develop insight.

11.3.2 Treatment selection

Research is scarce about how depressed people develop their treatment preferences and there is a paucity of theoretical models that could be used to explain this process. Based on the findings of this study I suggest that patients develop their preferences based on their insight into how depression affects their life, leading them to better understanding the treatment outcomes they require. This understanding is a product of having knowledge and more personal experience with depression. At the same time, patients' emotional states are seen influential, suggesting that development of treatment preferences is affected by the irrational factors. The impact of professionals appears to be more indirect. For example, they might help patients by providing relevant information and helping them make best use of their own experience to select treatment options.

11.3.3 Adherence

My findings can be related to the necessity-concerns framework that has been used to explain and address adherence to medication (Aikens et al., 2008). According to the framework, a patient is more likely to adhere to treatment better if they hold

beliefs that support the overall perception of necessity of treatment. Poorer adherence is therefore associated with an increased perception of the concerns about treatment. This was identified as a part of the factor related to making informed decisions. My findings suggest that patients' beliefs about the necessity and their concerns about treatment are closely related to their past experiences and a personal insight into their depression. Addressing these factors together with the patients' emotional states might therefore help improve their adherence.

11.3.4 Shared decision-making

Although a shared decision-making (SDM) is a generally accepted as the most appropriate approach to patients, including mental health patients, theoretical models that would effectively explain the SDM process are lacking (Gray, 2014). Adoption of the SDM principles in practice can have a positive impact on patients' involvement in decisions, acceptance of treatment and adherence (Loh et al., 2007a). The findings of this study suggest that insight and emotional states are the key aspects of treatment decision-making, which are further influenced by the patients' knowledge, understanding, experience and depressive symptoms. By understanding the underlying processes of these factors' interaction, health professionals could become better equipped to help patients make sense of the available information and benefit from their experience.

11.4 Practice implications

The findings of this study demonstrate that depressed people take treatment decision-making seriously and that they strongly rely on the internal representations and an understanding of their situations. Based on the findings, I suggest that health and mental health professionals should be wary not to rely on their personal assumptions about particular patients. Instead, they should adopt a more open-minded approach and help patients to address the issues that they find troubling. Based on their roles of the treatment gatekeepers, they should be vigilant to the patients' individual perspectives, in order to provide most appropriate treatment and facilitate shared decision-making. Similar suggestions have been

made in relation to other conditions, for example, schizophrenia (Gray et al., 2010). My findings show that in order to provide a more tailored care for depressed patients, professionals might need to adopt a more open-minded approach to the way the people with depression make their treatment choices.

11.5 Suggestions for future research and work in this area

The findings of this study show that a number of different factors influence treatment decisions depressed patients make and that family and healthcare professionals do not share the perspectives of patients about the most important aspects of the process. In order to help patients make more effective treatment choices, I suggest that future research should explore the following questions.

- I identified twelve distinct, but related factors that influence patients' treatment decisions and I explored their relative importance as perceived by the stakeholder groups involved in the study. Future research should be done to investigate the predictive validity of these factors on the patients' treatment choices, and the applicability of the findings in more diverse populations. For example, it should be determined whether depressed people could improve their insight as a result of gaining information tailored to their personal needs and reflecting on their personal experiences with depression.
- This study shows that there are a number of points about which patients and professionals disagree. Since these issues are directly related to the ways patients decide about the issues that are the subject of consultations with the professionals, these misunderstandings should be addressed. One way of supporting health professionals in facilitating shared decision-making, would be to develop an educational programme that would improve the professionals' understanding of how depressed patients make their treatment choices. The main purpose of such training would be to encourage the professionals' empathy and improve their abilities to address patients' needs specific to the decision-making about depression treatment. The effectiveness of such educational programme could be a subject of further research.

- Future research should also aim to test the feasibility of the interventions that involve peer support workers helping depressed patients to make their treatment decisions. Because GPs have limited time available for patient consultations, they might not be able to understand fully the factors that patients find most troubling. Involving a person with a prior relevant experience, such as a peer support worker in the decision-making process, might provide an additional time and a more empathetic approach to patients.

11.6 Conclusion to thesis

In this thesis, I described and discussed an exploratory study about how depressed people make treatment decisions, and how their perspectives compare to those held by family and friends and health professionals. Demonstrating that patients and professionals differ considerably in their views about the decision-making process, I suggest that health professionals should adopt a more individual approach to patients. By helping patients address their specific, rather than assumed problems, professionals could provide the support the patients need when dealing with depression. Consequently, patients could engage in shared decision-making about their treatment in more straightforward ways.

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Appendices

Appendix 1: Ethical approval

NHS

National Research Ethics Service

NRES Committee East of England - Essex

East of England Rec Office 1
Victoria House
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18 October 2011
(Revised 03 November 2011 to add the Refusal letter to non-participants v2 31/08/2011, underlined below)

Miss Ada Mackovova, PhD student
School of Nursing Sciences
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

Dear Miss Mackovova

Study title:	**What factors that influence treatment choices made by people with depression? A concept mapping study about views of people with depression, their family and friends, and healthcare workers.**
REC reference:	**11/EE/0321**

Thank you for your letter of 30 September 2011, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC

A final change is required to the Participant Information Sheet: Friends and Family to comply with the Provisional Opinion letter dated 16 August 2011:The phrase on page 1 "....or alternatively in your home" must be changed to "....if that would be difficult for you please discuss alternatives with the researcher." The researcher is reminded that home visits should be a last resort, since as discussed, potential participants may be unknown to the service, having responded to community placed advertisements.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Advertisement	Version 2.0	31 August 2011
Advertisement	Version 2.0	31 August 2011
Covering Letter		29 July 2011
Evidence of insurance or indemnity		28 June 2011
Investigator CV		27 July 2011
Letter from Sponsor		26 July 2011
Other: CV Richard John Gray		14 July 2011
Other: CV Bridget Penhale		13 July 2011
Other: Invitation Letter to Healthcare Workers	Version 2.0	31 August 2011
Other: Reply slip: People with Depression	Version 2.0	31 August 2011
Other: Reply slip: Family and Friends	Version 2.0	31 August 2011
Other: reply slip: Healthcare Workers	Version 2.0	31 August 2011
Other: Useful Information Sheet	Version 2.0	31 August 2011
Participant Consent Form: People with Depression	Version 2.0	31 August 2011
Participant Consent Form: Family and Friends	Version 2.0	31 August 2011

Participant Consent Form: Healthcare Workers	Version 2.0	31 August 2011
Participant Information Sheet: People with Depression	Version 2.0	31 August 2011
Participant Information Sheet: Family and Friends	Version 2.0	31 August 2011
Participant Information Sheet: Healthcare Workers	Version 2.0	31 August 2011
Protocol	Version 2.0	31 August 2011
Questionnaire: Baseline Information Questionnaire People with Depression	Version 2.0	31 August 2011
Questionnaire: Baseline information Questionnaire family and Friends	Version 2.0	31 August 2011
REC application	Version 3.2	29 July 2011
REC application	draft	03 October 2011
Response to Request for Further Information		03 October 2011
Refusal Letter to non-participants	Version 2.0	31 August 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/EE/0321	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

PP. **Dr Niki Bannister**
Chair
Email: Suzanne.emerton@eoe.nhs.uk

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Cc: Mrs Susan Steel
        University of East Anglia
        Research Enterprise and Engagement Office
        The Registry
        Norfolk
        NR4 7TJ

        Dr Bonnie Teague,
        Norfolk and Waveney Mental Health NHS Foundation Trust
        R&D Department
        Drayton High Road
        Norwich
        NR6 5BE

Appendix 2: Research and Development Governance approval: Norfolk and Waveney Mental Health Trust

Norfolk and Waveney **NHS**
Mental Health
NHS Foundation Trust

Research and Development Dept
Hellesdon Hospital
Drayton High Road
Norwich
NR65BE
Telephone 01603 421552
E mail: RDofficemailbox@nwmhp.nhs.uk

Ada Mackovova
c/o Karen Lester
School of Nursing
Edith Cavell Building
University of East Anglia
Norwich
NR4 7TJ

2nd November 2011

Dear Miss Mackovova,

Re: The Choice Study (2011MH48)

Thank you for submitting the above project for local research governance approval. I am pleased to inform you that your project has been given full approval and you may begin your research at the following site:

- Norfolk & Waveney Mental Health NHS Foundation Trust

I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign both copies returning one copy to the Research and Development office, at the above address, and keeping the other in your study file. Failure to return the standard terms and conditions may affect the conditions of approval. **Under the agreed Standard Terms and Conditions of Approval you must inform the R&D department of any proposed changes to this study and submit annual progress reports to the R&D department.**

Any researcher(s) whose substantive employer is not the Norfolk & Waveney Mental Health NHS Foundation Trust must have a Letter of Access or Honorary Research contract before coming on site to conduct their research in this project. Please note that you cannot take part in this study until you have this documentation. If a Letter of Access / Honorary Research Contract has not been issued – please contact us immediately.

If you have any queries regarding this or any other project, please contact, Tom Rhodes, Research Governance Administrator, at the above address.

The reference number for this study is: **2011MH48,** and this should be quoted on all correspondence.

Yours sincerely,

Luk Ho
Acting Medical Director

Chair: Maggie Wheeler
Chief Executive: Aidan Thomas
Trust Headquarters: Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE
Tel: 01603 421421   Fax: 01603 421440   www.nwmhft.nhs.uk

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Documents approved by NWMHFT

Item	Version	Date
Protocol	2	31/08/2011
Advertisement (GP Poster)	2	31/08/2011
Letter of invitation to participant (Healthcare workers)	2	31/08/2011
Press Release	2	31/08/2011
Refusal for non-participants	2	31/08/2011
Useful Info Sheet	2	31/08/2011
Reply Slip - PwDepression	2	31/08/2011
Reply Slip - Family and Friends	2	31/08/2011
Reply Slip - Healthcare Workers	2	31/08/2011
Participant Consent Form: PwDepression*	3	18/10/2011
Participant Consent Form: Family and Friends*	3	18/10/2011
Participant Consent Form: Healthcare workers	2	31/08/2011
PIS: PwDepression*	3	18/10/2011
PIS: Family and Friends*	3	18/10/2011
PIS: Healthcare workers	2	31/08/2011
Questionnaire: People with depresion	2	31/08/2011
Questionnaire: Family and Friends	2	31/08/2011

*subject to final ethical acceptance, as per approval letter dated 18/10/2011

Appendix 3: Research and Development Governance approval: NHS Norfolk Primary Care Trust

Ref: 2011MH48

NHS Norfolk

Research & Development
NHS Norfolk
Lakeside 400
Old Chapel Way
Broadland Business Park
Thorpe St Andrew
Norwich
NR7 0WG

Miss Ada Mackovova
PhD Student, School of Nursing Sciences
University of East Anglia
Norwich
NR4 7TJ

Tel: 01603 257283
Fax: 01603 257292
E-mail: paul.mills@norfolk.nhs.uk
www.norfolk.nhs.uk/research

24 October 2011

Dear Miss Mackovova

Re: **2011MH48. What factors that influence treatment choices made by people with depression? A concept mapping study about views of people with depression, their family and friends, and healthcare workers. The Choice Study.**

REC Number: 11/EE/0321

Chief Investigator: Miss Ada Mackovova, University of East Anglia

Sponsor: University of East Anglia

Further to your submission of the above project to the R&D office at NHS Norfolk your project has now been reviewed and all the mandatory research governance checks have been satisfied. I am therefore pleased to inform you on behalf of **NHS Norfolk** that NHS permission (R&D approval) was granted on **18th October 2011** for your study to take place at the following sites:

- GP Practices in NHS Norfolk

Please note that NHS Permission is granted on the basis of the information supplied in the application form, protocol and supporting documentation, if anything subsequently comes to light that would cast doubts upon, or alter in any material way, any information contained in the original application, or a later amendment application there may be implications for continued NHS Permission.

Please note the following conditions of approval:
- It is noted that the REC Letter of Favourable Opinion has omitted the document "*Refusal Letter to Non-Participants*", version 2, 31st August 2011. The R&D office understands that this is a REC error, and it is advised to ask for a corrected letter with this document included.
- Please supply the R&D office with an updated Participant Information Sheet for Family & Friends to comply with REC condition of approval.
- Please provide the NHS Norfolk R&D Office with details of all participating GP practices within NHS Norfolk on an ongoing basis

Stonewall
DIVERSITY CHAMPION

Chair: Sheila Childerhouse
Chief Executive: Andrew Morgan

Visit our website: www.norfolk.nhs.uk

You may now begin your study at the above sites.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework. I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign and return one copy to the R&D office at the above address. Failure to return the standard terms and conditions may result in NHS permission being revoked.

Please note, under the agreed standard terms and conditions you must inform the R&D Office at NHS Norfolk of any proposed changes to this study, whether minor or substantial, and to keep the Committee updated on progress. Please note also, if you wish to extend approval to any sites other than those listed above you must apply for this through the relevant R&D office.

If you have any queries regarding this or any other project please contact Paul Mills, R&D Officer, at the above address. Please note, the reference number for this study is **2011MH48** and this should be quoted on all correspondence.

The following documents were reviewed:

Letter of Favourable Opinion from NRES Committee East of England – Essex. dated 18th October 2011
- Advertisement – Poster, Version 2, 31st August 2011
- Advertisment – Press Release, version 2, 31st August 2011
- Evidence of Insurance/Indemnity, 28th June 2011
- Letter from Sponsor, 26th July 2011
- Investigator CV – Ada Mackovova
- Investigator CV – Richard Gray
- Investigator CV – Bridget Penhale
- Participant Invitation Letter – Healthcare Workers, Version 2, 31st August 2011
- Reply Slip – People with Depression, Version 2, 31st August 2011
- Reply Slip – Family & Friends, Version 2, 31st August 2011
- Reply Slip – Healthcare Workers, Version 2, 31st August 2011
- Useful Information Sheet, Version 2, 31st August 2011
- Participant Information Sheet – People with Depression, Version 2, 31st August 2011
- Participant Information Sheet – Family & Friends, Version 2, 31st August 2011
- Participant Information Sheet – Healthcare Workers, Version 2, 31st August 2011
- Participant Consent Form – People with Depression, Version 2, 31st August 2011
- Participant Consent Form – Family & Friends, Version 2, 31st August 2011
- Participant Consent Form – Healthcare Workers, Version 2, 31st August 2011
- Protocol, version 2, 31st August 2011
- Baseline Information Questionnaire – People with Depression, Version 2, 31st August 2011
- Baseline Information Questionnaire – Family & Friends, Version 2, 31st August 2011
- Response to Request for Further Information, 30th September 2011

Other Documents Reviewed
- Refusal Letter to Non-Participants, Version 2, 31st August 2011 (see note above)
- Fully Signed R&D Form, Lock Code 81087/236767/14/808
- Signed SSI Form, Lock Code 81087/236400/6/470/108625/219556

Yours sincerely

Dr Jenny Harries
Joint Director of Public Health
NHS Norfolk & Norfolk County Council

cc: Professor Richard Gray, University of East Anglia, Academic Supervisor
Sue Steel, University of East Anglia, Sponsor Representative
File

Enc

Appendix 4: Research and Development Governance approval: NHS Great Yarmouth and Waveney

NHS
Great Yarmouth and Waveney

Research & Development
NHS Norfolk
Lakeside 400
Old Chapel Way
Broadland Business Park
Thorpe St Andrew
Norwich
NR7 0WG

Miss Ada Mackovova
PhD Student, School of Nursing Sciences
University of East Anglia
Norwich
NR4 7TJ

Tel: 01603 257283
Fax: 01603 257292
E-mail: paul.mills@norfolk.nhs.uk
www.norfolk.nhs.uk/research

24 October 2011

Dear Miss Mackovova

Re: **2011MH48. What factors that influence treatment choices made by people with depression? A concept mapping study about views of people with depression, their family and friends, and healthcare workers. The Choice Study.**

REC Number: 11/EE/0321

Chief Investigator: Miss Ada Mackovova, University of East Anglia

Sponsor: University of East Anglia

Further to your submission of the above project to the R&D office at NHS Norfolk your project has now been reviewed and all the mandatory research governance checks have been satisfied. I am therefore pleased to inform you on behalf of **NHS Great Yarmouth & Waveney** that NHS permission (R&D approval) was granted on **18th October 2011** for your study to take place at the following sites:

- GP Practices in NHS Great Yarmouth & Waveney

Please note that NHS Permission is granted on the basis of the information supplied in the application form, protocol and supporting documentation, if anything subsequently comes to light that would cast doubts upon, or alter in any material way, any information contained in the original application, or a later amendment application there may be implications for continued NHS Permission.

Please note the following conditions of approval:

- It is noted that the REC Letter of Favourable Opinion has omitted the document *"Refusal Letter to Non-Participants"*, version 2, 31st August 2011. The R&D office understands that this is a REC error, and it is advised to ask for a corrected letter with this document included.
- Please supply the R&D office with an updated Participant Information Sheet for Family & Friends to comply with REC condition of approval.
- Please provide the NHS Norfolk R&D Office with details of all participating GP practices within NHS Norfolk on an ongoing basis

You may now begin your study at the above sites.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework. I have enclosed two copies of the Standard Terms and

NHS Norfolk hosts the Research Management and Governance Services for NHS Norfolk, NHS Suffolk, NHS Great Yarmouth & Waveney and Norfolk Community Health & Care NHS Trust

Conditions of Approval. Please sign and return one copy to the R&D office at the above address. Failure to return the standard terms and conditions may result in NHS permission being revoked.

Please note, under the agreed standard terms and conditions you must inform the R&D Office at NHS Norfolk of any proposed changes to this study, whether minor or substantial, and to keep the Committee updated on progress. Please note also, if you wish to extend approval to any sites other than those listed above you must apply for this through the relevant R&D office.

If you have any queries regarding this or any other project please contact Paul Mills, R&D Officer, at the above address. Please note, the reference number for this study is **2011MH48** and this should be quoted on all correspondence.

