Treatment decision making for young people diagnosed with major depressive disorders

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Abstract

Adolescence is a crucial period of risk for depression, with one in every five people experiencing a depressive episode before the time they are 18 years old. Engaging young people in effective treatment during this time is essential to prevent potential long-term negative impact. Guidelines advocate for young people to be involved in treatment decision making, both in terms of receiving information about treatment options, and also making choices about their own care. These recommendations are in line with a model of decision making called 'shared decision making' (SDM), one of several models of medical decision making. Yet little is known about processes related to treatment decision making in this age group or young people's preferred model of treatment decision making. What little literature that exists suggests young people would value involvement in treatment decision making and that such involvement may enhance engagement. In order to address this gap in our understanding of treatment decision making in young people, semi-structured, qualitative interviews were conducted with clients (n=10), caregivers (n=5) and clinicians (n=22) about their experiences and beliefs about treatment decision making for young people diagnosed with major depressive disorder (MDD). Thematic analysis was used to identify key themes in the data. Clients and caregivers reported a range of experiences regarding how involved they were in treatment decision making, yet, consistent with the small body of literature identified, they all wanted involvement of some sort. Clinicians also wanted clients, and caregivers as appropriate, to be involved. All participants (clients, caregivers and clinicians) reported a lack of information exchange (e.g. information about potential risks and benefits of different treatment options) and wanted resources to fill this gap. Overall, the findings from these interviews indicated a preference for involvement in treatment decision making that was in line with a SDM model. In response, an evidence-based decision aid that facilitates SDM was developed for young people diagnosed with MDD who are faced with the decision about which treatment option is best for them. The decision aid was developed according to international standards, and included field-testing with clients (n=5) and clinicians (n=3), who all found the tool acceptable and useful. The current study provides the basis from which an understanding of treatment decision making for young people diagnosed with MDD can be

further built, and from which additional resources can be developed and tested in order to contribute to the emerging field of youth SDM. Approaches that support young people to make evidence-based and preference-based treatment decisions have the potential to increase guideline-concordant care, satisfaction, adherence and clinical outcomes.

This is to certify that:

(i) the thesis comprises only my original work towards the PhD except where indicated in the Preface,

(ii) due acknowledgement has been made in the text to all other material used,

(iii) the thesis is fewer than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

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(Magenta Bender Simmons)

Work from this thesis has appeared in the following publications:

1. Simmons MB, Hetrick SH, Jorm AF. Shared decision-making: benefits, barriers and current opportunities for application. Australasian Psychiatry. 2010;18(5):394-7.

2. Simmons MB. Shared decision making and youth mental health: Interviews with clients, carers and clinicians from early intervention services about their experiences and beliefs about treatment decision making [abstract]. Early Intervention in Psychiatry. 2010;4(Suppl. 1):38-187.

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In loving memory of Adib & Jessie

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Glossary of abbreviations and key terms

Client

This term is used to refer to any person attending a service (e.g. tertiary mental health service, primary care service) for mental health reasons. This term is used in place of, for example, 'patient', 'service user' or 'consumer'.

Clinician

This term is used to refer to any health professional (e.g. psychiatrists, general practitioners, clinical psychologists, other allied health professionals).

Cognitive behavioural therapy (CBT)

CBT is a psychological therapy that has demonstrated effectiveness for both adults and young people diagnosed with major depressive disorders.

Decision aids (DA)

Also known as *decision support technologies* and *patient decision aids*, DAs are evidence-based tools that present information about the potential risks and benefit of different healthcare options (e.g. treatment options, deciding whether or not to undertake a screening test).

Decision-making process

The analytical stages of decision making, whereby information is offered and/or obtained, and such information is deliberated on in order to make a decision.

Diagnostic and statistical manual for mental disorders, fourth edition, text revision (DSM-IV-TR)

The DSM-IV-TR is a manual produced by the American Psychiatric Association, which details diagnostic criteria for mental disorders.

headspace Barwon

headspace Barwon is an enhanced general practice service for young people aged 12-25 years living in the satellite city of Geelong (and surrounding areas), 75kms south-west of Melbourne

Interpersonal therapy (IPT)

IPT is a psychological therapy that has demonstrated effectiveness for both adults and young people diagnosed with major depressive disorders.

Major depressive disorder (MDD)

MDD, as defined by the DSM-IV-TR, is a mood disorder characterised by low mood and/or loss of interest in things usually enjoyed (or irritability in adolescents), with at least five of the following symptoms: eating significantly more or less than usual, or otherwise unexplained weight loss or gain; sleeping more or less than usual; feeling very tired or very low energy; feelings of worthlessness, hopelessness, helplessness and/or inappropriate and excessive guilt; diminished ability to think, concentrate and/or make decisions; psychomotor agitation or retardation; and suicidal ideation and/or behaviours.

Orygen Youth Health (OYH)

A specialist youth mental health service for young people aged 15-24 years living in the north western metropolitan area of Melbourne, Australia.

Randomised controlled trial (RCT)

A study design whereby participants are randomly allocated to one or more treatment arms, with one of these arms being a control condition (e.g. placebo).

Selective Serotonin Reuptake Inhibitor (SSRI)

SSRI is a class of antidepressant medication (e.g. fluoxetine), and is the only class that has demonstrated effectiveness for children and adolescents diagnosed with MDD.

Shared decision making (SDM)

SDM is a model of treatment decision making whereby both clinician and client play equal roles in the three stages of treatment decision making: sharing information relevant to the decision; deliberating on this information; and making a decision about what treatment choice to select.

Treatment decision making
This term is used to refer to the three stages described above in the definition of SDM. As an alternative to a shared model of treatment decision making, this activity can also be paternalistic or autonomous in nature. Broader terms such as 'medical decision making' have also been used to reflect the fact that healthcare decisions may include treatment decision making and other decisions, such as whether or not to undertake a screening test. However, this thesis focuses on decisions about treatment only and therefore uses this term for simplicity.

Treatment for Adolescent Depression Study (TADS)
A RCT conducted with young people diagnosed with MDD, comparing four treatment arms: placebo; fluoxetine; CBT; combination of fluoxetine and CBT.

Youth shared decision making (YSDM)
An emerging field of research so far focused on SDM for young people diagnosed with mental disorders.

Chapter 1: Overview of the problem.

Background

Depression is a disabling and often recurrent condition that affects approximately 120 million people globally, and it is predicted to be the leading cause of disability by the year 2030 (1). In terms of disability, the World Health Organization classifies severe depression alongside acute psychosis, quadriplegia and terminal stage cancer (2).

Phenomenology and prognosis

A diagnosis of major depressive disorder (MDD), as described in the Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV-TR (3)) is primarily based on one or more of the following: depressed mood (or irritability in adolescents) and/or loss of interest and pleasure in things that the person normally enjoys, for most of the day, nearly every day for at least two weeks (3). Additionally, five or more of the following symptoms must be present: eating significantly more or less than usual, or otherwise unexplained weight loss or gain; sleeping more or less than usual; feeling very tired or very low energy; feelings of worthlessness, hopelessness, helplessness and/or inappropriate and excessive guilt; diminished ability to think, concentrate and/or make decisions; psychomotor agitation or retardation; and suicidal ideation and/or behaviours. These symptoms must have caused significant clinical distress or impairment in functioning; not be directly caused by substance use or a medical condition; and not be accounted more appropriately for by bereavement. The criteria for each type of MDD (e.g. single episode versus recurrent MDD) and related specifiers (e.g. mild, moderate, severe, severe with psychotic features) are based on the frequency, severity and type of symptoms. Another common diagnostic system is the International Classification of Disorders (ICD-10) (4), which uses similar criteria. Other mood disorders in the DSM-IV-TR include dysthymic disorder and depressive disorder not otherwise specified, however the focus of this study is MDD and as such the other depressive disorders will not be considered here.