The following documents were reviewed:

Letter of Favourable Opinion from NRES Committee East of England – Essex, dated 18th October 2011

- Advertisement – Poster, Version 2, 31st August 2011
- Advertisment – Press Release, version 2, 31st August 2011
- Evidence of Insurance/Indemnity, 28th June 2011
- Letter from Sponsor, 26th July 2011
- Investigator CV – Ada Mackovova
- Investigator CV – Richard Gray
- Investigator CV – Bridget Penhale
- Participant Invitation Letter – Healthcare Workers, Version 2, 31st August 2011
- Reply Slip – People with Depression, Version 2, 31st August 2011
- Reply Slip – Family & Friends, Version 2, 31st August 2011
- Reply Slip – Healthcare Workers, Version 2, 31st August 2011
- Useful Information Sheet, Version 2, 31st August 2011
- Participant Information Sheet – People with Depression, Version 2, 31st August 2011
- Participant Information Sheet – Family & Friends, Version 2, 31st August 2011
- Participant Information Sheet – Healthcare Workers, Version 2, 31st August 2011
- Participant Consent Form – People with Depression, Version 2, 31st August 2011
- Participant Consent Form – Family & Friends, Version 2, 31st August 2011
- Participant Consent Form – Healthcare Workers, Version 2, 31st August 2011
- Protocol, version 2, 31st August 2011
- Baseline Information Questionnaire – People with Depression, Version 2, 31st August 2011
- Baseline Information Questionnaire – Family & Friends, Version 2, 31st August 2011
- Response to Request for Further Information, 30th September 2011

Other Documents Reviewed

- Refusal Letter to Non-Participants, Version 2, 31st August 2011 (see note above)
- Fully Signed R&D Form, Lock Code 81087/236767/14/808
- Signed SSI Form, Lock Code 81087/236404/6/471/117664/219558

Yours sincerely

Dr Augustine Pereira
Consultant in Public Health Medicine, and Research & Development Lead
NHS Great Yarmouth & Waveney

cc: Professor Richard Gray, University of East Anglia, Academic Supervisor
       Sue Steel, University of East Anglia, Sponsor Representative
       File

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Appendix 5: Good Clinical Practice training certificate (2010)

NHS
National Institute for
Health Research

Clinical Research Network
Coordinating Centre

Certificate of Attendance

Ada Mackovova

attended

Introduction to Good Clinical Practice (GCP):
A practical guide to ethical and scientific
quality standards in clinical research

on 29/11/2010

Sessions include:
1. The Value of Clinical Research and the role of the NIHR CRN
2. GCP: the standards and why we have them
3. Study set up: responsibilities, approvals and essential documents
4. The process of informed consent
5. Case report form, source data and data entry completion
6. Safety reporting in clinical trials

Paul Maher

Paul Maher
NIHR CRN GCP Training Manager

U:/NTProfile/Documents/.../NIHR CRN Certificate of Attendance.htm

Appendix 6: Good Clinical Practice training certificate (2012)

Certificate of Attendance

Good Clinical Practice and Regulatory Requirements for Clinical Trials: A Refresher Session

Wednesday 21st November 2012 at

Norfolk & Norwich University Hospitals NHS Foundation Trust

This certificate has been awarded to

Ada Mackovova

Training Provider (T Symons Associates Ltd): TSymons   Date: 21/11/2012
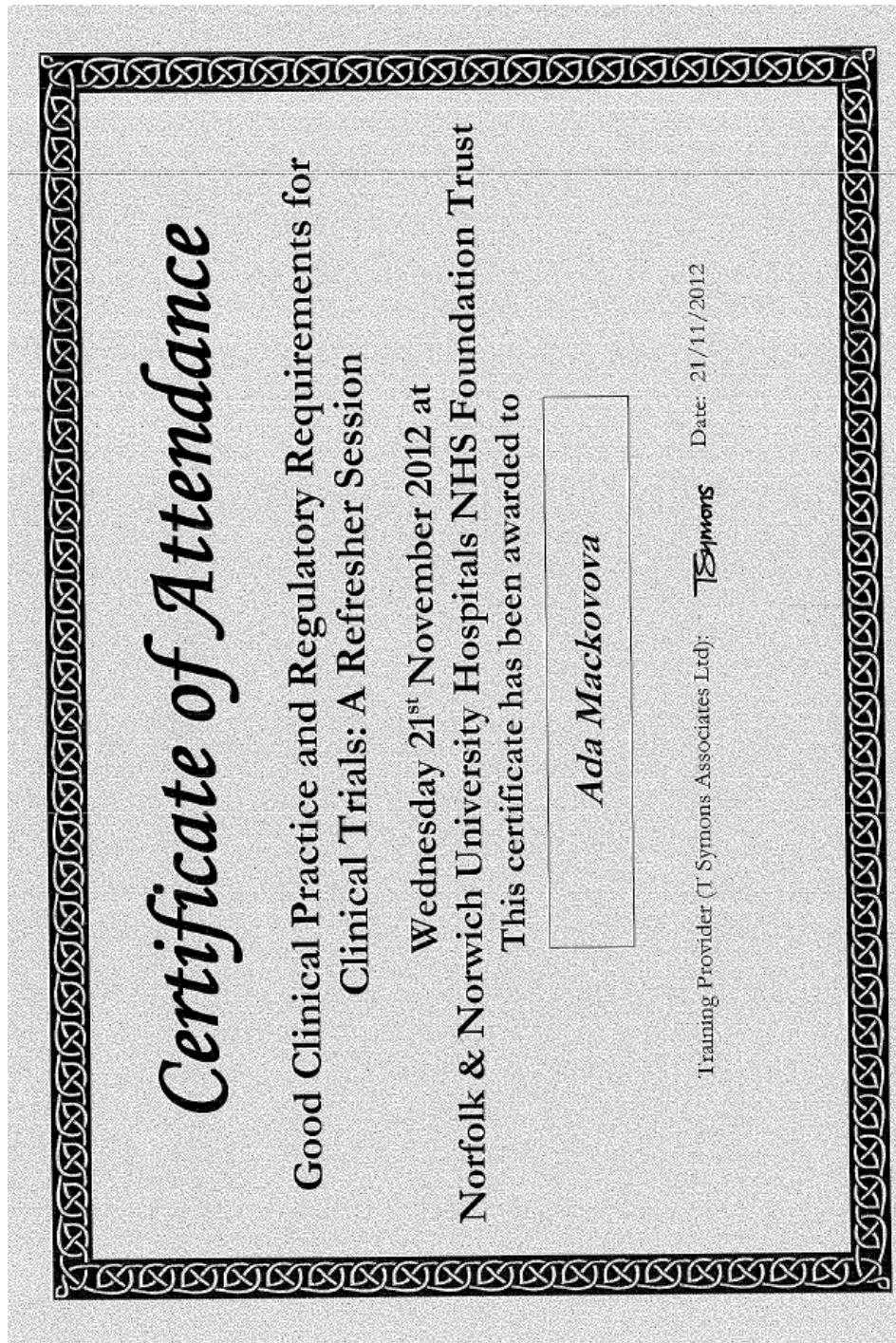
Appendix 7: Study protocol

Research Protocol

General Information

Project Title: What factors influence treatment choices made by people with depression? A concept mapping study about views of people with depression, their family and friends, and healthcare workers.
Working Title: The Choice Study
Researchers:
Ada Mackovova – Chief Investigator and PhD student
PhD student School of Nursing Sciences, University of East Anglia, Norwich, NR4 7TJ
Professor Richard Gray – Primary Academic Supervisor
Edith Cavell Building 1.13, University of East Anglia, Norwich, NR4 7TJ
Dr Bridget Penhale – Secondary Academic Supervisor
Edith Cavell Building 1.21, University of East Anglia, Norwich, NR4 7TJ

Funding:
This study is a PhD research project which is funded by the University of East Anglia.

Other Organisations Involved in this Study:
Norfolk and Suffolk NHS Foundation Trust
Foundation Trust Office, Norfolk & Suffolk NHS Foundation Trust, Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE

NHS Norfolk
Lakeside 400, Old Chapel Way, Broadland Business Park, Thorpe St Andrew, Norwich, NR7 0WG.
NHS Great Yarmouth and Waveney
1 Common Lane North, Beccles, Suffolk, NR34 9BN

Age UK, Norwich
Boardman House, Redwell Street, Norwich, NR2 4SL

Project summary

Depression is a common mental illness that is typically treated with antidepressant medication or talking therapies. Treatment choices made by people with depression have a large impact on their behaviour, including selection of a practitioner and adherence to therapy. People should make informed decisions about treatment but that can be hard to facilitate if healthcare workers do not comprehend what factors influence patients' decisions. We therefore aim to provide a better understanding of how people with depression make treatment choices.

We will use concept mapping, an established methodology to compare and collate views of three stakeholder groups: 30 people with depression, 30 family and friends, and 30 healthcare workers.

In the first part of the study, participants join in focus groups to produce as many statements as possible, about how people with depression make treatment decisions. In the second part, the same volunteers are invited to perform two individual tasks: (1) rank the importance of each statement (prioritizing), and (2) put the statements that seem to go together, into groups (clustering). This data will be analysed using a specialised software package called Ariadne, and a concept map will be produced depicting importance and relations of the statements, as viewed by participants. The results of this analysis will provide a better understanding about the factors that influence patients' treatment choices.

The findings of this study can help healthcare workers better understand the patients' perception of different treatment options, and support patients in their informed decision-making. It could be used to inform future policy making about depression treatment, and help service managers to tailor the services to better meet patients' needs.

1.1 Abbreviations:

AM – Alternative Medicine

CBT – Cognitive Behavioural Therapy

GP – General practitioner

IAPT – 'Improving Access to Psychological Therapies' government program launched in 2007 to provide psychological treatment to patients who need them

NHS – National Health Service

NICE – the National Institute for Health and Clinical Excellence

NHS Norfolk – Norwich and Norfolk Primary Care NHS Trust

NSFT – Norfolk and Suffolk NHS Foundation Trust

UK – United Kingdom

WHO – World Health Organization

2 Background information

2.1 Depression

Depression is a common treatable mental illness. It affects approximately 3% of general population at any one time (Singleton et al. 2001) and at least one third of GP time is spent to treat people with this mood disorder (Unit 2004). In primary care patients, depression is most common in women aged 30-39 years (20%) and in men aged 40-49 years (almost 10%) (Martín-Merino 2010). Symptoms include feelings of sadness, worthlessness, disturbed sleep and problems concentrating and making decisions (WHO 1992). Left untreated, depression is a potentially fatal illness with more than two thirds of acutely depressed people experiencing thoughts of suicide (Moller 2003). It causes a significant burden to the patient, their family as well as the society (WHO, 2008). In England, the total estimated cost of depression in adults is £9 billion (Thomas and Morris 2003).

2.2 Treatment for depression

The majority of people with depression are seen in primary care where optimised treatment should achieve remission in about 50-67% of patients (Dawson et al. 2004). Antidepressants, such as SSRIs (e.g. fluoxetine) are prescribed to about 90% of primary care patients with depression (Martín-Merino 2010) and should be administered for at least 6 months following improvement of symptoms. Used alone or combined with medication, psychological therapies such as cognitive behaviour therapy (CBT), interpersonal therapy (IPT) and counselling are also effective for depression if patients receive 16 to 20 sessions of therapy (NICE 2009). As a therapy for depression, physical exercise may be recommended for patients in addition to their usual care. A recent Cochrane systematic review showed that exercise can be as effective as cognitive therapy in alleviating symptoms of depression, but more research is needed to determine the most suitable type (e.g. aerobic, anaerobic) and the exact therapeutic effect (Mead et al. 2009). Other publicly available therapies for depression include the Alternative medicines (AMs) such as St John's Wort, nutritional supplements, Acupuncture or Neuro-linguistic Programming. The results from the Health Survey for England showed that despite the lack of scientific evidence of most of the AMs' effectiveness, 35% of respondents with depression and/or anxiety symptoms had used some AM, compared to 25% of those who had good mental health (Hunt et al. 2010).

2.3 Adherence to treatment

Psychological and pharmacological therapies have been found equally effective for depression, but patients' adherence to them is poor, regardless of the type received. Up to one third of patients discontinue in the first month (Fairman et al. 1998) and as few as one third of patients complete only 3 months of their prescribed treatment (Olfson et al. 2006). In attempt to understand this

phenomenon, researchers found that patients generally express the need for a better understanding of their illness and side effects of treatment (Prins et al. 2009). Interventions designed to improve adherence, that focus solely on patient education, are not effective (Haynes et al. 2002) as they do not address the real reasons why patients do not compete their therapy course (Donovan 1995). Other researchers suggest a link between adherence and patients' treatment choices as an explanation.

2.4 Treatment preferences held by people with depression

Preferences held by people with depression appear to have a strong influence on their actions, such as help-seeking behaviour, choice of therapy or practitioner, and adherence (Prins et al. 2009). Studies show that around 51-66% of people with depression would prefer talking therapies over medication if given the choice (van Schaik et al. 2004). Despite of its effectiveness, exercise is rarely offered as a therapy of choice in studies on patients' treatment preferences for depression (Prins et al. 2008). Compared to antidepressants and talking therapies, limited information is available about patients' preferences for exercise or alternative medicines.

Receiving the preferred choice of therapy, regardless of its type, appears to be related to better concordance and higher patient satisfaction (Hunot et al. 2007). Many patients feel uncomfortable if a treatment they do not want is given to them (Nolan and Badger 2005). Other researchers suggest it is not the preference itself but rather their strength that has an effect on the extent to which patients follow their health advice (Raue et al. 2009). The importance of including patients in decision-making and prescribing has also been recognized by the NICE. Health professionals are recommended to use the person-centred care approach (NICE 2009) and encourage patients to play an active role in treatment decisions.

2.5 What factors influence treatment choices made by people with depression?

Treatment preferences held by people with depression influence their help-seeking behaviour and a number of researchers have attempted to understand the individual differences related to particular treatment choices, but conflicting results are often shown. Women seem to be more likely to opt for talking therapies (Prins et al. 2008) but in a study with mostly male patients, almost one quarter of them preferred psychotherapy and more than 60% combination of antidepressants and psychological treatment (Lin et al. 2005). Beliefs and opinions are also important. People who believe that antidepressants are addictive seem to prefer counselling (Churchill et al. 2000) and if individuals believe a particular treatment can help them, they are more likely to use it (Jorm et al. 2000). A review of studies about treatment preferences has shown that a large number of beliefs, e.g. perceived consequences of the illness, and beliefs about importance of treatment and its side

effects, have an effect on patients' preference for therapy (Prins et al. 2008). The direct effect of these beliefs has not yet been shown and a limited number of studies investigating what factors influence patients' treatment choices have been published. In this study, we aim to combine the ideas and perspectives of three different stakeholder groups about how people with depression make their treatment decisions. Members of the three groups will first generate a variety of ideas on the topic, and then they will structure the ideas in terms of their importance and meaning. Concept mapping methodology will be used for this task.

2.6 Concept Mapping

Concept mapping is an established, mixed design methodology that combines qualitative and quantitative aspects. It is a systematic process of developing and evaluating ideas of different stakeholder groups. For its nature it is ideal for bringing a number of groups with different viewpoints together, and analysing their perspectives to aid decision-making and policy development (Kane 2007). Researchers have applied concept mapping to explore and analyse perspectives of patients with schizophrenia, their carers and health professionals (Kikkert et al. 2005). In this study it will be used to understand the differences and similarities of opinions held by people with depression, their family and friends, and healthcare workers about how people with depression make their treatment choices.

3 Rationale

People are actively involved in decision-making about their health care in everyday life, and not exclusively during consultations with their health care worker. Preferences for particular type of therapy are often formed outside of the practitioner's office, and may be based on misunderstanding or anecdotal information from friends or media. These choices and beliefs about therapies have a strong influence on people's behaviour (Prins et al. 2008) but it is not yet clear what factors influence these choices. Exploring this issue further is eminent as only a third of people with depression seek medical help (NICE 2009), what means the majority of those affected do not get professional help and continue suffering. In addition, meeting patients' expectations in general practice is challenging, and not helped by a common misunderstanding between patients and healthcare workers (Britten et al. 2000). Understanding how people with depression make treatment choices would be informative and could help us tailor the healthcare to better meet patients' needs. It can also inform healthcare workers about how to help people make informed choices about their depression therapy, and help them seek treatment when needed.

In this study we will collect information about how people make depression treatment choices, from three stakeholder groups: people with depression, their family and friends, and their healthcare workers. This will help us understand the most important issues that people with depression consider when choosing a therapy and using the concept mapping methodology will enable us study the differences between the three groups.

4 Aims and objectives

4.1 Aim

The aim of this study is to develop a conceptual framework portraying the factors that influence treatment decisions made by people with depression. Using concept mapping methodology, we will demonstrate the differences and similarities between the views of health workers, people with depression and their family and friends (i.e. close friends or family members). Our study will provide an in-depth analysis of the aspects people with depression consider when selecting a treatment for depression. A better understanding about the factors that influence patients' treatment choices will be presented, not shown to this extent elsewhere. To achieve this aim we will work with people with depression; partners, family members or close friends helping these patients (family and friends) and healthcare workers currently or recently involved in treatment of people with depression.

4.2 Objectives

The primary objective is to identify differences and similarities between the perspectives of three stakeholder groups on what factors influence treatment choices made by people with depression, using concept mapping methodology. We aim to develop a conceptual framework which can be used to inform healthcare workers about helping patients make informed decisions about their treatment, and help improve the health care offered to people with depression.

The secondary objective is to analyze the data in terms of sub-groups' differences of the stakeholder groups. We will seek to view differences in perspectives of people with depression according to their gender, age groups, number of depression episodes, treatment received and possibly other baseline characteristics listed in section 6.1.1.4. For healthcare workers, we will analyse differences according to their profession. Understanding the effect of participants' individual differences in relation to treatment decisions will provide further information about how people make treatment decisions.

We also aim to develop visual 'maps' of the factors that influence treatment choices made by people with depression. The 'maps' will depict the importance of individual statements, and their relations to each other from perspectives of the three stakeholder groups. They will serve as a basis for development of the conceptual framework of the factors important for all groups of participants.

5 Study design

This study is a mixed methods participatory research involving members of the public in the design and management of the research, analysis of results and dissemination of findings.

5.1 Steering group and the research team

5.1.1 Steering Group

A steering group will be established and will include: an adult person with depression; a healthcare worker with experience of treating people with depression (Nesta Reeve); and the academic supervisory team (Professor Richard Gray, Dr Bridget Penhale and the researcher (Ada Mackovova).

5.1.2 Research Team

The research team includes Ada Mackovova, Professor Richard Gray and Dr Bridget Penhale. Research assistants will also be involved and will assist with data collection, and will be trained in appropriate consent procedures and how to assist in the concept mapping process. They will be Dr Katherine Deane (Senior Lecturer in Research Related to Nursing) and postgraduate research students in the School of Nursing Sciences: Helen Flaherty, Katrina Emerson, Kelda Hargreaves and Stephen Smith. All members of the research team and research assistants have been trained in Good Clinical Practice (GCP).

5.2 Concept mapping method

This study is designed to produce a graphical illustration of the factors that influence treatment decisions made by people with depression, using concept mapping methodology.

Concept mapping is an established, mixed methodology design where participants take part in two activity sessions. Focus groups form the qualitative part of the study. The second part of the study involves participants prioritizing and clustering statements about how people with depression make treatment choices (structuring sessions). The data from this part will be analysed using a specialized software package called Ariadne, and it is the quantitative aspect of the study. Using this method allows researchers to collect and analyse new and unique ideas from different stakeholder groups, and compare the individual groups to understand the differences in their views. The results can be used to develop a theoretical model to help explain the process of decision-making about treatment options that patients undertake.

Concept mapping is a phased methodology and will be conducted in the following steps:

5.2.1 Step 1: Preparation

5.2.1.1 Development of the focus

The focus is a sentence used as the starting point in focus groups. In order to complete it, participants will be asked to articulate as many relevant statements as possible. Focus for people with depression will differ from that of health care workers and the family and friends, and will be as follows:

People with depression: 'My most recent choice of treatment for depression was influenced by..'

Healthcare workers and the family and friends: 'Treatment choices made by people with depression are influenced by ...'

5.2.1.2 Participants' selection

Three groups of stakeholders will take part in the study: 30 people with depression, 30 family and friends (e.g. partner, family member, a close friend) and 30 healthcare workers experienced in treating people with depression.

5.2.1.3 Setting a schedule

Times and dates of the focus groups and the structuring sessions will be set, considering the participants' preferences. A meeting room will be booked for each of the three groups (people with depression, family and friends and healthcare workers) separately.