Compared with adults, young people diagnosed with MDD more often experience mood lability and irritability, and behavioural changes such as somatic complaints and social isolation rather than melancholic symptoms such as diurnal variation and feelings of excessive guilt (5).

The average age of onset of MDD for all ages is 25.7 years (6) and the average duration of depressive episodes in young people is between one and two months, as measured in community samples, and approximately eight months, as measured in clinical samples (7). Approximately two thirds of children and adolescents who have a diagnosis of MDD also have at least one other comorbid mental disorder (8), and are more likely to engage in substance abuse (9).

Depression is the strongest risk factor for suicidal thoughts and behaviour (10). The incidence of completed suicide increases rapidly with age in adolescents and young adults, with 1 death in 100,000 people for those aged 12 to 14 years, 5 deaths in 100,000 people for those aged 15 to 17 years, and 13 deaths in 100,000 people for those aged 18 to 24 years (11). A report by the Australian Institute of Health and Wellbeing (11) revealed that in 2005, acts of suicide and self harm were the second leading cause of injury in young people, second only to road traffic accidents. Suicide deaths comprised one fifth of all fatalities in young people, and 14% of all completed suicides in the population were young people (11). Estimates of deaths caused by suicide are likely to be conservative, particularly in young people (12).

In addition to the increased risk of completed suicide, experiencing depression as a child or adolescent can have a significant impact on the overall emotional, physical, social and occupational functioning of the young person (13), (14). Mental disorders such as depression lead to increased disability, reduced quality of life, impaired productivity, and increased levels of morbidity and mortality (15). Depression is a risk factor for interpersonal issues, adverse events in life, legal problems, poor educational and vocational outcomes, and physical illnesses, including serious illness such as cancer and heart disease (1), (16), (9), (17), (18).

Further, the effect of experiencing depression in adolescence lasts into adulthood. If the onset of depression occurs before puberty, a person is more likely to be diagnosed with a comorbid mental disorder in adulthood, whereas if the onset of depression occurs after puberty, a person is at higher risk for relapse of depressive episodes (8).

Prevalence

Adolescence is a crucial period of risk for the onset of MDD; although overall lifetime prevalence rates are one in every four persons, one in every five persons will suffer a major depressive episode by the time they reach 18 years of age (19), (14), (20). Within any given 12 month period, it is estimated that 3% of all Australians aged 6-17 years (21) and 6-7% of those aged 16-24 years will experience a major depressive episode (15). However, in this age range 12-month prevalence rates differ by gender, with approximately 8.4% of females, compared with 4.3% of males, experiencing MDD (15).

Risk factors

There are several risk factors for MDD, including genetic predisposition (22); experiencing frequent 'ups and downs' in mood (23); exposure to family adversity during childhood (24); and low self esteem (25). Young people are more likely to be diagnosed with MDD if they are from a blended, sole parent, or low income family (21), are Aboriginal or Torres Strait Islander, a refugee, have a disability, are homeless or institutionalised, or are from a sexual minority or gender diverse group (26). Adolescent females and young women are twice as likely to experience depression than males (27), (28).

Treatment

Interventions with the most evidence for treating MDD in adults include cognitive behavioural therapy (CBT), interpersonal therapy (IPT), antidepressant medication (for moderate to severe depression), and electroconvulsive therapy (29). Clinical guidelines for the treatment of depression in children and adolescents provide recommendations according to depression severity (e.g. (30), (26)). For mild depression, suggested interventions include monitoring; group psychotherapy; the provision of information; and assistance with lifestyle changes (e.g. diet and exercise). For moderate to severe depression, individual psychotherapy, such as CBT or IPT, is recommended. Antidepressant medication is not recommended as a first line treatment unless the young person is acutely unwell; in these cases fluoxetine is recommended as the agent to trial, and only in conjunction with individual psychotherapy rather than as a monotherapy.

Both CBT and IPT have common therapeutic foundations in that they aim to build a therapeutic alliance; to make the person feel heard and understood; to provide a rationale and plan for treatment; and to encourage positive, successful experiences (31), (32). Both therapies focus on the present, are time limited and aim to solve problems in the person's life. However, there are differences in the way each approach achieves this.

Cognitive behavioural therapy

CBT encourages people to look at the ways in which their thoughts influence their emotions and behaviour. In doing so, it supports people to identify and change negative thoughts that encourage depressive symptoms, to focus on more positive thoughts and feelings, and to equip people with strategies to manage problems in their life (31). As well as looking at the interaction between thoughts and behaviour, CBT also addresses each of these areas individually (e.g. assisting with behavioural issues such as exercise). In order to maximise the effect of CBT, people may be asked to undertake activities (or 'homework') in between sessions, such as scheduling pleasant activities (e.g. socialising with friends, going for a walk, having a bath). CBT has been adapted for children and adolescents, whereby the intervention accounts for the developmental age of the young person (33). For MDD, CBT is effective in this age group at achieving remission (34), although newer studies that are more methodologically sound show a smaller effect size (35). Notwithstanding these limitations, along with IPT, CBT is still one of the most effective treatment approaches for young people diagnosed with MDD.

Interpersonal therapy

IPT focuses on the way in which interpersonal interactions (e.g. relationships) contribute to and maintain psychological distress (29). IPT aims to contextualise an individual's distress (i.e. depressive symptoms) within life events, and is based on two guiding principles: that depression is a treatable condition; and that a person's mood and life events are linked and influence one another (36). By acknowledging that life events affect mood and vice versa, IPT aims to resolve negative life events, develop social skills and organise a person's life so that negative life events are ameliorated and depressive symptoms resolve as a consequence (36). IPT has been adapted for adolescents; modifications include shorter duration and a stronger focus on parental relationships (32). IPT for adolescents has demonstrated efficacy and effectiveness in a range of clinical settings (32).

Antidepressant medication

Antidepressant medication is also a common treatment approach. The two main classes of antidepressant medication are tricyclic drugs and selective serotonin reuptake inhibitors (SSRIs). There are also newer classes of antidepressants such as serotonin–norepinephrine reuptake inhibitors, however there is very limited data about their effectiveness in children and adolescents (37). Tricyclic antidepressants have been found to have little benefit for children and adolescents, result in undesirable side effects and are not recommended for this age group as a result (38). SSRIs are commonly used (39), although there is little evidence to support use of this class of medication as a whole (40).

A recent Cochrane review examining the effectiveness of SSRIs for children and adolescents diagnosed with MDD demonstrated that fluoxetine is the only agent with consistent superiority in placebo-controlled RCTs (41). Even so, this benefit equated to a score 5.63 points lower on the Children's Depression Rating Scale – Revised (CDRS-R; total scores range from 17-113), which authors highlight is of unknown clinical relevance. Furthermore, this meta-analysis confirmed that there is an almost two-fold increased risk of suicide-related outcomes for those taking SSRIs.

The problem lies not only with the limited benefit and potential risks of such medication, but also with the lack of studies undertaken in this area. A clear gap in the literature is an understanding of the potential risks and benefits of SSRIs for young people more representative of 'real world' clients seen at clinical services, for example, those with more severe depression, suicidal ideation and behaviours, and comorbid disorders.

Treatment for Adolescent Depression Study (TADS)

The *Treatment for Adolescents With Depression Study* (TADS) aimed to address some of the limitations of earlier studies (e.g. by recruiting 'real world' participants) (42-46). TADS is the most comprehensive intervention study on youth depression to date and the results are widely promoted as strong evidence for the superiority of a combined treatment approach of both CBT and fluoxetine. However, criticisms have been made of the study, and these criticisms are representative of issues in the area of treatment for youth depression in general. Because of this, consideration will now be given to both the results of the study and the ensuing controversy.