5.2.2 Step 2: Generation of statements

5.2.2.1 Focus groups

In the focus groups about 5-10 participants will work together to generate as many statements as possible in order to complete the focus sentence. An example of a statement is: 'My most recent choice of treatment for depression was influenced by... **my belief that only antidepressants would be helpful for me'**.

5.2.2.2 Statements review and reduction

After all focus groups have taken place, the research team will review wording of statements, discard any duplicates and ensure their final number does not exceed 80. Several sets of statements will be printed, each statements on a separate card.

5.2.3 Step 3: Structuring of statements

A second session will be held for small groups of participants to prioritize and cluster the statements according to their views. These tasks are performed individually. The structuring session will take place within approximately 5 months after the initial focus groups.

5.2.3.1 Prioritizing

In the prioritizing task participants organize the statements into five equal piles according to their opinion of statements' importance.

5.2.3.2 Clustering

In the clustering task participants decide which statements are thematically related and group them together. Each participant should name their clusters.

5.2.4 Step 4: Concept mapping analysis

Data from the clustering and prioritizing tasks will be analysed using a software package called Ariadne. A 'map' of the statements (concepts) will be produced for each stakeholder group, as well as all participants together.

5.2.5 Step 5: Interpretation of the maps

The concept map is a graphical illustration of the relations among statements: the more often statements were grouped together by participants, the closer they are shown on the 'map'. The similarities and differences between the three stakeholder groups are demonstrated and from these results a conceptual framework is developed.

The Ariadne software also allows analysis of differences between any sub-groups, e.g. age groups, gender, number of depression episodes, treatment received, or profession of healthcare workers.

5.2.6 Step 6: Application of the results

At this stage, the application and future usage of the 'maps' is determined.

6 Method of investigation

6.1 Study population

Three stakeholder groups will take part in the study, 1) people with depression, 2) family and friends (e.g. partner, spouse, a close family member of the patients, and 3) healthcare workers experienced in treating people with depression. The total number of participants will be approximately 90, with 30 volunteers in each group:

6.1.1 People with depression

6.1.1.1 Inclusion criteria

The criteria all people with depression must meet in order to take part in the study are shown in Table 1.

Table 1: People with depressions' inclusion criteria

Have been recommended or receiving treatment for unipolar depression currently or within past 12 months.
Age over 18 years, for participants to be adults with the capacity to consent. Ten people aged over 65 will be included to ensure the elderly population is represented in the study. There is no upper age limit.
Speak English. This is to enable discussion about wording of statements.

Provide written informed consent

6.1.1.2 Recruitment

We will recruit 30 people with depression using the following strategies:

a) Contact via the healthcare workers: as agreed with their team leaders, the healthcare workers from any locality or team of the NSFT, the NHS Norfolk and the NHS Great Yarmouth and Waveney may be asked to give the information sheets for people with depression to their clients meeting the inclusion criteria in this study.

b) Press release in the local newspaper: A press release will be published in the local newspaper (Eastern Daily Press). It will provide brief information about the study and the researcher's contact details for queries or interest in participation.

c) Advertising in GP surgeries: Posters briefly informing about our study and inviting patients to participate will be distributed in GP practices in Norwich.

d) Contact via the Age UK charity: We will attend the charity's support group meetings and invite older people with depression to take part in the study.

e) <u>Article in charity newsletters and/or magazines</u>: We will publish an article briefly describing the study and inviting people with depression and their family and friends to take part in this research, as approved by the individual charities operating in the Norwich area.

f) <u>Snowball sampling:</u> We will invite people who have already agreed to participate in the study to tell their family, friends and colleagues about the project. They will be encouraged to give them the researcher's contact details should anyone be interested in having more information or in taking part in the study.

6.1.1.3   Obtaining consent

The researcher's work address, email and phone number will be provided in the press release and all posters distributed. People who express their interest by post, email or telephone call will be posted an information pack with a reply slip and a pre-paid return envelope. All potential participants will be advised to take time (at least 24 hours) to read through the information sheet and discuss it with their friends or people close to them. They will be asked if they would like to nominate a member of their family or a friend (i.e. partner, spouse, close family member) and hand them the information pack for family and friends. People with depression can take part in the study regardless of whether they nominate a member of family or friend, or not. The potential participants will be asked to post the filled reply slip to the researcher who will contact the respondents by telephone and inform them whether they are invited to take part in the study. This will be decided based on the number of participants already recruited in the study and the inclusion criteria. Personal meetings will be arranged with those invited to participate to discuss the study in more detail, fill in the baseline information questionnaire, obtain their written informed consent and answer any outstanding questions. These meetings will take place at agreed public places or alternatively in the potential participants' homes.

All participants will be asked to note their preference for time and day of the focus group, in order to meet people's individual needs and increase the response rates.

6.1.1.4   Information collected from people with depression

People with depression will be asked to provide the information listed in Table 2. This information will be collected for statistical purposes.

<u>Table 2: People with depression: information to be collected</u>

Name	Treatment prescribed and received/receiving for depression
Address	Year of first period of depression
Email and phone number	Number of depression periods
Age	Level of education and employment status
Gender	Marital status

| Ethnicity | Relationship with the family and friend (if nominated) |

6.1.2 **Family and friends**

6.1.2.1 Inclusion criteria

Family and friends of people with depression will be recruited based on the criteria shown in Table 3:

Table 3: Family and friends: inclusion criteria

Be close to a person with unipolar depression as their family member or a friend

Age 18 or above, to ensure participants are adults with the capacity to consent.

Speak English

Provide written informed consent

6.1.2.2 Recruitment

We will approach the family and friends using the following strategies:

a) Via people with depression: In the information sheet we will ask the people with depression to nominate their 'family and friend' for this study if they wish to, and give them the information pack for family and friends that will be attached.

b) Via adverts and posters: It is anticipated that some people with depression might not wish anyone close to them to participate in the study. To make sure we include a sufficient number of 'family and friends', the posters in GP practices and the press release will also be used to recruit people who know a person with depression who is close to them.

c) A press release (Spring 2012): A press release will be publicised in local media outlets specifically inviting people who are close to someone with depression (i.e. their family and friends) to take part in the study. This decision is based on a good response rate that was a result of the first press release targeting people with depression.

d) An article in charity newsletters and/or magazines: We will publish an article briefly describing the study and inviting people with depression and their family and friends to take part in this research, as approved by the individual charities operating in the Norwich area.

e) Posters: Posters (version 3 F&F: 21/02/2012) will be displayed at public places such as churches in order to be seen by as wide a population as possible. This will be done as approved by the relevant authorities governing the particular public places.

f) Snowball sampling: We will invite people who have already agreed to participate in the study to tell their family, friends and colleagues about the project. They will be encouraged

to give them the researcher's contact details should anyone be interested in having more information or in taking part in the study.

6.1.2.3   Obtaining consent

Those who contact the researcher expressing their interest to take part in the study will be sent the information pack for family and friends and asked to return the reply slip in the prepaid envelope provided if they wish to. Informed consent will be obtained at a personal meeting with the researcher, taking place at a community location or in people's homes if necessary. Individuals who are close to a person with depression (i.e. family and friends) can take part in the study regardless of whether the other joins in the research, or not.

6.1.2.4   Information collected from the family and friends

The family and friends will be asked to provide the information as shown in Table 4. This information will be collected for statistical purposes.

Table 4: Family and friends: information to be collected

Name	Level of education
Address, email and phone number	Marital status
Age	Relationship to the person with depression who is close to them
Gender	Having received treatment for depression
Ethnicity	Details of most recent treatment received (if any)
Employment status	Participation of the person with depression who is close to them

6.1.3   Healthcare workers:

6.1.3.1   Inclusion criteria

All healthcare workers taking part in the study will meet the criteria shown in Table 5:

Table 5: Healthcare workers: inclusion criteria

Currently/ within past 12 months treating/ having treated people with unipolar depression. This is to ensure healthcare workers have a recent experience of helping people with depression.

Provide written informed consent

Alternative medicine (AM) practitioners will be recruited on the basis of meeting the inclusion criteria listed in Table 6 (below), in addition to those in Table 5.

Table 6: AM practitioners: Additional inclusion criteria

There is anecdotal evidence for effectiveness of the therapy they offer for depression

Practice in Norwich

6.1.3.2 Recruitment

Approximately 30 healthcare workers will take part in the study, including GPs, nurses, mental health nurses, IAPT and Wellbeing Service workers, link workers, AM practitioners and other healthcare workers meeting the inclusion criteria.

6.1.3.2.1 IAPT and Wellbeing Service workers

The IAPT and Wellbeing Service workers will be recruited from the Norfolk and Suffolk NHS Foundation Trust as a whole. They will include link workers, counsellors, high and low intensity IAPT and Wellbeing Service workers in order to provide a wider variety of views. The Service leads in each cluster location will be invited to send workers the information packs with information sheets, consent forms, reply slips and prepaid return envelopes. A researcher will also present the study to the individual teams and give the information packs to those interested in the study.

6.1.3.2.2 GPs and nurse practitioners

The GPs and nurse practitioners treating people with depression will be invited to take part in the study by the Wellbeing Service team leads who will approach GPs with interest in mental health and send or give them the invitation sheets and/or the information packs for healthcare workers. In addition a researcher will contact the practice managers or staff members dealing with research in medical practices in the Norfolk area to invite GPs and nurse practitioners to take part in the study. They might be invited by a researcher briefly explaining the project at their practice meetings or other means as agreed with the designated staff members in individual surgeries.

6.1.3.2.3 All healthcare workers

If we do not receive sufficient responses through the above processes, we will recruit additional participants by sending reminder letters to individuals we have previously contacted, invitation letters to individuals not previously contacted and by delivering presentations via the IAPT and the Wellbeing Service. Other mental health teams within the NSFT will be invited to join in the study, as agreed with their team leaders in advance.

We will also use a snowballing method and invite healthcare workers who know about this study (who might or might not have already agreed to join in the study) to tell their colleagues about the project. They will be encouraged to give those interested in having more information the researcher's contact details and/or the invitation letter for healthcare workers. Using the

snowballing method we aim to invite healthcare workers treating people with depression and working in any team within the NHS Trusts collaborating with us on this study: the Norfolk and Suffolk NHS Foundation Trust (NSFT), the NHS Norfolk Primary Care Trust and the NHS Great Yarmouth and Waveney Primary Care Trust.

6.1.3.2.4 AM practitioners

Purposive sampling will be used to recruit two to three AM practitioners in order to provide their views for this research. Low interest of this group is anticipated but we believe it is an important population to access because there is a public perception that these treatments, although not evidence based, may be effective against depression. We therefore intend to include this perspective.

In order to identify the AM practitioners for this study, we will first list the alternative therapies for which there is anecdotal evidence for effectiveness against depression. The Yellow Pages and Google will be searched with the aim to create a directory of practitioners offering these therapies in Norwich. We will purposively select ten practitioners from this directory in order to include as many different therapies as possible, and send them an invitation letter via email or post. The first three therapists interested in taking part in the study and meeting the inclusion criteria will be invited to the focus group session. Any other not invited practitioners will be sent a letter informing they were not selected to join in the study. If there is insufficient uptake of participants from this population we will approach another ten practitioners from the directory and repeat this procedure until we have recruited two or three AM therapists.

6.1.3.3   Obtaining consent

We do not intend to meet healthcare workers face-to-face to gain informed consent. They will complete the consent form and return it to us by post. All healthcare workers who meet the inclusion criteria, and send the reply slip and consent form to the researcher, will be contacted by the researcher and informed whether they are invited to take part in the study. This will be decided based on the number of participants already joining in, and the inclusion criteria. The focus groups will be scheduled in accordance with participants' preferences for time and location.

6.1.3.4   Information collected from the healthcare workers

Healthcare workers will be asked to provide the information listed in Table 6. This information will be collected for statistical purposes.

Table 7: Healthcare workers: information collected

Name	Email
Age and gender	Phone number
Work address	Profession

The information about the participants from reply slips and consent forms will be analysed and used as descriptive information of the groups.

6.2 The concept mapping process

Concept mapping methodology consists of two phases. In the first part participants join in focus groups to generate statements about what factors influence treatment choices made by people with depression. In the second part the same participants are invited to perform two individual tasks: prioritizing and clustering of the statements. Data will then be analysed.

For each part, participants will be asked to attend a group meeting which should last no more than 2 hours each. Separate activity sessions will be organized for members of each stakeholder group to prevent interaction between people with depression and the family and friends. These meetings may take place at the same time (in separate rooms) in order to ease travel and time organisation of participants. The groups should include approximately 5-10 people, but sessions will also be held for fewer individuals if needed, to reduce their waiting times. Activity sessions on a one to one basis might be organized on some occasions to meet participants' individual needs. Healthcare workers will have an opportunity to take part via telephone, a short personal meeting with the researcher or in writing, if they cannot attend any of the offered group sessions. This is to maximize their representation in the study.

All participants will be sent a time, date and place reminder two days prior the session via post, email or telephone call.

The sessions will take place in a suitable venue at the University of East Anglia, provided by the NHS Trusts included in the study (e.g. at the Hellesdon Hospital), or in other location as appropriate and agreed with participants. The group meetings will be facilitated by the researcher (or another facilitator) and an assistant, and will last for a maximum of two hours. Attendees will be informed of the health and safety issues, and the ground rules of the meeting (respect of others, no judgement of ideas expressed). The aim of the study and particular tasks will be explained in detail before beginning of each session.

6.2.1 Focus groups

Focus groups are held in the first phase of the concept mapping procedure and will take place within approximately 6 weeks of participants expressing their interest to join in, at a time (and location if applicable) scheduled according to their preferences. During these sessions participants are required to generate as many statements as possible, in response to the given focus. A poster with the focus sentence printed will be put up clearly for all to see throughout the session and to help the cognitive processes. People with depression will be asked to generate as many statements as possible, in

order to complete the following sentence: 'My most recent choice of treatment for depression was influenced by...' Health care workers and family and friends will be asked to complete the following sentence: 'Treatment choices made by people with depression are influenced by...'

All statements used in the latter steps are produced in this phase, and will be recorded on a flip chart and a voice recorder. The quality of the sessions and statements produced depend on the participants' free association and interaction with other group members. Discussion at the meeting will be supported by the facilitator and assistant and they will make sure participants do not feel inhibited to express their ideas.

The focus groups will be audio-recorded to make sure no statements or ideas are missed during the data analysis. The recordings will be transcribed after the sessions and securely stored for 3 years following publication of research reports. After this time the necessity of data storage will be reviewed.

6.2.1.1 *Characteristics of statements*

The facilitator and the assistant are responsible for 'quality' of the focus groups and the statements produced. Statements must meet the following criteria to justify and enable their use in the prioritizing and clustering phases:

a) <u>Clear</u>: Statements must be sufficiently clear to enable their possible applicability to other participants in that group and their use within a concept map. They need to be concrete but not too specific. For example, the statement *'Dr House told me that Prozac is the best medicine for me'* is too specific. Reference to the participant's own GP or to a particular medicine might not apply to other participants. A less specific and more generally useful statement might be: *'My health professional's advice is important for me'*. While being too specific is to be avoided, so is being too general. *'We need a therapy'* is an example of a too general statement.

b) <u>Singular</u>: A statement should only refer to one topic to enable its use in prioritizing and clustering phases. The statement: *'I try to obey my GP and my wife'* contains two different aspects other participants may not find equally important and therefore is not singular.

c) <u>Understandable</u>: Statements must be understandable and unambiguous for all participants and should not contain medical or technical words. An example of an ambiguous statement is: 'I should be prescribed more medication...' 'More' in this case might mean a larger dose of a particular medicine, but could equally mean other drugs in addition to drugs already prescribed. Long and complicated statements should be avoided as should any words that may be the jargon commonly used within one of the groups and not in the others, e.g. 'euthymia' and 'remission'. If in doubt, group members may discuss if the sentence is likely to be understood, bearing in mind that health professionals might understand words or phrases that other participants do not, or vice versa.

After all focus groups have taken place, the research team will review the statements. Any duplicates will be removed and the total number of statements will be kept below 80. Sets of cards will be printed one statement on one card and these cards will be used in the next phase of the study. Below is an example of a card:

Treatment choices made by people with depression are influenced by:

Understanding the side effects of medication.

Structuring sessions: Prioritizing and clustering tasks

After the 'statements review' phase, all participants who had joined in the focus groups will be invited to take part in the second, structuring session. This will take approximately two hours, including a short break with refreshments provided. At the second session each participant will receive one set of cards with statements and will be asked to perform two individual tasks, prioritizing and clustering of the statements. Structuring sessions will take place within approximately 5 months of the focus group meetings.

6.2.1.2 Prioritizing

In the first task participants are asked to sort the cards into five equal piles according to their view of statements' importance, using the following ratings:

Pile 1 = relatively unimportant

Pile 2 = somewhat important

Pile 3 = moderately important

Pile 4 = very important

Pile 5 = extremely important

6.2.1.3 Clustering

Clustering the cards into categories or piles is the second task of the second session. Participants are asked to group together the statements that they think are thematically related. All statements have to be used, and each can only be used once. Participants may not put all statements into a single category, and piles must contain more than one statement. At the end of this task participants should label the categories according to their own views.

6.2.2 Data analysis

The qualitative data (statements) will be noted for each stakeholder group separately and a thematic analysis will be performed to understand differences in topics covered by individual groups.

All statements will then be pooled, reviewed, and if necessary reworded, by the research team. They will be used in the second, quantitative part of the study where participants rank each statement's importance and group the similar ones together. This data will be analysed using a specialised software package called Ariadne:

1) First, a graphical representation of all participants' perspectives will be presented in a two-dimensional graph called 'concept map'. An example of a concept map is shown in Figure 1. Each statement is shown as a single point, and their positions on the 'map' and distances to other points will have been determined by participants' responses during the clustering task. The closer the statements are displayed on the map, the more participants had perceived them to be related.

2) In the cluster analysis Ariadne will group the points on the 'map' that are located close to each other, into approximately 6-9 clusters. The number of clusters will depend on the meaning of sentences. A 'box' will be drawn around each cluster (by Ariadne) to make clear distinctions between them (see Figure 1).

3) Based on the data from prioritizing task, the average rankings of importance will be calculated for each statement individually, and for the clusters. The average importance of each cluster can be viewed on the concept map, and is reflected by the 'height' or thickness of the clusters.

4) The average importance rankings of statements and clusters, as viewed by each stakeholder group and their subgroups, will also be calculated.

In step 5, Interpretation of results, the clusters on the concept map will be given a label which best describes the content or theme of the cluster. This task will be performed as a group discussion within the steering group. An example of a concept map produced by Ariadne software is shown in Figure 1.

Figure 1: A concept map produced by Ariadne software package. Image adapted from (van Bon-Martens et al. 2011)
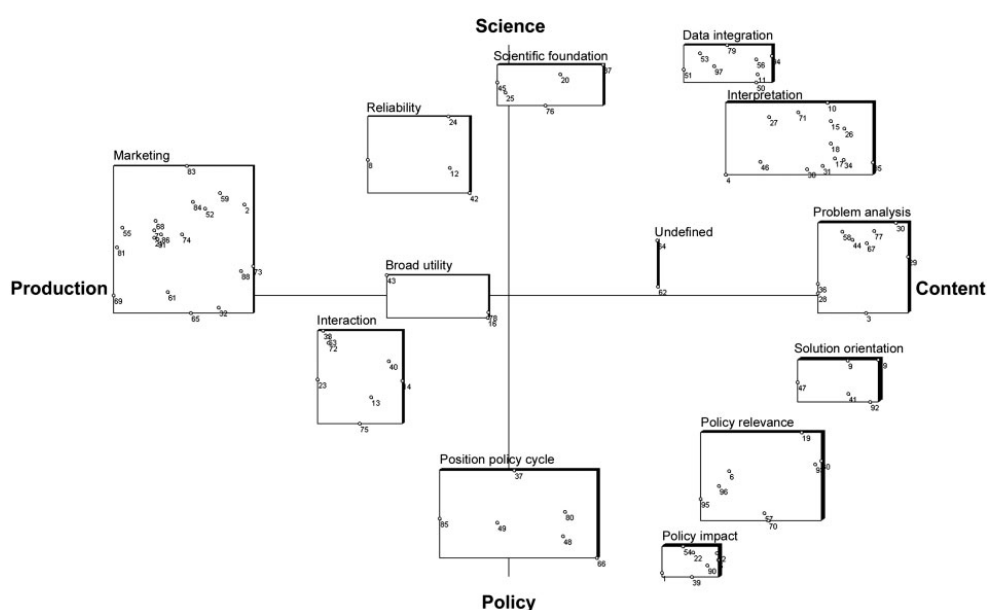
Stage 6 involves the translation of the concept map and agreement on how the results can be used in practice as agreed by the steering group. The concept map sheds light on the views and priorities of the group as a whole and this information can be used as the basis for improving health professionals' and public awareness of the factors that influence choices in depression treatment.

7 Duration of the project

This project will be carried out as a three year PhD study and should be completed by the end of September 2013.

8 Dissemination of the findings

Findings of the study will be disseminated to professionals through the academic journals and conferences. We will work closely with the NHS and charities concerned about mental health to distribute the research findings to health care workers as well as the general public. In addition, all participants will be sent a short final report after the study completion.

The study findings can be used to inform health care providers of the factors affecting patients' treatment choices. This can then help improve doctor patient communication and patients' active participation in treatment decisions.

9 Problems anticipated

9.1 Researcher bias

Some authors suggest that people who are rather communicative and cooperative, and have more socially desirable opinions might be more likely to participate in research studies (Lauber 2005). This may be true especially for focus groups as when discussing ideas within a group, some individuals can feel inhibited to express their views in case the group was to disagree with them. To help participants feel comfortable and to achieve good quality of focus groups, ground rules will be set at every session. These will include no judgement posed on people or opinions expressed, and respecting those who speak. The facilitator and assistant will make sure the rules are followed. In order to limit potential researcher bias facilitators and assistants will support the participants and ask questions on occasion but will not add any ideas or opinions to the group.

9.2 Sampling bias

9.2.1 People with depression

There is a potential for sampling bias when using some recruitment strategies and different methods will be applied to address this issue. Charity clients are likely to be more active in the community than non-clients. A press release or an advert in local newspaper (EDP) can be accessed by a wide scope of the population, but is limited to those buying the particular paper and those who read the relevant pages. To reduce the risk of bias we will also invite volunteers to participate via adverts in GP practices and via contact with healthcare workers. Information about level of education and other demographic data will be collected from participants, to allow us to assess and report these issues in more detail.

9.2.2 Family and friends

Family and friends will be recruited primarily via people with depression, but it is anticipated that some people might not want anyone close to them to take part. In the GP practice poster and the press release we will mention the need to include family and friends in the study, to ensure we recruit a sufficient number of participants in this stakeholder group.

9.2.3 Healthcare workers

We will recruit healthcare workers using convenience sampling, as opposed to random selection. GPs with special interest in mental health will be approached by the service leads of the IAPT and

Wellbeing Service in Norfolk. The researcher will also contact the medical practices in Norwich that are already involved in the study displaying the posters to invite people with depression to take part. This is to maximise recruitment rates of the interested GPs and nurse practitioners.

The decision to include the whole NSFT Trust in inviting the healthcare workers to take part in this study has been made to increase the possibility of recruiting a sufficient number of participants in this stakeholder group. This method will also minimise the unnecessary strain placed on the Service and the participants, and will enable us to include a wider variety of perspectives about the focus question of the study.

9.3 Assessment of depression

People with depression will be recruited to take part in the study if they were recommended to, or they had received treatment for unipolar depression within the past 12 months. They will be asked to provide brief information about their depression treatment in the Baseline questionnaire during a personal meeting with the researcher. This strategy has been decided upon to allow the inclusion of people with depression who have not been clinically diagnosed by their GP and treatment received might include therapies not provided by the NHS.

9.4 Geographical area

9.4.1 People with depression and family and friends

This study is based in Norwich and people from ethnic minorities, those not speaking English and living in rural areas are more likely to be underrepresented in the study. This is likely to negatively affect generalisation of results to other parts of UK with more diverse population and differences in health services provided by other NHS Trusts.

9.4.2 Healthcare workers

Healthcare workers may be recruited from any locality of the NSFT, the NHS Norfolk and the NHS Great Yarmouth and Waveney, as agreed with the relevant team leaders. This method has been chosen to maximise recruitment rates for this stakeholder group, as including all workers from one cluster location would cause significant strain on the Service and workers.

Alternative medicine (AM) therapists practicing in Norwich will be identified via the Yellow Pages and Google. It is likely that AM practitioners who do not have a website or are not listed in the Yellow Pages directory will not be represented in the study.

10 Study administration and ethical issues

10.1 Informed consent

All people who are sent the information sheet will be asked to read it carefully and take at least 24 hours to think about their wish to participate, before they return the reply slip.

Personal meetings with the researcher will be scheduled for people with depression and the family and friends to make sure they understand what the participation involves, to obtain their informed consent and fill in the baseline information questionnaire. These meetings will take place at agreed public places or if necessary, at people's homes. The researcher will strictly adhere to the University Lone worker policy at all times.

Healthcare workers will be asked to post the signed consent form with the reply slip if interested in participation, we do not intend to meet them individually for consenting purposes. Should any suitable participants arrive at any of the meetings without having been consented, consent will be taken face-to-face before the session commences.

Participants will be fully explained what the focus groups and structuring sessions will involve before the beginning of each session. Process consent will be obtained throughout the study to make sure everyone is fully aware of their right to withdraw from the study at any time without giving any reason.

10.2 Safety

10.2.1 Lone worker policy

Visiting participants in their homes or meeting tem in public places in order to obtain their informed consent and discuss the study involves an element of risk for the researcher. The University's Lone Worker Policy will be followed in these situations. In practice this means that prior to every visit, the academic supervisor (or designated member of the research team) will be informed of the address and time of the meeting. The researcher will always carry a fully charged mobile phone with her, and will contact the supervisor (or a designated member of the research team) immediately before and after every meeting, and in case of any problem arising. Should the researcher feel unsafe during a meeting with a participant, she will leave the property immediately and telephone the academic supervisor (and the appropriate emergency services if necessary).

10.2.2 Health and safety at group sessions

Health and safety precautions and insurance for the meeting room will be covered by the venue owners.

10.3 Risks for participants

10.3.1 Unprofessional practice and maltreatment

For health care workers joining in the study, there is a risk the facilitator could be made aware through discussion of unprofessional practice, e.g. prescribing inadequate treatment. For people with depression and their family and friends there is a potential risk that during discussions the researcher could be made aware of maltreatment or abuse. Any practice that is potentially detrimental to a vulnerable person may have to be reported to an appropriate authority. All participants will be advised of this risk in the information sheet provided to them.

10.3.2 Distress and withdrawal of participants

This project is low risk in that all participants are competent, able to give full consent and are being asked questions that are not overly sensitive or personal. Taking part in focus groups and the structuring sessions is anticipated to pose minimal direct risk to participants but some people might experience distress when talking about the factors that influenced their choice of treatment for depression. To deal with such situations the facilitator will inform all participants they can take a break and have tea/coffee provided, at any time. In addition, during the sessions there will be a person available to talk to participants, should anyone become upset. Participants will be free to withdraw from the study at any time without providing a reason and their health care will not be affected in any way. They will also be aware of a confidential method of disclosing information to the researcher or assistant if they prefer a certain issue not to be discussed in a group setting.

If a participant shows signs of stress during the research activities, the researcher will advise them to seek professional help regarding the issue (e.g. from their GP or healthcare worker of usual contact).

There is a potential for additional distress in some people who might make the effort to read the information sheets and return the reply slips and might not be invited to take part in order not to exceed the planned number of participants. This possibility will be emphasized in the information sheet to prevent any unrealistic expectations.

Contact details of the NHS Direct, a mental health charity and the Samaritans will be provided in case people would like to discuss their concerns with an anonymous listening service.

10.4 Benefits for participants

No immediate benefits are anticipated for the participants, but this research has a potential to improve the quality of care offered to future patients with depression. Through discussing the factors that influenced people with depression choose a particular treatment, participants may benefit from better awareness of options available, and meeting other people in similar situations.

Participation in the study will be voluntary and except for travel expenses, no financial or material incentives will be offered. For their effort chief investigator will offer to send the participants a short summary of the results and a reference to the paper once it is published. Free refreshments will be provided during the sessions.

10.5 Participants with disabilities

In order to meet the inclusion criteria of this study, participants must be able to understand and speak English well. This is due to the nature of group and individual exercises performed in this study, i.e. agreeing on wording of statements.

If a participant indicates they are illiterate or have visual impairments, the researcher/facilitator and/or the assistant will make sure the person has fully understood the written information provided, and is able to provide the informed consent. The researcher will take time to read the documents out in full and give simplified explanations if necessary.

10.6 Loss of capacity to consent

A loss of capacity to consent in a participant who had given informed consent is an unlikely situation not anticipated to occur in this study. In the unlikely event of a loss of capacity, the research team would retain the statements generated by that person, and their personal information, such as age, gender, prescribed/recommended treatment for depression. The audio-recordings of the focus groups meetings will be destroyed after transcription. No personally identifiable information of participants will be published and all quotes will be anonymised.

10.7 Anonymity and confidentiality

10.7.1 Access to participant information

In any of the recruitment methods used in this study the researcher is not required and able to access any personal or medical information about any potential participants unless they directly contact the researcher and provide this information. In order for any individual to take part in this research they will be required to first phone or write to the researcher. The relevant contact information is listed in all documents and advertising material. Having expressed their interest in joining in the study they will be contacted by the researcher and the recruitment process will continue as appropriate to the particular method.

10.7.2 **Anonymity and confidentiality of collected data**

Paper documents that contain personal data of participants, or information that could be used to identify participants, will be kept in a locked cabinet in a locked room at the University of East Anglia. These documents will only be accessible to the researcher and her Primary Academic Supervisor. Potential participants will be made aware of the security and storage arrangements of all data, and their informed consent will be sought prior to any data collection. All documents relating to each participant (i.e. consent form, reply slip, questionnaire, data answer sheet) will be allocated a random reference code. The use of the anonymised code will ensure that individuals cannot be identified directly but the researchers can trace back the participants at a later stage if necessary. All data will be anonymised within 12 months of the end of this study. Names and contact information will only be kept for contact purposes.

10.8 Transfer and storage of research data

10.8.1 **Transfer of data**

All data collected during the personal meetings (to obtain consent), focus groups and structuring sessions will be taken to the University of East Anglia by the researcher/facilitator in person as soon as possible after each meeting, and stored appropriately. During transfer from the research site to the UEA the documents containing confidential information will be carried in a lockable briefcase. Depending on location of the research site the researcher will travel to the UEA by various means, including public and private transport. She will attend to the briefcase at all times and will bring the documents to the UEA as soon as possible after the research session, at which point they will be transferred to a locked cabinet in a locked room.

10.8.2 **Storage of data**

All data will be collected and processed according to the Data Protection Act 1998.

10.8.2.1 Personal data

Any electronic documents that contain personal information about participants will be securely stored on the UEA central network server within UEA firewall and will be saved as a password protected document. They will not at any time be transferred by mobile devices. Electronic documents related to this study will be anonymised within 12 months after the end of this study.

All paper documents that contain personal information about participants and (e.g. reply slips, consent forms) will be kept in a locked cabinet in a locked room at the University of East Anglia. The information will be transcribed to digital format and anonymised within 12 months after the end of the study. Paper documents containing personal data will be securely destroyed within 12 months of the end of the study.

10.8.2.2 Research data

Focus groups discussions with participants will be recorded on an audio device and transcribed into digital format after each session by the researcher. All raw data, including focus group recordings, will be securely stored for a minimum of 3 years following publication of research reports. After this time the necessity of data storage will be reviewed.

Reports and publications may contain respondents' direct quotes. These will have been anonymised and will contain no information that could be used to identify any individuals

After the end of the study the Primary Academic Supervisor will take responsibility for all data generated during this research. The data in paper form will be stored in a locked cabinet within a locked room at the University of East Anglia. Electronic files related to the study will be stored in line with the University's guidelines. After 5 years of the end of the study the storage of data and its necessity will be reviewed.

10.9 Resource requirements

Below is a list of requirements for conducting this study:

- A research assistant joining the researcher for group sessions

- Additional facilitator and assistant to run group sessions for family and friends. These sessions are expected to be run in parallel with sessions for people with depression.

- Concept mapping software (Ariadne) for data analysis

- A suitable meeting room for group sessions

- Stationary (pens, paper, flip chart), cards for statements printing, audio recording device

- Paper for printing the information packs, invitation and thank you letters

- Postage costs and envelopes for sending the invitations and information packs

- Refreshments for all group meetings

- Travel expenses for participants, facilitators and assistants

11References

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Appendix 8: Amendment 1, Notice of changes

NRES Committee East of England – Essex

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The Choice study,

Edith Cavell Building

University of East Anglia

Norwich, NR4 7TJ

Email: a.mackovova@uea.ac.uk

Mobile: 07898 287 055

05/03/2012

Dear Sir or Madam,

RE: The Choice study: What factors influence treatment choices made by people with depression? A concept mapping study about views of people with depression, family and friends and healthcare workers.

Reference number: 11/EE/0321

I am writing to submit proposed amendments to the protocol for the above research project to be reviewed by the Research Ethics Committee. Please find enclosed the Notice of substantial amendment, the original and new versions of amended documents, and the new documents proposed to be used in the study. All proposed changes are listed in the table below and explained in detail in the revised version of the protocol (enclosed).

Table 1: The proposed changes in the study documentation and participant recruitment methods

Proposed changes in the study documentation and methods		
Document	**Change proposed**	**Justification of the change**

All participant documentation and the research protocol	The phrase "Norfolk and Waveney Mental Health NHS Foundation Trust" (NWMHFT) to be changed to "Norfolk and Suffolk NHS Foundation Trust" (NSFT). Where abbreviations are used, "NWMHFT" will be changed to "NSFT". The version number and date of the amended documents will be updated.	Change of the NHS Trust name.
All consent forms	Reference to the relevant information sheet for participants has been changed in each consent form.	This is to reflect the version number and date changes.
Research protocol	**Recruitment methods to be added for people with depression:** • An article published in charity newsletters/ magazines briefly explaining the study and inviting people with depression and their family and friends to take part in this research, as approved by the individual charities operating in the Norwich area. • Snowball sampling: we will invite people who have already agreed to take part in the study to tell their family, friends and colleagues about the project. They will be encouraged to give them the researcher's contact details should anyone be interested in having more information or in taking part in the study. **Recruitment methods to be added for family and friends:** • A press release to be publicised via local media outlets specifically inviting people who are close to someone with depression (i.e. their family and friends) to take part in the study. • An article to be published in charity newsletters/ magazines briefly explaining the study and inviting people with depression and their family and friends to take part in this research, as approved by the individual charities operating in the Norwich area. • A poster to be displayed at community places, e.g. churches, supermarkets, etc. in order for it to be seen by as wide a population as possible. This will be done as approved by the relevant authorities governing the particular public places. • Snowball sampling: we will invite people who have already agreed to take part in the study to tell their family, friends and colleagues about the project. They will be encouraged to give them the researcher's contact details should anyone be interested in having more information or in taking part in the study.	The additional recruitment methods have been selected to increase the number of participants in the study.

	Recruitment methods to be added for healthcare workers: • The IAPT (Improving Access to Psychological Therapies) and Wellbeing Service workers to be recruited from the Norfolk and Suffolk NHS Foundation Trust as a whole by the team leads sending workers the information packs and/or the researcher presenting the study to the individual teams. • The GPs and nurse practitioners to be invited to take part in the study by the researcher directly contacting medical practices. The researcher will send the invitation letters, attend the practice meetings or use other similar methods of recruitment as agreed with the practice managers or other staff members specifically dealing with research. • Snowball sampling: we will invite healthcare workers who are aware of the study or who have already agreed to take part to tell their colleagues about the project. They will be encouraged to give those interested in having more information the researcher's contact details and/or the invitation letter for healthcare workers.	
Research protocol	I have amended the following sections in the protocol: 9.2.3 Sampling bias: healthcare workers, and 9.4.2 Geographical area: healthcare workers	This was done to reflect the changes of recruitment methods used in the study and to ensure the information provided in the protocol is consistent.

Thank you for your review of the proposed amendments in advance.

Please do contact me if you require additional information or have any comments.

Kind regards

Ada Mackovova, Chief Investigator

Appendix 9: Amendment 1, Ethics approval

NHS

Health Research Authority

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29 March 2012

Miss Ada Mackovova
PhD student School of Nursing Sciences
University of East Anglia
Norwich
NR4 7TJ

Dear Miss Mackovova

Study title:	What factors that influence treatment choices made by people with depression? A concept mapping study about views of people with depression, their family and friends, and healthcare workers.
REC reference:	11/EE/0321
Amendment number:	
Amendment date:	

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Poster for Family & Friends	Version 1	29 February 2012
No Thank You Letter	Version 3	29 February 2012
Reply Slip for Healthcare Workers	Version 3	29 February 2012
Reply Slip for Family & Friends	Version 3	29 February 2012
Reply Slip for People with Depression	Version 3	29 February 2012
Questionnaire: Family & Friends	Version 3	29 February 2012
Questionnaire: People with Depression	Version 3	29 February 2012
Letter of invitation to participant	Version 3	29 February 2012
Participant Consent Form: Healthcare Workers	Version 3	29 February 2012
Participant Consent Form: Family & Friends	Version 4	29 February 2012
Participant Consent Form: People with Depression	Version 4	29 February 2012
Participant Information Sheet: Healthcare Workers	Version 3	29 February 2012

A Research Ethics Committee established by the Health Research Authority

Participant Information Sheet: Family & Friends	Version 4	29 February 2012
Participant Information Sheet: People with Depression	Version 4	29 February 2012
Protocol	Version 3	29 February 2012
Notice of Substantial Amendment (non-CTIMPs)		
Covering Letter		
Reply Slip for Family & Friends	Version 2	31 August 2011
Reply Slip for People With depression	Version 2	31 August 2011
Useful Information Sheet	Version 3	29 February 2012
Charity Article	Version 1	29 February 2012
Press Release for Family & Friends	Version 1	29 February 2012
Participant Information Sheet: Healthcare Workers	Version 2	31 August 2010
Participant Information Sheet: Family & Friends	Version 3	18 October 2011
Participant Information Sheet: People With Depression	Version 3	18 October 2011
Protocol	Version 2	31 August 2011
No Thank You Letter	Version 2	31 August 2011
GP Practice Poster	Version 3	29 February 2012
GP Practice Poster	Version 2	31 August 2011
Useful Information Sheet	Version 2	31 August 2011
Reply Slip for Healthcare Workers	Version 2	31 August 2011
Questionnaire: Family & Friends	Version 2	31 August 2011
Questionnaire: People with Depression	Version 2	31 August 2011
Letter of invitation to participant	Version 2	31 August 2011
Participant Consent Form: Healthcare Workers	Version 2	31 August 2011
Participant Consent Form: Family & Friends	Version 3	18 October 2011
Participant Consent Form: People With depression	Version 3	18 October 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/EE/0321:	Please quote this number on all correspondence

Yours sincerely

Dr Niki Bannister
Chair

E-mail: suzanne.emerton@eoe.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Mrs Susan Steel
Research Contracts Manager
UEA
Norwich
NR4 7TJ

Dr Bonnie Teague,
Norfolk and Waveney Mental Health NHS Foundation Trust
R & D Dept
Drayton High Road
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NRES Committee East of England - Essex

Attendance at Sub-Committee of the REC meeting on 23 March 2012

Name	Profession	Capacity
Dr Niki Bannister	Retired Hospital Doctor	Expert
Mrs Helen Watkins	Financial Manager	Lay

A Research Ethics Committee established by the Health Research Authority

Appendix 10: Amendment 1, Norfolk and Suffolk NHS Foundation Trust approval

Norfolk and Suffolk NHS

NHS Foundation Trust

Research and Development Dept
Hellesdon Hospital
Drayton High Road
Norwich
NR6 5BE
Telephone 01603 421552
E mail: RDOfficemailbox@nwmhp.nhs.uk

Ada Mackovova
c/o Karen Lester
School of Nursing
Edith Cavell Building
University of East Anglia
Norwich
NR4 7TJ

14th May 2012

Dear Miss Mackova

Re: The Choice Study (2011MH48), AMENDMENT 1 APPROVAL.