Involving 13 sites across the United States, TADS enrolled a total of 439 participants aged between 12 and 17 years with a diagnosis of MDD in a multi-centre randomised controlled trial that involved four treatment arms: 1) fluoxetine only; 2) placebo pill only; 3) CBT only; and 4) both fluoxetine and CBT. The trial consisted of four stages: in stage one, participants received 12 weeks of their respective interventions; in stage two, partial- and non-responders were offered community and open label treatment by the TADS team respectively, and responders continued with their original treatment for a further 6 weeks; in stage three, all remaining participants received maintenance treatment and monitoring; and in stage four, all remaining participants were followed up twelve months after the completion of stage three with no controlled treatment being given in that time. The placebo group was included in phase one only.

The main outcome measures were the total score on the CDRS-R (with remission being defined as a score of <29) and response to treatment as measured by a rating of 'much improved' or 'very much improved' on the Clinical Global Impression (CGI). Secondary outcome measures included assessments of depression symptoms (as measured on validated scales), improvement, impairment, and functioning, and were rated by independent evaluators, participants themselves, their parents and clinicians.

There were no significant differences between the groups in terms of baseline demographics, symptom severity and other characteristics. Participants were predominantly white (73.8%), had slightly more females (54.4%), with a mean age of 14.6 years (SD 1.5) and a mean depression severity in the moderate to moderate-severe range (based on the CDSR-R). 293/439 (82%) participants completed stage one (i.e. 12 weeks of treatment), however intention to treat analysis was used and therefore all randomised participants were included. In terms of remission, results after 12 weeks of treatment showed a significant benefit for the combination treatment, but not for either of the single therapy groups, compared with placebo on the main outcome measure (total CDRS-R score ≤28). Although fluoxetine was not significantly better than placebo, it was significantly better than CBT on the same outcome. In terms of response, 71% of the combination group; 60.6% of the fluoxetine group; 43.2% of the CBT group; and 34.8% of the placebo group achieved a score of 'much improved' or 'very much improved' on the clinician rated CGI scale. These rates increased to 85% for the combination group, 69% for the fluoxetine group, and 65% for the CBT group at week 18 (end of phase two), and 86% for the combination group, 81% for the fluoxetine group, and 81% for the CBT group at 36 weeks (end of phase three) (46). The placebo group was not followed up past 12 weeks.

As mentioned above, stage four involved a naturalistic follow up. 196/439 (44.65%) completed at least one assessment at this time. There were no significant differences between those who participated in the follow up and those that did not in terms of treatment group or response to treatment in stage one, but there were other significant differences (44). 46.6% of the included sample experienced a recurrence of MDD during the follow-up period. Recovery was defined as remission lasting for eight weeks or more, and at 12 months post baseline 68.8% had recovered, which increased to 91.5% of the sample by two years post baseline. Rather than being associated with any particular intervention, recovery at two years post baseline was significantly more likely for those who responded to treatment in phase one (i.e. the first 12 weeks of the trial).

Criticism of TADS and controversy surrounding SSRIs

Concerns have been raised (47) about the March and colleagues (45) interpretation of stage one TADS data. Criticism of TADS is representative of two main controversies surrounding the use of SSRI medications in children and adolescents in general. Firstly, there is a lack of consistent evidence of the efficacy of many of the SSRI medications, except for fluoxetine. Even in this case, one of the criticisms levelled related to a lack of understanding of the clinical relevance of 'response' and the inconsistent way in which response is measured (as discussed above). It has been suggested that even though there is a statistically significant difference between fluoxetine and placebo, it is misleading to simply say that this medication is effective for this age group, because it is unknown how this might translate into real benefits for young people being treated in 'real world' settings (48). Secondly, there is a two-fold increased risk of suicidal ideation and behaviour seen across SSRIs in comparison to placebo for children and adolescents (49), (50) and young adults (51). Because of this increased risk, the United States Food and Drug Administration, and subsequently other regulatory bodies around the world including the Australian Therapeutic Goods Administration, released documents discouraging the use of SSRIs in children and adolescents. The main result of this was the inclusion of a black box warning on medication labels for SSRIs, which is the strongest action that they can take aside from banning agents.