Further to the initial study approval letter, dated 2nd November 2011, minor amendments have been received for research governance review and approval. We understand that Ethical Approval for the amendment was granted on 29th March 2012 by NRES Committee East of England - Essex

I am pleased to inform you that the amendments have been approved, and so may proceed. This approval is valid in the following organisation:

- **Norfolk and Suffolk NHS Foundation Trust**

The final list of amendment documents reviewed and approved are as follows:

Document	Version #	Date
Poster for Family and Friends	1	29/02/2012
No Thank You Letter	3	29/02/2012
Reply Slip for Healthcare Workers	3	29/02/2012
Reply Slip for Family and Friends	3	29/02/2012
Reply Slip for People with Depression	3	29/02/2012
Questionnaire: Family and Friends	3	29/02/2012
Questionnaire: People with Depression	3	29/02/2012
Letter of Invitation to Participant	3	29/02/2012
Participant Consent Form: Healthcare Workers	3	29/02/2012
Participant Consent Form: Family and Friends	4	29/02/2012
Participant Consent Form: People with Depression	4	29/02/2012
Participant Information Sheet: Healthcare Workers	3	29/02/2012
Participant Information Sheet: Family and Friends	4	29/02/2012
Participant Information Sheet: People with Depression	4	29/02/2012
Protocol	3	29/02/2012

Chair: Maggie Wheeler
Chief Executive: Aidan Thomas
Trust Headquarters: Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE
Tel: 01603 421421   Fax: 01603 421440   www.nsft.nhs.uk
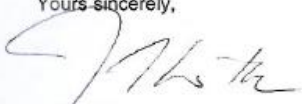
Useful Information Sheet	3	29/02/2012
Charity Article	1	29/02/2012
GP Practice Poster	3	29/02/2012

Your research governance approval is valid providing you comply with the conditions set out below:

1. You notify the Research and Development Office should you deviate or make changes to the approved documents.
2. You alert the Research and Development Office by contacting me, if significant developments occur as the study progresses, whether in relations to the safety of individuals or to scientific direction.
3. You complete and return the standard annual self-report study monitoring form when requested to do so at the end of each financial year. Failure to do this will result in the suspension of research governance approval.
4. You comply fully with the Department of Health Research Governance Framework, and in particular that you ensure that you are aware of and fully discharge your responsibilities in respect to Data Protection, Health and Safety, financial probity, ethics and scientific quality. You should refer in particular to Sections 3.5 and 3.6 of the Research Governance Framework.
5. You ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice, Data Protection Act and Human Rights Act. Unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

If you require any further confirmation, please contact me at the above address.

Yours sincerely,

Dr Jon Wilson
Deputy Medical Director (Research)

Appendix 11: Amendment 2, notice of changes

UEA
University of East Anglia

NRES Committee East of England – Essex

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08/05/2012

Dear Sir or Madam,

RE: The Choice study: What factors influence treatment choices made by people with depression? A concept mapping study about views of people with depression, family and friends and healthcare workers.

Reference number: 11/EE/0321

I am hereby submitting a notice of protocol amendment for the above research project to be reviewed by the Research Ethics Committee. Through supervision it has become evident that there is an undesired degree of ambiguity about the inclusion criteria and the recruitment of participants. In order to make the information in the protocol clearer we propose the sections below to be added to/ changed in the study protocol. Please find enclosed the current and revised versions of the protocol and the IRAS amendment notice form.

Section in the Protocol/ IRAS form	Proposed change	Reason for the change
Protocol	*Recruitment of people with depression [change in*	This is to ensure sufficient

section 6.1.1.2 (a)	*wording]:* Contact via the healthcare workers: as agreed with their team leaders, the healthcare workers from any locality or team of the NSFT, the NHS Norfolk and the NHS Great Yarmouth and Waveney may be asked to give the information sheets for people with depression to their clients meeting the inclusion criteria in this study.	numbers of participants are recruited in the study.
Protocol section 6.1.3.2	*Recruitment of healthcare workers [change in wording]:* Approximately 30 healthcare workers will take part in the study, including GPs, nurses, mental health nurses, IAPT and Wellbeing Service workers, link workers, AM practitioners and other healthcare workers meeting the inclusion criteria.	This is to ensure that any relevant healthcare workers can be included in the study to provide their views about the research topic.
Protocol section 6.1.3.2.3	*Recruitment of healthcare workers*: Other mental health teams within the NSFT will be invited to join in the study, as agreed with their team leaders in advance.	This is to ensure that any relevant healthcare workers meeting the inclusion criteria can be included in this study.
	We will also **use a snowballing method and** invite healthcare workers who know about this study (who might or might not have already agreed to join in the study) to tell their colleagues about the project.	Wording changed for clearer meaning
	Using the snowballing method we aim to invite healthcare workers treating people with depression and working in any team within the NHS Trusts collaborating with us on this study: the Norfolk and Suffolk NHS Foundation Trust (NSFT), the NHS Norfolk Primary Care Trust and the NHS Great Yarmouth and Waveney Primary Care Trust.	This statement has been added to make clear how the snowballing method is used.
Protocol section 6.2; IRAS form section A18	The sessions will take place in a suitable venue at the University of East Anglia, **provided by the NHS Trusts included in the study** (e.g. at the Hellesdon Hospital), **or at other location as appropriate and agreed with participants**.	This is to ensure that the participants who might be unable to attend the group sessions can take part in the study. On such occasions the location of sessions will be agreed with the participants.
Protocol section 9.2.1	To reduce the risk of bias we will also invite volunteers *[people with depression]* to participate via adverts in GP practices and via contact with **healthcare workers.**	This is to reflect the above changes in recruitment of people with depression.
Protocol section 9.4.2	Healthcare workers may be recruited from any locality of the NSFT, the NHS Norfolk and the NHS Great Yarmouth and Waveney, as agreed with the relevant team leaders. This method has been chosen to maximise recruitment rates for this stakeholder group, as including all workers from one cluster location would cause significant strain on the Service	Wording of this section has been amended to reflect the above changes in recruitment of healthcare workers.

	and workers.	

Please do contact me if you require additional information or have any comments regarding the proposed changes to the protocol.

Thank you in advance for your review of the above amendments.

Kind regards

Ada Mackovova

Chief Investigator

Appendix 12: Amendment 2, Ethics approval

NHS
Health Research Authority

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a.mackovova@uea.ac.uk

07 June 2012

Miss Ada Mackovova
PhD student School of Nursing Sciences
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Norwich
NR4 7TJ

Dear Miss Mackovova

Study title:	**What factors that influence treatment choices made by people with depression? A concept mapping study about views of people with depression, their family and friends, and healthcare workers.**
REC reference:	**11/EE/0321**
Amendment number:	**Amendment AM02**
Amendment date:	10 April 2012
Amendment Summary:	**Substantial Amendment to protocol, Change of wording in protocol for recruitment of people with depression, change to wording in Protocol for recruitment of healthcare workers, Recruitment of Healthcare Workers other mental health teams within the NSFT will be invited to join in the study, use of snowballing method inviting healthcare workers who know of the study to join in the study, Sessions to take place in a suitable venue at the University of East Anglia provided by the NHS Trusts included in the study or at other locations as appropriate and agreed with participants, To reduce the risk of bias we will also invite volunteers (with depression) to participate via adverts in GP practices and via contact with healthcare workers, Wording of section 9,4.2 of the Protocol has changed to reflect the above changes in recruitment of healthcare workers.**

T

The above amendment was reviewed by the Sub-Committee on 08 June 2012 by email correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	Version 4	10 April 2012
Notice of Substantial Amendment (non-CTIMPs)		10 April 2012
Covering Letter		08 May 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/EE/0321:	Please quote this number on all correspondence

Yours sincerely

PP *M. Johnson.*

Dr Niki Bannister
Chair

E-mail: melanie.johnson@eoe.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust
bonnie.teague@nsft.nhs.uk

Mrs Susan Steel: **ue.Steel@uea.ac.uk**

NRES Committee East of England - Essex

Attendance at Sub-Committee of the REC meeting on 08 June 2012

Name	Profession	Capacity
Dr Niki Bannister	Retired Hospital Doctor	Expert
Mr Alan Edwards	Retired Company Director	Lay
Dr Alan Lamont	Consultant Oncologist	Expert

Appendix 13: Amendment 2, Norfolk and Suffolk NHS Foundation Trust approval

Norfolk and Suffolk **NHS**

NHS Foundation Trust

Research and Development
The Knowledge Centre
Hellesdon Hospital
Drayton High Road,
Norwich, NR65BE
Telephone 01603 421255
E mail: RDofficemailbox@nsft.nhs.uk

Miss Ada Mackovova
PhD student School of Nursing Sciences
Edith Cavell Building
University of East Anglia
Norwich
NR4 7TJ

27th June 2012

Dear Miss Mackovova

Re: The Choice Study (2011MH48) AMENDMENT 2 APPROVAL.

Further to the initial study approval letter, dated 2nd November 2011, a substantial amendment has been received for research governance review and approval. We understand that Ethical Approval for the amendment was granted on 7th June 2012 by NRES Committee East of England – Essex.

I am pleased to inform you that the amendments have been approved, and so may proceed. This approval is valid in the following organisation:

- **Norfolk and Suffolk NHS Foundation Trust**

The final list of amendment documents reviewed and approved are as follows:

Documents	Version	Date
Protocol	4	10.04.12

Your research governance approval is valid providing you comply with the conditions set out below:
1. You notify the Research and Development Office should you deviate or make changes to the approved documents.
2. You alert the Research and Development Office by contacting me, if significant developments occur as the study progresses, whether in relations to the safety of individuals or to scientific direction.
3. You complete and return the standard annual self-report study monitoring form when requested to do so at the end of each financial year. Failure to do this will result in the suspension of research governance approval.
4. You comply fully with the Department of Health Research Governance Framework, and in particular that you ensure that you are aware of and fully discharge your responsibilities in respect to Data Protection, Health and Safety, financial probity, ethics and scientific quality. You should refer in particular to Sections 3.5 and 3.6 of the Research Governance Framework.
5. You ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice, Data Protection Act and Human Rights Act.

Chair: Maggie Wheeler
Chief Executive: Aidan Thomas
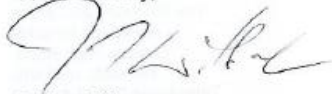Trust Headquarters: Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE
Tel: 01603 421421   Fax: 01603 421440   www.nsft.nhs.uk

Unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

If you require any further confirmation, please contact me at the above address.

Yours sincerely,

Dr Jon Wilson
Deputy Medical Director (Research)

Appendix 14: Amendment 1 and 2, NHS Norfolk and Waveney approval

2011MH48 Acceptance of Amendments

Symms Clare [Clare.Symms@norfolk.nhs.uk]

Sent: 25 June 2012 15:10
To: Ada Mackovova (NSC)
Cc: Richard Gray (NSC); Susan Steel (REN)

Miss Mackovova

Re: 2011MH48. What factors that influence treatment choices made by people with depression? A concept mapping study about views of people with depression, their family and friends, and healthcare workers. The Choice Study.

Amendment Ref: Substantial Amendment 1 (29th February 2012)

Substantial Amendment 2 (10th April 2012)

Amendment Description:

- SA1 – Update of information to reflect updated name of Trust (NSFT); Further recruitment methods added including article in charity magazines, press release, posters in community venues, snowballing via friends & families / work colleagues; Update to protocol to reflect changes
- SA2 – Clarification of wording in protocol relating to recruitment methods

Further to your submission of the above amendment this has now been reviewed for any research governance implications.

Apologies for the delay in notification, however I am pleased to inform you that the following NHS organisations are able to accommodate the above amendment and the amendment may be implemented under the existing NHS permission within these sites / PICs:

- GP Practices in NHS Norfolk & Waveney

You are reminded to update the R&D office at NHS Norfolk with details of all practices involved in your study.

Please note that continued NHS Permission is granted on the basis of the information supplied in the amendment notice/letter and supporting documentation, if anything subsequently comes to light that would cast doubts upon, or alter in any material way, any information contained in this or any other amendment, or the original application, there may be implications for continued NHS Permission.

If you have any queries regarding this or any other project please contact Paul Mills, R&D Officer at paul.mills@norfolk.nhs.uk. Please note, the reference number for this study is **2011MH48** and this should be quoted on all correspondence.

Kind Regards

Clare Symms
Research Governance Manager

NHS Norfolk, Lakeside 400, Old Chapel Way, Broadland Business Park, Thorpe St Andrew, Norwich, NR7 0WG

Switchboard - 01603 257000
Direct Dial - 01603 257020
Fax - 01603 257292
www.norfolk.nhs.uk/research

NHS Norfolk host the research management and governance services for NHS Norfolk, Norfolk Community He
& Care NHS Trust, NHS Suffolk and NHS Great Yarmouth & Waveney.

CATCH IT, BIN IT, KILL IT

Before printing, think about the environment

Appendix 15: Recruitment press release 1

Press release for the Eastern Daily Press, Version 2: 31/08/2011

Researchers at the University of East Anglia are looking for people who have depression* to help them understand more about how people make treatment choices.

Patients' preferences for treatment have a strong influence on their adherence to treatment but we do not know what those are based on. 'The Choice Study' aims to find out what factors patients consider when selecting a therapy for depression.

As well as surveying people with depression themselves, the researchers also want to interview their family and friends.

Professor Richard Gray, who is leading the research in the University's School of Nursing Sciences, said: "Our aim is to understand how people with depression make decisions about their treatment."

"We want to find out what people take into account when choosing a treatment. Do patients really know what they are opting for when selecting antidepressants or talking therapy for their depression, or not taking any treatment at all?"

The researchers are looking for 60 people to volunteer to take part – 30 who have been recommended or have received treatment for depression* by a health care worker using antidepressants, psychological therapy, or alternative therapies, and 30 family members and friends.

"We are interested to talk to volunteers about the treatment choices that were offered to them, what treatment they chose, and how they made that decision," said Professor Gray.

"Their views are really important for us and will be used to help patients make informed decisions about treatment for depression" he added.

Volunteers must be over 18, and have been recommended or treated for depression* within the last 12 months, or be a close family member or friend to such person. Participants will be invited to join in two small group sessions (with about 6 other volunteers) at the University of East Anglia, taking about 2 hours each.

* We are inviting people with depression to take part. The study is not seeking to recruit people with bipolar disorder or other mental illness.

To find out more about the research or to volunteer, please contact the researcher Ada Mackovova by emailing a.mackovova@uea.ac.uk or call 07707 298 277.

Appendix 16: Recruitment press release 2

Press Release for recruitment of family and friends, version 1: 29/02/2012

FOR IMMEDIATE RELEASE

Family and friends of people with depression are needed for research at UEA

Researchers at the University of East Anglia are looking for close friends and family of people suffering from depression for a study investigating how people with the illness make treatment choices.

Patients' preferences for treatment have a strong influence on their adherence to treatment but it is not yet known what those are based on. The 'Choice Study' aims to find out what factors patients consider when selecting a therapy for depression.

Prof Richard Gray, the lead researcher in the University's School of Nursing Sciences, said: "Our aim is to understand how people with depression make choices about their treatment. Do people really know what they are opting for when taking medication, talking therapies or no treatment at all?"

"The views of family and friends are really important for us, and will be used to help patients make informed decisions about treatment for depression in the future."

Volunteers must be over 18, and be a close family member or friend to a person who has received or been recommended to receive treatment for depression within the past year. The study is not seeking to recruit family or friends of people with bipolar disorder or other mental illness other than depression.

Participants will be invited to join in two small group sessions (with about four other volunteers) at the University of East Anglia, taking about two hours each.

To find out more about the research or to volunteer, please contact Ada Mackovova by emailing a.mackovova@uea.ac.uk or calling 07707 298 277.

ENDS

EDITOR'S NOTES

1/ For more information or to set up an interview, please contact Fiona Billings in the UEA Press Office on 01603 592226 or email f.billings@uea.ac.uk.

2/ The University's School of Nursing Sciences is ranked third in the UK for Nursing and Paramedical Studies (Guardian University Tables, 2012) and seventh in the UK for Nursing (The Complete University Guide, 2012). www.uea.ac.uk/nsc.

Appendix 17: Recruitment article published in the Eastern Daily Press

NORWICH

Volunteers are needed for new UEA study

University of East Anglia researchers are looking for volunteers for a study about depression.

The Choice Study will look at what factors patients consider when selecting a therapy for depression. As well as surveying people with depression, the researchers also want to interview family and friends. It is not seeking to recruit people with bipolar disorder or other mental illness.

Prof Richard Gray, who is leading the research at the School of Nursing Sciences, said: "We want to find out what people take into account when choosing a treatment. Do patients really know what they are opting for when selecting anti-depressants or taking therapy for depression, or not taking any treatment at all?"

The researchers are looking for 60 volunteers – 30 who have been recommended for or have received treatment for depression and 30 family members and friends.

Volunteers must be over 18 years old.

■ To find out more or to volunteer, call researcher Ada Mackovova on 07707 298277 or email a.mackovova@uea.ac.uk

Appendix 18: Recruitment article published in the Norwich Evening news

News

Newsdesk ☎ 01603 772443

People needed to help with research into depression

Researchers at the University of East Anglia are looking for volunteers to help with a study about depression.

The Choice Study aims to find out what factors patients consider when selecting a therapy for depression.

As well as surveying people with depression themselves, the researchers also want to interview their family and friends. The study is not seeking to recruit people with bipolar disorder or other mental illness.

Prof Richard Gray, who is leading the research in the university's School of Nursing Sciences, said: "We want to find out what people take into account when choosing a treatment. Do patients really know what they are opting for when selecting antidepressants or talking therapy for their depression, or not taking any treatment at all?"

The researchers are looking for 60 volunteers – 30 people who have been recommended for or have received treatment for depression, and 30 family members and friends.

Volunteers, who must be over 18 years old, will be invited to join two small group sessions with about six other volunteers at the UEA. Each session should take about two hours.

→ To find out more or to volunteer, call researcher Ada Mackovova on 07707 298277 or email a.mackovova@uea.ac.uk

Have you got a crime story?

Contact Peter Walsh on 01603 772439 or email peter.walsh@archant.co.uk

Two charged with kidnap

Two people have appeared in court charged with kidnap and false imprisonment offences.

Lee Grey, 26, of Waterloo Road, Norwich, and Rozzanne Matthews, 33, of Waterloo Road, Norwich, both appeared at Norwich Magistrates Court yesterday charged with kidnap and false imprisonment in Norwich on November 3 this year.

Applications to bail both defendants, who appeared in custody, were refused by magistrates.

They were sent for trial at Norwich Crown Court and will be remanded in custody until the next hearing on November 21.

www.eveningnews24.co.uk 7

Appendix 19: Recruitment article published in the Ipswich Star

Support for footballer

BY CHRIS HARRIS

chris.harris@archant.co.uk

IPSWICH/SAXMUNDHAM: Friends have rallied to boost a popular Suffolk footballer who was allegedly stabbed during an incident at an Ipswich home.

William Felton, from Saxmundham, is recovering in hospital after suffering serious knife wounds in the disturbance in Witney Close.

The footballer, who was allegedly attacked at around 5am on April 6, is believed to be 32 years old and a player for Saxmundham Sports Football Club.

Friends of Mr Felton, nicknamed 'Bubs', have posted on his page on social networking site Facebook in a bid to help lift his spirits.

Angie Brown, formerly of Leiston High School, said: "I hope you're doing okay today and not feeling too much pain. Best wishes for the quickest possible recovery, hope to see you back on your feet soon."

Karen Moore, one of around 20 people to post message of support, said: "[You're] such a fighter and we love you more than words can say."

KNIFE WOUNDS: William Felton, who is recovering in hospital

Three women and two men from Ipswich – who were arrested on suspicion of attempted murder in connection with the incident – have been released on bail while police complete their investigations.

■ Would you like to send a message of support to Mr Felton? Write to: Your Letters, Ipswich Star, 30 Lower Brook Street, Ipswich, IP4 1AN or e-mail starletters@archant.co.uk

Volunteers needed for new study

EAST ANGLIA: Researchers are looking for close friends and family of people suffering from depression for an investigative study.

The study, which will be carried out at the University of East Anglia, will investigate how people with the illness make treatment choices.

The Choice Study aims to find out what factors patients consider when selecting a therapy for depression as patients' preferences have a strong influence on their adherence to treatment.

Lead researcher professor Richard Gray said: "The views of family and friends are really important for us, and will be used to help patients make informed decisions about treatment for depression in the future."

To find out more, contact Ada Mackovova on 07707 298277.

Appendix 20: Recruitment article published in the MIND magazine

Do you or does someone you know have depression?

Volunteer Opportunities

How do you decide where to seek help and what therapy to choose?

Researchers Ada Mackovova and Prof Richard Gray from the University of East Anglia are looking for people with depression and their family and friends to help understand more about how people make treatment choices.

Ada explains "People make their own decisions about how to treat depression and we are keen to find out what they take into account when choosing their treatment. We want to know what reasons draw some people to prefer medication and others talking therapy for their depression. What makes some select complementary therapies and why do others not seek any help at all?"

Prof Gray added: "People's views are really important for us and will be used to help patients make informed decisions about treatment for depression in the future."

Volunteers must be over 18 and have been recommended or treated for depression within the last 12 months, or be a close family member or friend to such a person. Participants will be invited to join in two small group sessions (with about 4 other volunteers) at the University of East Anglia, taking about 2 hours each. To find out more about the research or to volunteer, please contact researcher Ada Mackovova at a.mackovova@uea.ac.uk

Call 07707 298 277.

Appendix 21: Recruitment poster 1

Volunteers Needed!

For a research project:

The Choice Study

How do people choose their treatment for depression?

- Are you aged over 18?
- Have you received treatment for or been recommended for treatment for depression* within the past year?
- Are you close to a person with depression?

We would like to talk to you about the treatment choices that were offered to you or the person close to you, what treatment they chose and how the decision was made.

* We are inviting people with depression to take part. This study is not seeking to recruit people with bipolar disorder or other mental illness.

Free Refreshments and Travel Expenses Paid

For more information contact:
Ada Mackovova
Email: a.mackovova@uea.ac.uk or telephone 07707 298277

This study is run in collaboration with **Norfolk and Suffolk NHS Foundation Trust**, NHS Norfolk, NHS Great Yarmouth and Waveney, and Age UK.

NHS

Version 3: 29/02/2012

Appendix 22: Recruitment poster 2

Appendix 23: Invitation letter to healthcare workers

![UEA University of East Anglia logo]

Ada Mackovova, The Choice Study

Edith Cavell Building, University of East Anglia

Norwich Research Park

Norwich, NR4 7TJ

Email: a.mackovova@uea.ac.uk, Tel: 07707 298 277

Dear Sir or Madam

Re: Invitation to participate in The Choice Study: What factors influence treatment choices made by people with depression?

We would like to invite you to take part in a research study about how people with depression make treatment decisions. People's preferences have a strong influence on adherence to therapy, but we do not know what they are based on. The purpose of this study is to provide a better understanding of what factors influence treatment choices made by people with depression. We are interested in your opinion about how people with depression make treatment choices.

You are invited to take part if you have worked with a person with depression within the past 12 months. Participation is voluntary and you can withdraw from the study at any time without giving a reason. The project is conducted in two parts:

1) **Focus group sessions** to produce as many statements as possible, completing the sentence: "Treatment choices made by people with depression are influenced by..." The location, time, and form of these sessions will be of your preference, e.g. a short (15 minutes) phone conversation or a personal meeting. Responses from all participants will be reviewed and individually printed on cards as statements.

2) **Structuring session** will take place within 5 months of the focus group meeting. You will be invited to (1) rank the importance of the individual statements about how people with depression make treatment choices, and to (2) put statements that seem to go together into groups. Duration of this part will depend on the number of statements but should take no longer than 1-2 hours.

The results of this study will be published in academic journals and we will also send you a summary of findings once the study is completed.

If you have any questions or would like to take part in this study, please do contact me. Thank you very much for your time and effort, and for reading this letter.

Yours Sincerely,

Ada Mackovova, researcher

Appendix 24: Participant Information sheet
for people with depression

University of East Anglia

Information sheet – People with depression (Version 4. 29/02/2012)

The Choice Study: What factors influence treatment choices made by people with depression?

Dear Sir or Madam,

We would like to invite you, a person with depression, to take part in a research study looking at the factors that influenced your choice of treatment. Your opinion is very important to us. After talking to you we will collate the information gathered and use it to enable healthcare workers to have a better understanding of people's needs in this matter.

We are also interested in views of a person who is close to you, i.e. your family and friend. This can be your partner, spouse, or someone close to you. If you would like to nominate such a person for this study, please hand them the sheet titled "Information sheet for family and friends". You can join in the study even if you do not nominate a family and friend.

The following pages contain information about our project. Yours and your family and friend's participation is entirely optional and if you change your mind and do not want to take part anymore you are free to withdraw from the study at any time. You do not have to give us any reason. Before you decide whether or not you would like to take part it is important that you understand why this study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

If you would like to take part please complete the enclosed reply slip and return it to us in the pre-paid envelope provided. Ada, the researcher will contact you within one week of receiving your reply slip to arrange a personal meeting to discuss the study with you, answer your questions and ask you to sign a consent form. You will also be asked to fill in a short questionnaire that should take no more than 10 minutes to complete. This meeting will take place at a community location agreed with you. If that would be difficult for you please discuss alternatives with the researcher. If you have any comments or questions about this study, please contact the researcher Ada Mackovova.

Thank you for your time, Yours faithfully, Ada Mackovova, researcher

NHS

*This study is run in collaboration with **Norfolk and Suffolk Foundation NHS Trust**, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.*

What is the purpose of this research?
Healthcare workers and patients often have different perceptions about treatment for depression. Patients' preferences play an important role in their acceptance and adherence to therapy, and even ultimate treatment outcomes, but we still do not know what they are based on. In this study, we aim to gain a better understanding of how people with depression make their treatment choices, and what is important to them.

To do this we will gather the opinions of 30 people with depression, 30 family members and friends of these people and 30 healthcare workers. We will compare these groups to see how similar or different their views are about people's treatment choices.

The findings of this study can help healthcare workers better understand the patients' perception of different treatments and support patients in their informed decision-making.

This study is being undertaken for educational purposes, as part of Ada Mackovova's PhD.

Are there any inclusion criteria?
We invite people with depression who have been recommended or prescribed treatment by a healthcare worker or alternative medicine therapists. This includes your GP, nurse practitioner, psychologist, herbalist or other practitioners.

We are inviting people with depression to join in this research, including people with pre-natal and post-natal depression. The study is not seeking to recruit people with bi-polar disorder or other mental illness.

All participants need to be adults aged over 18 and speak English.

Do I have to take part?
It is completely up to you whether you take part. It is important that you read this information sheet so that you can make an informed decision. If you change your mind, you can withdraw from the study at any time. You do not have to give us any reason and your health care will not be affected in any way.

Who is the 'family and friend' and why should they participate?
The 'family and friend' is an English speaking adult who is close to you, for instance your partner, spouse, parent, sibling, or a close friend or family member. Their views are very important and will help us understand better how people make their treatment choices. If you would like to nominate a person for this study, please write their name in the reply slip, and give them the Information sheet for family and friends, that is enclosed. You can take part even if you do not nominate a family and friend for this study.

What will happen to me if I take part?
After receiving your reply slip, Ada, the researcher will contact you within one week to arrange a personal meeting with you and your family and friend (if participating). This will be a short, up to 30-60 minute discussion and will normally take place at a community location as agreed with you. Ada will talk to you about the study, and answer your queries. If you wish to take part you will be asked to sign the consent form and fill in a short questionnaire that takes no more than 10 minutes.

Within another 4-6 weeks you will be invited to an informal group discussion with about 6 other people at the University of East Anglia in Norwich, at a time and day you prefer. You are welcome to arrive together with your family and friend as there will be two separate sessions taking place at the same time. The task for the group will be to think of as many ideas as possible, to complete the sentence: "**My most recent treatment choice for depression was influenced by...**" You can say as many or as few things as you feel comfortable with. We will note the group's ideas on a flip chart, and record the session on a tape to make sure we do not miss any important issues discussed. We will not note details about who said any particular statement.

The second session will take place within 5 months of the initial session and you will work on two individual tasks. We will give you a set of cards with statements about how people make depression

treatment choices. First, you will be invited to say which are more or less important in informing people's treatment choices. In the second part you will be asked to put the statements that seem to go together into groups.

All meetings will be led by a trained and friendly facilitator (this will be the researcher, Ada Mackovova or her colleague/supervisor) and at least one assistant. Each session will take maximum of 2 hours including a break. We will provide the refreshments and reimburse you for travel expenses.

Have a problem with group sessions?
If you are interested in taking part but for any reason feel uncomfortable with any aspect of this study, please contact us and we can discuss other options with you.

If I want to take part what do I need to do?
If you would like to take part, please:
1. Give the pack titled "Information sheet for the family and friends" to a person you nominated. You can still take part if you do not nominate anyone.
2. Fill in the reply slip and send it to us in the pre-paid envelope provided.
3. Take part in a focus group at time and day that is convenient for you.
4. Take part in the second session within about 5 months later. We will arrange it at your convenience.

Expenses and payments
We will pay your travel expenses for our study and provide free refreshments, but unfortunately we do not have funds to compensate you for your time.

What are the possible disadvantages and risks of taking part?
The risk of harm as a result of participation in this study is very low. On some occasions thinking about, and discussing your depression treatment decisions might make you feel upset. You are welcome to take a break or stop your participation if you wish to, without giving us any reason. If your feelings of distress persist, we recommend that you visit your GP or other healthcare worker of usual contact.

A disadvantage arising from your participation is that you spend approximately four hours of your time, which will not be paid for. We will reimburse you for travel expenses and provide free refreshments during both activity sessions.

What are the possible benefits of taking part?
There might be no immediate or direct benefits to you. We will try to make the sessions enjoyable and interesting for you, and you will have the opportunity to meet new people – other participants. This research will help us understand how people make their treatment choices and we hope that health care workers will use our findings when treating future patients.

Will my taking part in this study be kept confidential?
All of the information that you provide us for this study will be kept **strictly confidential**. Your personal details, such as your name and contact details, will be recorded and stored according to the Data Protection Act (1998). To protect your privacy the following measures will be taken to ensure that no-one, apart from the researcher (Ada Mackovova) and her primary supervisor (Professor Richard Gray) has access to your personal information:
- Your name and other indentifying details (e.g. your address) will not appear on any report or publication which arises from this research.
- We will only use your name and contact details to invite you to take part in the forthcoming sessions.
- You will be allocated a code number which might be used when the study results are produced. Only you, the researcher and her supervisor will know your name and code number. The documents showing a link between your name and other information will be securely destroyed within 12 months after the end of the study.
- All electronically stored personal information will be securely stored on the UEA central network server within UEA's firewall, and saved as a password protected documents.

- All data will be anonymised, and our records of your personal information will be securely destroyed within 12 months after the end of the study.
- Raw data including focus group recordings will be securely stored in a locked cabinet at the UEA for 3 years following publication of research reports. After this time the necessity of data storage will be reviewed.
- Should you withdraw from this research, or in the unlikely event of a participant losing their capacity to consent during the study any data already collected with consent would be retained and used in the analysis.

Important:
If there is any information disclosed during the sessions that concerns the researcher (e.g. information that a crime is about to be committed or somebody is at risk of significant harm) then confidentiality may have to be broken.

What will happen to the results of the research study?
We will send you a summary of our findings after completion of the study. We hope you will find this report interesting and it will help you understand other people's views about depression treatment decisions. We will also produce reports and publications based on the study results. No names or contact details of participants will be included in any publications and no individuals will be identifiable.

Who is organising and funding the research?
This research is being undertaken as part of a PhD study of Ada Mackovova. She is supervised by Professor Richard Gray and Dr Bridget Penhale from the School of Nursing Sciences, University of East Anglia, Norwich. Our study is funded by the University of East Anglia.

Who has reviewed the study?
The study's protocol has been reviewed and approved by the NHS Research Ethics Committee East of England – Essex and the Research and Development Teams in the **Norfolk and Suffolk NHS Foundation Trust**, NHS Norfolk and NHS Great Yarmouth and Waveney.

Can I talk to anyone about this study?
Feel free to discuss this study with anyone you wish to. You can ask your GP for opinion and talk to your family and friends.

Who can I contact for further information?

Further information about the study is available from Ada Mackovova:

The Choice Study   Tel number: 07707 298 277
Edith Cavell Building   Email: a.mackovova@uea.ac.uk
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

For general information about taking part in research studies, please contact the Research and Development department, Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE.

What if there is a problem or I have a complaint?
If you have a concern about any aspect of this study, you should ask to speak to the researcher Ada Mackovova, who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by writing to [**Professor Richard Gray, Edith Cavell Building, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ**].

Alternatively, you can complain in writing to Professor Valerie Lattimer, Head of School of Nursing Sciences, Edith Cavell Building, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ. **Please note that you may have to pay for postage of complaint letters.**

Thank you for your time and effort!

Appendix 25: Participant Information Sheet

for family and friends

Information sheet – Family and friends (Version 4: 29/02/2012)

The Choice Study: What factors influence treatment choices made by people with depression?

Dear Sir or Madam,

We would like to invite you, a person close to someone with depression (i.e. the family and friend) to take part in a research study looking at the factors that influence a person's choice of depression treatment. Your opinion is very important to us. After talking to you we will collate the information gathered and use it to enable healthcare workers to have a better understanding of people's needs in this matter.

The following pages contain information about our project. Your participation is entirely optional and if you change your mind and do not want to take part anymore you are free to withdraw from the study at any time. You do not have to give us any reason. Before you decide whether or not you would like to take part it is important that you understand why this study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

If you would like to take part please complete the enclosed reply slip and return it to us in the pre-paid envelope provided. Ada, the researcher will contact you within one week of receiving your reply slip to arrange a personal meeting to discuss the study with you, answer your questions and ask you to sign a consent form. You will also be asked to fill in a short questionnaire that should take no more than 10 minutes to complete. This meeting will take place at a community location agreed with you. If that would be difficult for you please discuss alternatives with the researcher.

If you have any comments or questions about this study, please contact the researcher Ada Mackovova, contact details on page 5. Thank you for your time,

Yours faithfully, Miss Ada Mackovova, Researcher

This study is run in collaboration with Norfolk and Suffolk Foundation NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK

What is the purpose of this research?
Healthcare workers and patients often have different perceptions about treatment for depression. Patients' preferences play an important role in their acceptance and adherence to therapy, and even ultimate treatment outcomes, but we still do not know what they are based on. In this study, we aim to gain a better understanding of how people with depression make their treatment choices, and what is important to them.

To do this we will gather the opinions of 30 people with depression, 30 family members and friends of these people and 30 healthcare workers. We will compare these groups to see how similar or different their views are about people's treatment choices.

The findings of this study can help healthcare workers better understand the patients' perception of different treatments and support patients in their informed decision-making.

This study is being undertaken for educational purposes, as part of Ada Mackovova's PhD.

Who is the 'family and friend' and are there any inclusion criteria?
In this study the 'family and friend' is a person close to someone with depression. You could be their family member or a friend. We are inviting people with depression and those close to them to join in this research. The study is not seeking to recruit people with bi-polar disorder or other mental illness.

All participants need to be adults aged over 18 and speak English.

Do I have to take part?
It is completely up to you whether you take part. It is important that you read this information sheet so that you can make an informed decision. If you change your mind, you can withdraw from the study at any time. You do not have to give us any reason and your health care will not be affected in any way.

What will happen to me if I take part?
After receiving your reply slip, Ada, the researcher will contact you within one week to arrange a personal meeting with you and the person with depression who is close to you (if participating). This will be a short, about 30-60 minute discussion and will normally take place at a community location as agreed with you. Ada will talk to you about the study, and answer your queries. If you wish to take part you will be asked to sign the consent form and fill in a short questionnaire that takes no more than 10 minutes.

Within another 4-6 weeks you will be invited to an informal group discussion with about 6 other people at the University of East Anglia in Norwich, at a time and day you prefer. You are welcome to arrive together with your person with depression as there will be two separate sessions taking place at the same time. The task for the group will be to think of as many ideas as possible, about: "**Treatment choices made by people with depression are influenced by...**" You can say as many or as few things as you feel comfortable with. We will note the group's ideas on a flip chart, and record the session on a tape to make sure we do not miss any important issues discussed. We will not note details about who mentioned any particular issue.