Engaging young people in treatment

Amid this controversy, the imperative to provide timely and effective treatment remains. Despite the importance of ensuring effective treatment for young people diagnosed with MDD, help-seeking levels are generally low among young people diagnosed with mental disorders (see below). Further, controversies about appropriate treatment options have further diminished help seeking rates (52, 53). National surveys in Australia have revealed significant underutilisation of services by individuals with mental disorders (54-56), particularly in children, adolescents and young adults. Reports suggest only 29% of children and adolescents (56) and 32% of young adults (54) with mental disorders had seen a health professional in the past 12 months. Comparable results have been reported internationally, for example in the US ((6), (57)) and Europe (58-61). Supporting these findings of help-seeking rates, surveys investigating the attitudes of young people also report similar rates in terms of intention to seek treatment (e.g. (62)).

For those who do manage to access services and treatment, a large proportion will experience significant delays. Time between onset of symptoms and accessing services varies according to factors such as type of disorder, gender and geographical location (63, 64). Literature on factors related to delay to treatment for adults diagnosed with MDD highlights the importance of areas such as stigma (e.g. (65)); negative attitudes to, and experiences of, treatment (e.g. (66, 67)); and availability of services (e.g. (68)).

Delay in time taken to access treatment is also an important consideration for young people. A recent Australian study with adult participants investigated factors related to the time taken to access treatment after first experiencing symptoms of anxiety and depression (69). Taking longer to recognise that the problem was a mental health issue, and experiencing symptoms at an earlier age, were the two factors associated most strongly with long delays in accessing treatment. The mean time taken between first experiencing symptoms of depression and accessing treatment was 8.4 years (SD2.2). Given that experiencing symptoms at an earlier age was associated with long delays in accessing treatment, the importance of promoting help seeking, engaging young people in treatment and providing *effective* treatment is highlighted.

In a study investigating the duration of untreated depression, earlier onset of depressive symptoms was one factor predicting a longer duration of untreated illness (70). Although no national data are available for children and adolescents diagnosed with MDD specifically, in a 2007-2008 national survey of Australians with mental disorders aged 16-85, service use was poor generally (overall only 34.9% of respondents had accessed service in the past 12 months) and service use in the youngest group (16-34 year olds) was the lowest (28.6%) of all age groups (71). As mentioned earlier, rates of service use are poor in young Australians with any mental disorders in general (54-56).

Given that rates of service utilisation are likely to be poor in young people and that negative experiences and attitudes towards treatment for depression impact upon help seeking and engagement, it is important that once young people do reach a service, that they access the most effective treatment and have a positive experience. This is made more difficult by the complexities and controversies surrounding treatment provision, particularly with regard to medication, in this area (as discussed above). Successful engagement and treatment choice are paramount in order to make the most of the opportunity when young people attend health services.

Involving young people

In terms of deciding upon which treatment option to pursue, guidelines also advocate for the inclusion of young people in the decision-making process (and their caregivers where relevant) (26, 30). This includes the provision of information about the potential risks and benefits of treatment options, as well as being involved in treatment decision-making and other decisions that affect their care. The inclusion of young people and their caregivers reflects a growing shift towards involvement in healthcare as a basic right. The *Australian Charter of Healthcare Rights* promotes the importance of "a genuine partnership between patients, consumers and providers" and stresses that all clients should have the right "to be included in decisions and choices about (their) care" ((72), no page number). More specific to mental health are the Australian *National Standards for Mental Health*, for which a guiding principle is "informed decision making by individuals about their treatment" ((73), p.5). This is echoed in the Victorian report *Doing it with us not for us*, which includes as a standard of mental healthcare provision that "consumers, and, where appropriate, carers are involved in informed decision making about their treatment, care and wellbeing at all stages and with appropriate support" ((74), p.18).

The right to be involved as a healthcare consumer has also been gaining momentum internationally, with the *Crossing the Quality Chasm* report in the United States including the following as one of ten rules to guide the redesign of healthcare:

> "Patients should be given the necessary information and the opportunity to exercise a degree of control they choose over health care decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision making" ((75) p.9).

In specific relation to young people, a report form the *Bristol Royal Infirmary Inquiry* in the United Kingdom outlines a framework with recommendations focussing on the provision of information and involvement of young people and their caregivers (75), and the *United Nations Convention of the Rights of the Child* (76) details the legal right of children to be involved in making decisions about their own healthcare regardless of their caregivers wishes. Internationally and locally, youth mental health services (e.g. *headstrong* in Ireland (77), *Orygen Youth Health* in Australia (78)) and organisations (e.g. *Youth Move* across the US (79), *Mind Your Mind* in Canada (80), *Inspire Foundation* (81) and *Reachout!* (82) in Australia) advocate for the involvement of young people in various aspects of service provision, including in treatment decision making. Alongside this international momentum in support of involving young people, there is potential that such involvement could contribute to improving aspects of care such as satisfaction, engagement and treatment adherence. In doing so, involvement may play some part in alleviating confusion and miscommunication about the controversial aspects of treatment for depression in young people. Despite this, little is known about the nature or impact of such involvement.

Treatment decision making for young people diagnosed with MDD

The overarching aim of this study is to explore the involvement of young people diagnosed with MDD in their own care. As a starting point, I will review the available literature on the involvement of young people diagnosed with MDD in their own health care in chapter 2, including desire for involvement; treatment preferences; and studies relating to experiences of, and beliefs about, treatment decision making. Due to the paucity of data in the area, and in order to contextualise the aims and approach of this study further, related studies concerning experiences and beliefs about depression and treatment for depression will also be considered. The gaps in our understanding on this topic will then be highlighted before the specific aims of the current study are presented.

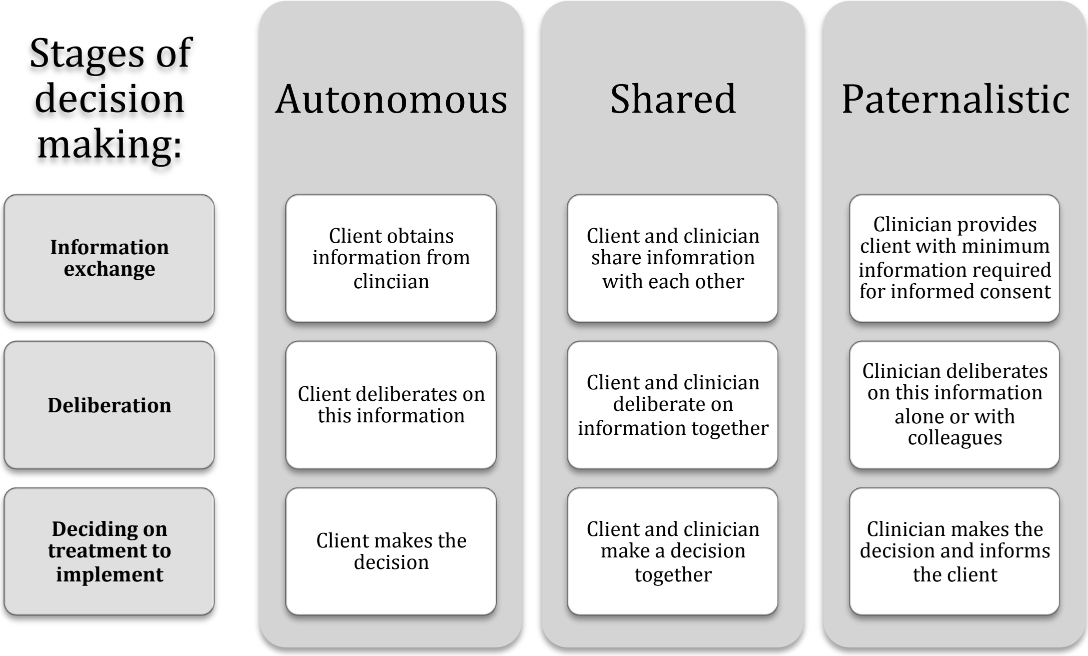
Chapter 2: Narrative review of treatment decision making for young people diagnosed with MDD

This chapter presents a narrative review of studies in the area of treatment decision making for young people diagnosed with MDD. To contextualise the findings of the review, models of involvement in treatment decision making are first described, before research into the involvement of young people in mental health services is reviewed. Due to the lack of research looking specifically at the involvement of young people diagnosed with MDD in mental health services and/or their own treatment, related studies, including those with adults diagnosed with MDD, are considered.