The second session will take place within 5 months of the initial session and you will work on two individual tasks. We will give you a set of cards with statements about how people make depression treatment choices. First, you will be invited to say which are more or less important in informing people's treatment choices. In the second part you will be asked to put the statements that seem to go together into groups.

All meetings will be led by a trained and friendly facilitator (this will be the researcher, Ada Mackovova or her colleague/supervisor) and at least one assistant. Each session will take maximum of 2 hours including a break. We will provide the refreshments and reimburse you for travel expenses.

Have a problem with group sessions?

If you are interested in taking part but for any reason feel uncomfortable with any aspect of this study, please contact us and we can discuss this with you.

If I want to take part what do I need to do?
If you would like to take part, please:
1. Fill in the reply slip and send it to us in the prepaid envelope provided.
2. Take part in a focus group at time and day that is convenient for you.
3. Take part in the second session within about 5 months later. We will arrange it at your convenience.

Expenses and payments
We will pay your travel expenses for our study and provide free refreshments, but unfortunately we do not have funds to compensate you for your time.

What are the possible disadvantages and risks of taking part?
The risk of harm as a result of participation in this study is very low. On some occasions thinking about, and discussing depression treatment decisions made by a person close to you might make you feel upset. You are welcome to take a break or stop your participation if you wish to, without giving us any reason. If your feelings of distress persist after the end of study, we recommend that you visit your GP or other healthcare worker of usual contact.

A disadvantage arising from your participation is that you spend approximately four hours of your time, which will not be paid for. We will reimburse you for travel expenses and provide free refreshments during both activity sessions.

What are the possible benefits of taking part?
There might be no immediate or direct benefits to you. We will try to make the sessions enjoyable and interesting for you, and you will have the opportunity to meet new people – other participants. This research will help us understand how people make their treatment choices and we hope that health care workers will use our findings when treating future patients.

Will my taking part in this study be kept confidential?
All of the information that you provide us for this study will be kept **strictly confidential**. Your personal details, such as your name and contact details, will be recorded and stored according to the Data Protection Act (1998). To protect your privacy the following measures will be taken to ensure that no-one, apart from the researcher (Ada Mackovova) and her primary supervisor (Professor Richard Gray) has access to your personal information:
- Your name and other indentifying details (e.g. your address) will not appear on any report or publication which arises from this research.
- We will only use your name and contact details to invite you to take part in the forthcoming sessions.
- You will be allocated a code number which might be used when the study results are produced. Only you, the researcher and her supervisor will know your name and code number. The documents showing a link between your name and other information will be securely destroyed within 12 months after the end of the study.
- All electronically stored personal information will be securely stored on the UEA central network server within UEA's firewall, and saved as a password protected documents.
- All data will be anonymised, and our records of your personal information will be securely destroyed within 12 months after the end of the study.
- Raw data including focus group recordings will be securely stored in a locked cabinet at the UEA for 3 years following publication of research reports. After this time the necessity of data storage will be reviewed.
- Should you withdraw from this research, or in the unlikely event of a participant losing their capacity to consent during the study any data already collected with consent would be retained and used in the analysis.

Important:

If there is any information disclosed during the sessions that concerns the researcher (e.g. information that a crime is about to be committed or somebody is at risk of significant harm) then confidentiality may have to be broken.

What will happen to the results of the research study?
We will send you a summary of our findings after completion of the study. We hope you will find this report interesting and it will help you understand other people's views about depression treatment decisions. We will also produce reports and publications based on the study results. No names or contact details of participants will be included in any publications and no individuals will be identifiable.

Who is organising and funding the research?
This research is being undertaken as part of a PhD study of Ada Mackovova. She is being supervised by Professor Richard Gray and Dr Bridget Penhale from the School of Nursing Sciences, University of East Anglia, Norwich. Our study is funded by the University of East Anglia.

Who has reviewed the study?
The study's protocol has been reviewed and approved by the NHS Research Ethics Committee East of England - Essex and the Research and Development Teams in the Norfolk and Suffolk NHS Foundation Trust, NHS Norfolk and NHS Great Yarmouth and Waveney.

Can I talk to anyone about this study?
Feel free to discuss this study with anyone you wish to. You can ask your GP for opinion and talk to your family and friends.

Who can I contact for further information?

Further information about the study is available from Ada Mackovova:

The Choice Study   Tel number: 07707 298 277
Edith Cavell Building   Email: a.mackovova@uea.ac.uk
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

For general information about taking part in research studies, please contact the Research and Development department, Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE.

What if there is a problem or I have a complaint?
If you have a concern about any aspect of this study, you should ask to speak to the researcher Ada Mackovova, who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by writing to [**Professor Richard Gray, Edith Cavell Building, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ**].

Alternatively, you can complain in writing to Professor Valerie Lattimer, Head of School of Nursing Sciences, Edith Cavell Building, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ.

Please not that you may have to pay for postage of complaint letters.

Thank you for your time and effort!

Appendix 26: Participant Information Sheet

for healthcare workers

UEA
University of East Anglia

Information sheet – Healthcare workers (Version 3: 29/02/2012)

The Choice Study: What factors influence treatment choices made by people with depression?

Dear Sir or Madam,

Thank you for your interest in our research study about how people with depression make treatment choices. Your opinion is very important to us. After talking to you we will collate the information gathered and use it to enable healthcare workers to have a better understanding of peoples' needs in this matter.

The following pages contain information about our project. Your participation is entirely optional and you can withdraw from the study at any time, without giving us any reason. Before you decide whether or not you would like to take part it is important that you understand why this study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish to.

If you would like to take part please complete the enclosed reply slip, sign the consent form, and return them to us in the envelope provided. Alternatively, you can contact the researcher, Ada Mackovova, by phone, email or post and discuss the possibilities of taking part.

If you have any queries or would like more information, please contact Ada Mackovova, contact details on page 4.

Thank you for your time,

Yours sincerely, Ada Mackovova, Researcher

NHS

This study is run in collaboration with Norfolk and Suffolk Foundation NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.

What is the purpose of this research?
Healthcare workers and patients often have different perceptions about treatment for depression. Patients' preferences play an important role in their acceptance and adherence to therapy, and even ultimate treatment outcomes, but we still do not know what they are based on. In this study, we aim to gain a better understanding of how people with depression make their treatment decisions, and what is important to them.

To do this we will collect the opinions of 30 people with depression, 30 family members and friends of these people and 30 healthcare workers. We will compare these groups to see how similar or different their views are about people's treatment choices.

The findings of this study can help healthcare workers better understand the patients' perception of different treatments and support patients in their informed decision-making.

This study is being undertaken for educational purposes, as part of Ada Mackovova's PhD.

Are there any inclusion criteria?
We invite healthcare workers and professionals with a recent (within the past 12 months) experience of treating a patient with unipolar depression.

What will my participation in the study involve?
The study is in two phases.
After signing the consent form you will be invited to a focus group session. Its aim is to produce as many statements as possible, to complete the sentence: "**Treatment choices made by people with depression are influenced by...**"

The second part will take place within 5 months after the focus group and will involve two individual tasks. We will give you a set of cards with statements about how people make depression treatment choices. First, you will be invited to say which are more or less important in informing patients' treatment choices. In the second task you will be asked to put the statements that seem to go together into groups.

What commitment is needed from me?
The focus group meeting might take form of a group session with other healthcare workers, a personal meeting with the researcher or a short phone call lasting 15 minutes. Duration will depend on participants' preferences but sessions will last for a maximum of two hours.

You can perform the second part of the project in your own time. Duration of this part depends on the number of statements but it should take no longer than an hour.

If I want to take part what do I need to do?
1. Fill in the reply slip and send it to us in the prepaid envelope provided, OR
   Contact us and we will discuss the options with you
2. Take part in the focus group session at location, time and form of your preference.
3. Take part in the second session within about 5 months, in your own time.

Do I have to take part?
It is entirely up to you to decide whether or not you participate. If you change your mind and do not wish to participate, you can withdraw from the study at any time and you do not have to give us any reason.

Expenses and payments
We will pay for your travel expenses for our study and provide free refreshments, but unfortunately we do not have funding to compensate you for your time.

What are the possible disadvantages and risks of taking part?
There is a minimal risk of harm as a result of participation in this study. We consider the greatest disadvantage for you to be the time you invest in our study. As a thank you we will send you a summary of the results after completion of this study.

What are the possible benefits of taking part?

There might be no immediate or direct benefits to you. This research will help us understand how people make depression treatment choices and we hope that health care workers will be informed by our findings when treating future patients.

Will my taking part in this study be kept confidential?

All of the information that you provide us for this study will be kept **strictly confidential**. Your personal details, such as your name and contact details, will be recorded and stored according to the Data Protection Act (1998). To protect your privacy the following measures will be taken to ensure that no-one, apart from the researcher (Ada Mackovova) and her primary supervisor (Professor Richard Gray) has access to your personal information:

- Your name and other identifying details (e.g. your address) will not appear on any report or publication which arises from this research.
- We will only use your name and contact details to invite you to take part in the forthcoming sessions.
- You will be allocated a code number which might be used when the study results are produced. Only you, the researcher and her supervisor will know your name and code number. The documents showing a link between your name and other information will be securely destroyed within 12 months after the end of the study.
- All electronically stored personal information will be securely stored on the UEA central network server within UEA's firewall, and saved as a password protected documents.
- All data will be anonymised, and our records of your personal information will be securely destroyed within 12 months after the end of the study.
- Raw data including focus group recordings will be securely stored in a locked cabinet at the UEA for 3 years following publication of research reports. After this time the necessity of data storage will be reviewed.
- Should you withdraw from this research, or in the unlikely event of a participant losing their capacity to consent during the study any data already collected with consent would be retained and used in the analysis.

Important:

If there is any information disclosed during the sessions, about practice potentially harmful to vulnerable people (e.g. information about mistreatment, abuse or a crime) then confidentiality may have to be broken.

What will happen to the results of the research study?

We will send you a summary of our findings after completion of the study. We hope you will find this report interesting and that it will help you understand better how patients make depression treatment decisions. We will also produce reports and publications based on the study results for academic journals. No names or contact details of participants will be included in publications and no individuals will be identifiable.

Who is organising and funding the research?

The research is being undertaken as part of a PhD study of Ada Mackovova. Ada is supervised by Professor Richard Gray and Dr Bridget Penhale from the School of Nursing Sciences, University of East Anglia, Norwich. Our study is funded by the University of East Anglia.

Who has reviewed the study?

The study's protocol has been reviewed and approved by the NHS Research Ethics Committee East of England - Essex and the Research and Development Teams in the Norfolk and Suffolk NHS Foundation Trust, NHS Norfolk and NHS Great Yarmouth and Waveney.

Can I talk to anyone about this study?

Please feel free to talk to anyone about this study.

Who can I contact for further information?

Further information about the study is available from Ada Mackovova:

The Choice Study   Tel number: 07707 298 277
Edith Cavell Building   Email: a.mackovova@uea.ac.uk
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

For general information about taking part in research studies, please contact the Research and Development department, Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE.

What if there is a problem or I have a complaint?
If you have a concern about any aspect of this study, you should ask to speak to the researcher Ada Mackovova, who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by writing to [**Professor Richard Gray, Edith Cavell Building, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ**].

Alternatively, you can complain in writing to Professor Valerie Lattimer, Head of School of Nursing Sciences, Edith Cavell Building, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ.

Please note that you may have to pay for postage of complaint letters.

Thank you for your time and effort!

Appendix 27: Participant Reply slip for people with depression

University of East Anglia

REPLY SLIP: People with depression (Version 3: 29/02/2012)
The Choice Study: What factors influence treatment choices made by people with depression?

Please complete this reply slip and return it to us in the envelope provided, if you have been recommended or have received treatment for depression within the past 12 months, you are aged over 18 and you would like to take part in the above study. All information you provide will be kept strictly confidential. We will not give your details to anybody outside of our research team here at the University of East Anglia.

Name: Title: ….. First name/s: …….. Surname: ….......

Address: House number/name:…………………………………………………………

Street: ……………………………………………………………….

Town/City: ………………………………………… Postcode: ………………

Please provide your phone number or email for us to talk to you about dates and times of meetings:

Phone: ………

E-mail: ………

NHS

This study is run in collaboration with Norfolk and Suffolk Foundation NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.

Personal meeting with the researcher

Upon receiving your reply slip we will schedule a personal meeting with you and your family and friend if you wish to nominate someone. Please answer the following questions or circle the appropriate:

a) I would like to identify my 'family and friend' for this study (**please confirm this with your friend/ relative before providing their name!**).   Yes / No
b) My family and friend's name is: ....
c) My relationship with this person is: ....

(Please hand them the pack titled: "Information pack for the family and friends").

You can take part even if you do not nominate anyone to join in.

1) **Focus group sessions**

If you are returning this reply slip to us, you should be willing to attend two two-hour meetings at the University of East Anglia in Norwich.

Which of the following session times would suit you best for the first session that will take place within the next 6 weeks?:

	Tues	Wed	Thurs
Morning (9am-12pm)			
Afternoon (12pm-4pm)			
Evening (6pm-9pm)			

If you are interested in taking part but for any reason feel uncomfortable with any aspect of this study, please contact us and we can discuss this with you.

The second session will take place within the next 5 months and we will contact you in due course to inform you about the time and day of the session.

2) **In this study all participants must be over 18 years old.**

Please confirm your age: ....

Signature: .... Date: ....

Thank you for completing this form. Please return it to us in the envelope provided by:
We will be in touch with you within one week of receiving this form.

Appendix 28: Participant Reply slip for family and friends

University of East Anglia

REPLY SLIP: Family and friends (Version 3: 29/02/2012)

The Choice Study: What factors influence treatment choices made by people with depression?

Please complete this reply slip and return it to us in the pre-paid envelope provided, if you are a family or friend of a person with depression, you are aged over 18 and would like to take part in the above study. All information you provide will be kept strictly confidential. We will not give your details to anybody outside of our research team here at the University of East Anglia.

Name: Title: ………… First name/s: ……………… Surname: ……………………………

Address: House number/name:……………………………………….

Street: ……………………………………………………

Town/City: ………………………. Postcode: ………………………………

Please provide your phone number or email for us to talk to you about dates and times of meetings:

Phone: ……………………………………………………………………………………………………

E-mail: ……………………………………………………………………………………………………

NHS

This study is run in collaboration with Norfolk and Suffolk Foundation NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.

3) Focus group sessions

If you are returning this reply slip to us, you should be willing to attend two two-hour meetings at the University of East Anglia in Norwich.

Which of the following session times would suit you best for the first session that will take place within the next 6 weeks?:

	Tues	Wed	Thurs
Morning (9am-12pm)			
Afternoon (12pm-4pm)			
Evening (6pm-9pm)			

If you are interested in taking part but for any reason feel uncomfortable with any aspect of this study, please contact us and we can discuss this with you.

The second session will take place within the next 5 months and we will contact you in due course to inform you about the time and day of the session.

4) In this study all participants must be over 18 years old.

Please confirm your age: ....

Signature: .... Date: ....

Thank you for completing this form. Please return it to us in the envelope provided by:

 We will be in touch with you within one week of receiving this form.

Appendix 29: Participant Consent form for people with depression

Consent form: People with depression (Version 4: 29/02/2012)

The Choice Study: What factors influence treatment choices made by people with depression?
Researcher: Ada Mackovova

Participant Identification Number for this study: [   ]   Please initial box

1. I confirm that I have read and understand the information sheet for the research project "The Choice Study: What factors influence treatment choices made by people with depression?", dated 29/02/2012 (version 4).

2. I have had a chance to think about taking part in the study and ask any questions. I confirm that my questions have been answered to my satisfaction.

3. I know that I do not have to take part and it is my own choice. If I start joining in this research study, I know that I can stop at any time if I want to. I do not have to give any reason for opting out if I decide to.

4. I agree to have the group meeting audio-recorded. I understand that the audio-recordings will be listened to by the research team at the University of East Anglia, they will be transcribed and securely stored for a minimum of 3 years.

5. I understand that if I disclose information about any person being at risk of harm or of any unprofessional practice (e.g. prescription of an inappropriate treatment) confidentiality may have to be broken.

6. I agree to take part in The Choice Study.

Name of Participant (please print): ....
Signature: .... Date: ....
Name of Person taking consent (please print): ....
Signature: .... Date: ....

When completed: 1 copy for participant; 1 copy (original) for researcher site file.

*This study is run in collaboration with **Norfolk and Suffolk Foundation NHS Trust**, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.*

Appendix 30: Participant Consent form for family and friends

University of East Anglia

Consent form: Family and friends (Version 4: 29/02/2012)
The Choice Study: What factors influence treatment choices made by people with depression?

Researcher: Ada Mackovova
Participant Identification Number for this study:

Please initial box

1. I confirm that I have read and understand the information sheet for the research project "The Choice Study: What factors influence treatment choices made by people with depression?", dated 29/02/2012 (version 4)

2. I have had a chance to think about taking part in the study and ask any questions. I confirm that my questions have been answered to my satisfaction.

3. I know that I do not have to take part and it is my own choice. If I start joining in this research study, I know that I can stop at any time if I want to. I do not have to give any reason for opting out if I decide to.

4. I agree to have the group meeting audio-recorded. I understand that the audio-recordings will be listened to by the research team at the University of East Anglia, they will be transcribed and securely stored for a minimum of 3 years.

5. I understand that if I disclose information about any person being at risk of harm or of any unprofessional practice (e.g. prescription of an inappropriate treatment) confidentiality may have to be broken.

6. I agree to take part in The Choice Study.

Name of Participant (please print): ....
Signature: .... Date: ....
Name of Person taking consent (please print): ....
Signature: .... Date: ....
When completed: 1 copy for participant; 1 copy (original) for researcher site file.

NHS

This study is run in collaboration with Norfolk and Suffolk Foundation NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.

Appendix 31: Participant Consent form for healthcare workers

University of East Anglia

Consent form: Healthcare workers (Version 3: 29/02/2012)

The Choice Study: What factors influence treatment choices made by people with depression?

Researcher: Ada Mackovova

Participant Identification Number for this study:

Please initial box

1. I confirm that I have read and understand the information sheet for the research project "The Choice Study: What factors influence treatment choices made by people with depression?", dated 29/02/2012 (version 3)

2. I have had a chance to think about taking part in the study and ask any questions. I confirm that my questions have been answered to my satisfaction.

3. I know that I do not have to take part and it is my own choice. If I start joining in this research study, I know that I can stop at any time if I want to. I do not have to give any reason for opting out if I decide to.

4. I agree to have the group meeting audio-recorded. I understand that the audio-recordings will be listened to by the research team at the University of East Anglia, they will be transcribed and securely stored for a minimum of 3 years.

5. I understand that if I disclose information about any person being at risk of harm or of any unprofessional practice (e.g. prescription of an inappropriate treatment) confidentiality may have to be broken.

6. I agree to take part in The Choice Study.

Name of Participant (please print): ....

Signature: .... Date: ....

Name of Person taking consent (please print): ....

Signature: .... Date: ....

When completed: 1 copy for participant; 1 copy (original) for researcher site file.

NHS

This study is run in collaboration with Norfolk and Suffolk Foundation NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.

Appendix 32: Participant Questionnaire for people with depression

University of East Anglia

Questionnaire: People with depression (Version 3: 29/02/2012)

Researcher: Ada Mackovova
Participant Identification Number for this study:

The Choice Study: What factors influence treatment choices made by people with depression?

Please complete this questionnaire if you have been recommended or have received treatment for depression within the past 12 months, you are aged over 18 years and you would like to take part in the above study.

1) Are you: (tick the appropriate):

□ **Male**   □ **Female**

2) What is your age?

3) What is your ethnicity (tick the appropriate):

White:	□ British	□ Irish	□ Other White background
Mixed:	□ White and Asian		□ White and Black African
	□ White and Black Caribbean		□ Other mixed background
Asian or Asian British:	□ Indian		□ Bangladeshi
	□ Pakistani		□ Other Asian background
Black or Black British:	□ African	□ Caribbean	□ Other Black background
Other Ethnic Groups:	□ Chinese		□ Other ethnic group (please state):

□ Not stated

4) What is your marital status?

□ single   □ divorced or separated

□ married or co-habiting   □ widowed

5) What is your highest level of education?

    □ No formal qualification

    □ GCSE/O Level or equivalent

    □ A' Level or equivalent

    □ University Degree or equivalent

    □ Postgraduate Degree/Diploma or equivalent

6) What is your employment status?

□ student   □ unemployed   □ employed part-time

□ employed full time   □ self-employed   □ retired

7) What treatment(s) for depression were you prescribed or recommended most recently?

8) What treatment for depression are you currently receiving?

9) What year did you have your first period of depression in?

10) How many periods of depression have you had?

Thank you for completing this questionnaire!

Appendix 33: Participant Questionnaire for family and friends

University of East Anglia

Questionnaire: Family and friends (Version 3: 29/02/2012)

Researcher: Ada Mackovova
Participant Identification Number for this study:

The Choice Study: What factors influence treatment choices made by people with depression?

_____

Please complete this questionnaire if you are close to a person with depression, you are aged over 18 years and you would like to take part in the above study.

1) **Are you: (tick the appropriate):**　　　□ **Male**　　　□ **Female**

2) **What is your age?**

3) **What is your ethnicity (tick the appropriate):**

White:	□ British	□ Irish	□ Other White background
Mixed:	□ White and Asian		□ White and Black African
	□ White and Black Caribbean		□ Other mixed background
Asian or Asian British:	□ Indian		□ Bangladeshi
	□ Pakistani		□ Other Asian background
Black or Black British:	□ African	□ Caribbean	□ Other Black background
Other Ethnic Groups:	□ Chinese		□ Other ethnic group (please state):

□ Not stated

NHS

This study is run in collaboration with Norfolk and Suffolk Foundation NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.

4) What is your marital status?

□ single   □ divorced or separated

□ married or co-habiting   □ widowed

5) What is your highest level of education?

□ No formal qualification

□ GCSE/O Level or equivalent

□ A' Level or equivalent

□ University Degree or equivalent

□ Postgraduate Degree/Diploma or equivalent

6) What is your employment status?

□ student   □ unemployed   □ employed part-time

□ employed full time   □ self-employed   □ retired

7) Are you (or have you recently been) receiving treatment for depression?

8) If applicable, what treatment for depression did you receive most recently?

9) What is your relationship to the person with depression who is close to you?

10) Is the person with depression who is close to you, taking part in this study?

Thank you for completing this questionnaire!

Appendix 34: Useful Information Sheet

Useful Information Sheet (Version 3: 29/02/2012)

Thank you for taking part in our study and for sharing your opinion with us. If you would like any additional information about this study contact Ada Mackovova (07707 298277 or a.mackovova@uea.ac.uk), address:

The Choice Study, School of Nursing Sciences, Edith Cavell Building, University of East Anglia, Norwich Research Park, Norwich NR4 7TJ.

Helpful telephone numbers and websites
Below is a list of several charity organisations that provide support to people who are in distress or emotional crisis. Please remember that you should contact your GP if your problems persist.

NHS Direct
Telephone: 0845 46 47
Lines are open 24-hours every day.

Samaritans: www.samaritans.org.uk
Samaritans provide 24-hour confidential emotional support to anyone experiencing feelings of distress.

Telephone: 0845 7909 090
Telephone from most mobile providers and some landlines: 116 123

Age UK Norwich: http://www.ageuk.org.uk/norwich/
The Age UK Group works to improve later life for everyone by providing life-enhancing services and vital support.

Local Service, telephone: 01603 496333
Lines are open 5 days a week Monday to Friday 10.00 am to 4.00 pm each day, except Wednesday when they close at 2.00 pm for staff training.

Sane: http://www.sane.org.uk/what_we_do/support/helpline/
SANE runs a national, out-of-hours helpline offering specialist emotional support and information to anyone affected by mental illness, including family, friends and carers.
Telephone: 0845 767 8000
Lines are open every day of the year from 6pm to 11pm.

Please note that rates for the above numbers vary. For details please check with your mobile/landline phone provider.

NHS

This study is run in collaboration with Norfolk and Suffolk Foundation

NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.

Appendix 35: Refusal letter to prevent over-recruitment (Version 3: 29/02/2012)

<div align="right">
Ada Mackovova
The Choice Study
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Norwich, NR4 7TJ
Email: a.mackovova@uea.ac.uk, Tel: 07707 298 277

Date:
</div>

Dear Sir or Madam,

We would like to thank you for your interest in our study. Unfortunately, we are unable to invite you to take part in this study because we have already recruited the necessary number of participants. We really appreciate your offer of help.

Kind regards,

Ada Mackovova

Researcher

NHS

This study is run in collaboration with Norfolk and Suffolk Foundation

NHS Trust, NHS Norfolk, NHS Great Yarmouth and Waveney and Age UK.

Appendix 36: Brainstorming session plan and list of prompts

The Choice study: What factors influence treatment choices made by people with depression?

Tasks before the sessions:

- Prepare the room set up
- Put post-it notes and pens on tables
- Water on each desk
- Start the voice recorders
- Refreshments
- Name badges, travel expenses forms, parking permits

Introduction to the session: all participants together (Ada)

- **Thank everybody** for coming and their time and effort
- **Introduce** myself and the helpers – briefly; let helpers say something about themselves
- **Roles**
  - mine and facilitators' – give everybody a chance to talk and make their point. Sometimes people talk a little or a lot and my role is to give everyone option to speak.
  - **people with depression** – to freely say what factors influenced your choice of treatment for depression
  - **Family and friends** – your views of the factors that influenced treatment choices made by the person with depression
- **Ground rules**
  - time limits –break at... finish at...
  - Speaking one at a time
  - No judgement of ideas/people
  - right to withdraw
  - Post-it notes and pens – feel free to use them
- **Agenda**
  - We are interested in understanding how people with depression make their decisions about what treatment for depression they take. What factors influence their preferences/choices of therapies they used/didn't use
  - today's task – to generate as many statements as possible to finish the focus sentence:
  - **'My most recent choice of treatment for depression was influenced by:'**
  - **'Treatment choices made by people with depression are influenced by:'**

Focus group suggested areas of discussion (prompts)

- **What first comes to your mind when you see the focus sentence?**
  - How did you make the choice of treatment you are taking?
- **Treatment options**
  - Different antidepressants
  - Talking therapies
  - Alternative therapies
  - What made you think of the particular therapy?
  - if people mention wanting a 'healthy' or 'non-drug' treatments: How would your view about treatments be different if you had e.g. a back pain?

- **Decision to seek help**
  - How did you realize you needed help?
  - How difficult/easy was this decision?
  - What made you visit the particular practitioner?
- **Beating it on your own** – many people mention this as an option, what do you think about it and how did it affect your decisions?
- **GP/ other health practitioners**
  - Relationship, expertise, behaviour, etc.
- **Family, friends, co-workers, other people**
  - What effect do people around you have on your decisions?
  - How do other people influence your preferences?
- **Attitudes towards depression and different treatments in society (your family, etc.)**
- **Information sources**
  - Where do you find information about depression/treatments?
  - How do you know you can trust them?

Topic areas - prompts

Medication or technology	Is there anything else you want to say about medication or any technology or equipment that has influenced decisions?
Attitudes	Is there anything about other people's attitudes? Professionals or colleagues, family, or any other people?
Environment	Anything about the home environment, or work environment, or the area/ town/ village the person with depression lives in?
Support and relationships	Is there anything about family relationships that makes a difference to decision-making? What about services that are provided, or the health system?
Physical health/condition	Anything about the person with depression's physical health/ condition?
Involvement in activities	Anything about being able or unable to take part in things the person with depression would like to be involved in?

End of session (Ada)

- **Thank everybody for coming and their contribution**
- **What will happen next –**
  - **we will run more focus groups with other participants**
  - **I will contact you within the next 5 months or so – to invite you to the next session**
  - **Next session – you will rank the statements and group them together**

Appendix 37: Instructions and helping sheets used in prioritising and clustering

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The Choice study
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Mobile: 07898 287 055
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7th September 2012

Dear (name),

RE: The Choice study: How do people with depression make treatment choices?

Thank you very much for taking part in a brainstorming session which was the first part of the above research study. I am now inviting you to complete two tasks which form the last phase of this project: 1) Prioritizing, and 2) Clustering. Each task should take approximately 30-60 minutes and all you will need is this sheet and a set of cards with statements about how people with depression make treatment choices (enclosed).

There are no right or wrong answers as we are interested in your own opinions on this issue. Therefore, I would be very grateful if you could complete these tasks on your own, without discussing them with other people.

Once you have completed the tasks, please post the sheets with your answers to me in the enclosed stamped envelope.

Thank you very much for your help with this research study. If you have any questions or would like to discuss this project further, please contact me.

Kind regards,

Ada Mackovova
Researcher

The Prioritising task:

Please sort the cards into five piles, according to how important you think the statements written on them are. Make sure there are no more than 12, and no less than 11 cards in each pile. Please use all cards, but remember that each card can only be used once:

Pile 1 = the least important statements

Pile 2 = somewhat important statements

Pile 3 = moderately important statements

Pile 4 = very important statements

Pile 5 = the most important statements

Once you have finished this task, please write the card numbers in the appropriate columns in the table below:

No. of Cards	Pile 1: the LEAST important	Pile 2: SOMEWHAT important	Pile 3: MODERATELY important	Pile 4: VERY important	Pile 5: the MOST important
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					

The Clustering task

This is completely separate from the first task. To complete the clustering task, please put into groups (clusters) the statements that you think go together. I would be very grateful if you could follow the rules below:

Please use all cards, but remember each card can only be used once.
You can create a minimum of 2 and a maximum of 12 groups, and:
Do not put all statements into one group.
Each group must contain more than one card.
Please note down the number of each card in each of your 'groups' in the table overleaf.
Please put a name/label to each group (cluster), as they make most sense to you.

Table 2: The Clustering task: Please note down the number of each card as you put them into groups

(clusters). There is an additional table on the following page, should you have more clusters.

	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6	Group 7
Group label:							
Card numbers:							

	Group 8	Group 9	Group 10				
Group label:							
Card numbers:							

The Helping sheet

The following worksheet might help you organize your clusters of cards. Are you do not have enough room here, working through the data you can place the cards that seem related to beans in the table. You can also write down ideas of labels for each cluster.
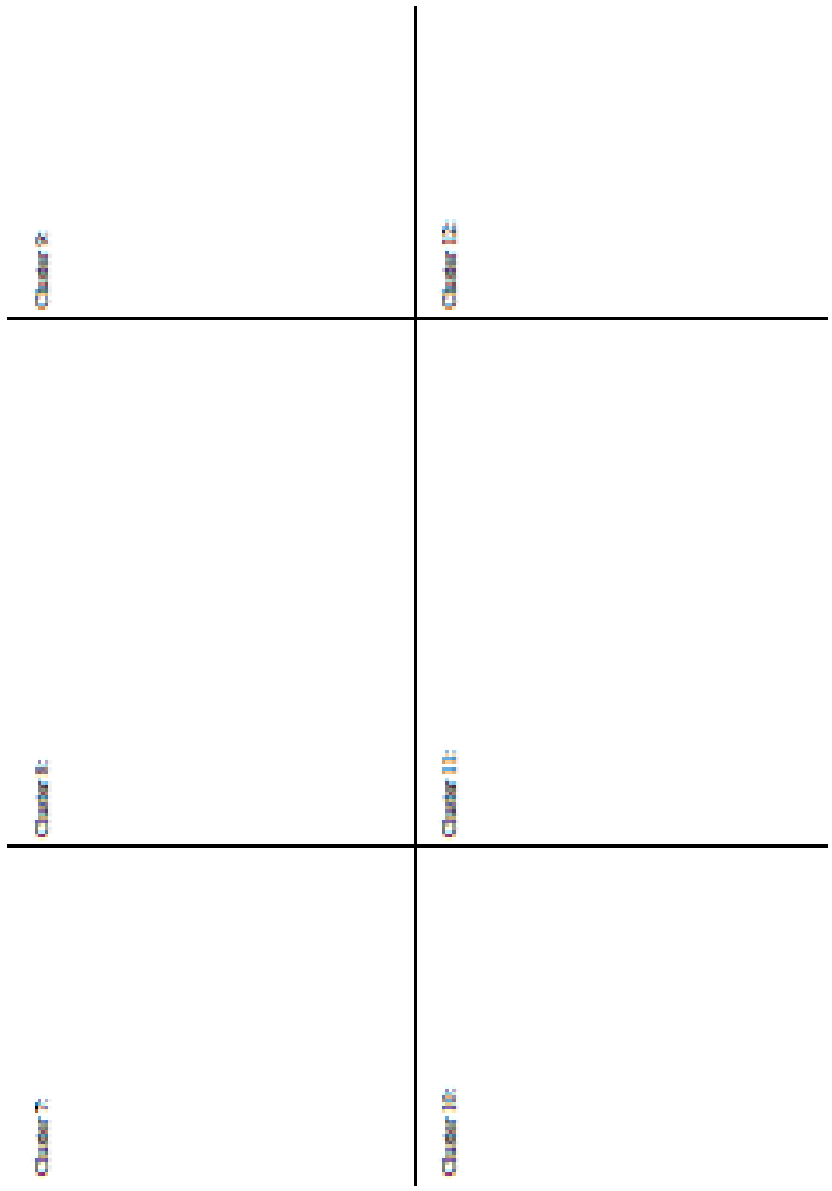
Cluster 1:	Cluster 2:	Cluster 3:
Cluster 4:	Cluster 5:	Cluster 6:

Cluster 8:

Cluster 9:

Cluster 14:

Cluster 15:

Cluster 7:

Cluster 16:

Appendix 38: Results of PCA: statements' scores on five dimensions

Statement		Scores Dimension:				
		1	2	3	4	5
1	Financial costs related to the particular treatment option	.05	.03	-.18	.18	.06
2	Practical issues related to starting treatment	.07	.12	-.14	.19	.02
3	Being given a choice of treatments	.01	.24	-.08	.04	.04
4	Recognizing I have a problem I need help with	.15	.05	.16	-.19	.2
5	Playing an active role in getting better	.15	.06	.14	-.15	.22
6	Desperation to try anything that could help	.15	-.05	.2	.15	-.02
7	Information about depression and its treatment	-.02	.23	-.09	-.02	-.04
8	Having my view about what is the best treatment confirmed	-.01	.23	-.07	-.02	.04
9	Inability to make a choice because of my depression	.14	-.08	.2	.14	-.05
10	Beliefs of family and friends about depression	0	-.2	-.14	-.05	-.13
11	Weighing up the risks and benefits of treatments	.07	.24	-.12	0	0
12	Wanting a treatment that works quickly	.12	.11	0	.23	.02
13	My past experiences of treatment	.09	.11	-.03	-.22	-.15
14	Feeling it's my fault for having depression	.14	-.11	.16	.12	-.13
15	Worries about the side effects of medication	.08	.17	-.1	.16	-.15
16	My knowledge and understanding of the effects of treatment	.06	.23	-.11	-.02	-.05
17	Wanting to share my experiences with depression with others	.07	-.03	-.05	-.26	-.24
18	Healthcare professionals' beliefs about depression and its treatment	-.22	.04	.1	0	.01
19	Healthcare professionals' knowledge and understanding about depression and its treatment	-.21	.05	.1	-.01	.02
20	My relationship with the healthcare professional	-.22	.04	.1	-.01	.03
21	My personal characteristics (age, being male or female, ethnicity - being black, white or other)	-.02	-.19	-.21	-.02	0.23

22	Culture (my background as well as my current culture)	0	-.2	-.23	-.01	.17
23	My religion	0	-.2	-.22	.01	.21
24	Continuity of care (seeing the same healthcare professional)	-.22	.04	.11	0	.02
25	Personal characteristics of the healthcare professional (age, being male or female, ethnicity - being black, white or other)	-.21	-.04	.01	0	.12
26	My understanding of the side effects of treatment	.05	.23	-.14	.06	-.1
27	My experiences with healthcare professionals	-.21	.04	.1	-.04	-.02
28	My expectations from healthcare professionals	-.21	.04	.11	-.01	0
29	Wanting to escape from the situation	.14	-.08	.21	.15	0
30	My past experience with depression (knowing whether I can feel better or not)	.09	.04	-.02	-.26	-.11
31	How I feel right now	.16	-.05	.2	.02	.08
32	Fear of dealing with problems	.14	-.09	.2	.13	-.05
33	Desire to get to the root (the bottom) of depression	.15	.07	.1	-.16	.19
34	Not wanting to have depression listed in health records	.02	-.08	-.05	.22	-.11
35	A desire to get better for people I care about	.12	-.08	.14	-.1	-.02
36	Isolation, and not having the support network close	.09	-.13	.08	.13	-.14
37	My belief that depression is a chemical imbalance	.09	.12	-.09	-.06	-.07
38	Understanding it is normal to have depression and I am not alone	.13	.08	.06	-.25	0
39	Thinking that nothing can help me	.14	-.08	.21	.15	-.07
40	Having an introverted or extroverted personality	.02	-.19	-.17	-.02	.27
41	Wanting to please the doctor (to be a good patient)	-.15	-.01	.09	.06	-.05
42	Realizing all people's experiences with depression are different	.09	.01	-.01	-.33	-.16
43	Being ready to accept treatment	.13	.12	.11	-.12	.27
44	Being ready to engage with treatment	.14	.13	.09	-.09	.28
45	Healthcare professionals being ready to discuss depression and its treatment with family and friends	-.21	.03	.11	0	0
46	Worries about becoming dependent on medication	.08	.18	-.09	.13	-.14
47	Realizing there is no quick fix	.15	.09	.09	-.17	.16
48	Views about depression in society	.01	-.17	-.17	-.06	-.17

49	Not wanting to be a burden on others	.12	-.11	.16	.03	-.12
50	Wanting the easiest treatment	.12	.11	.02	.2	.07
51	My upbringing	.01	-.21	-.21	-.02	.18
52	The healthcare professionals' personality	-.22	.02	.09	-.01	.06
53	Healthcare professionals discussing depression and its treatment openly	-.21	.05	.1	-.01	.02
54	Wanting a 'natural' treatment	.09	.14	-.17	.14	.05
55	Other people's experiences with depression and its treatment	.03	-.09	-.11	-.22	-.35
56	Being given a clear diagnosis	-.12	.17	.05	-.04	.02
57	Communication between different healthcare professionals	-.22	.03	.11	0	.02
58	Wanting what doctors say is the most effective treatment	-.15	.16	.05	.04	.01
59	Wanting a treatment that is provided with no time limitations	.09	.16	-.1	.15	.08