Models of involvement in treatment decision making

Charles et al (1997) (83) propose three styles of decision making (paternalistic, shared and autonomous), which are defined by who takes responsibility for each 'stage' of decision making (see figure 1). The stages of decision making include: 1) information provision; 2) deliberation; and 3) making the decision. Paternalistic decision making is described as when a clinician provides minimal information to a client (e.g. as legally required) and does not ask them for any more information than what they need to make the decision, then deliberates on this information themselves before making a decision and informing the client. SDM is described as when a clinician and client both share relevant information with each other, deliberate and decide together. Autonomous decision making is described as when a client obtains all of the information needed to make the decision from the clinician, then deliberates and makes a decision by themselves.

This model was updated to acknowledge that more complex combinations of responsibilities might occur, leading to styles of decision making that fall between the three described in the original model (84). Additionally, the updated model allows for the fact that involvement may change over time, either within a consultation or over several consultations, and expands on the stages of decision making (e.g. describing information exchange as being characterised by flow, direction, type and amount).



Stages of decision making:	Autonomous	Shared	Paternalistic
Information exchange	Client obtains information from clinciian	Client and clinician share infomration with each other	Clinician provides client with minimum information required for informed consent
Deliberation	Client deliberates on this information	Client and clinician deliberate on information together	Clinician deliberates on this information alone or with colleagues
Deciding on treatment to implement	Client makes the decision	Client and clinician make a decision together	Clinician makes the decision and informs the client

Figure 1. Models of treatment decision making (adapted from (83, 84)).

It is important to consider what constitutes involvement. In the above model, the conceptualization of involvement focuses on information sharing and making actual decisions. Entwistle and Watt (2006) (85) suggest a broadening of what comprises involvement to include both: 1) participation in activities related to decision making (with or without other people; described as the 'stages' of decision making by Charles et al (1997) (83), see above); and 2) the way that those involved (e.g. client and clinician) think and feel about such activities and the other individuals involved (e.g. how the client feels about the clinician). They describe three existing domains of involvement (communication between clients and clinicians about decision making; efforts made by the client in relation to decision making; and efforts made by the clinician in relation to decision making), and propose that two further areas should be considered in order to create a more meaningful understanding of client involvement: the way in which clients view, and feel about, these first three existing domains of involvement as well as their role as the client in, and contribution to, the decision-making process; and consideration of the feelings of both the client and clinician about their relationship with each other.

Trevena and Barratt (2003) (86) also suggest that models of decision making should be extended, however their focus is on consideration of the nature of the health issue that the decision relates to. This initial concern, they propose, should then guide the level of influence that remaining aspects of the decision-making process have, including client preferences, values and beliefs; recommendations made by the clinician; the available research evidence; as well as other clinical factors related to the decision, such as comorbidity. Tailoring the decision-making process in this way is of specific relevance to treatment decision making for depression, which is likely to be different to other disorders and health conditions (87), and for which clinical factors such as comorbidity are common.

Within these models, it is also important to consider the ways in which clients may wish to be involved in the decision-making process. Deber and colleagues (2007) (88) conceptualise two categories related to making decisions: 1) problem solving, which refers to a scenario where there is only one possible correct answer and is therefore not able to be influenced by client preferences; and 2) decision making, which may be based on problem solving, that can be influenced by client preferences and involves some consideration of the potential pros and cons of different scenarios (e.g. treatment options). For each of these categories, it is proposed that clients can prefer to 'keep' the responsibility themselves, 'share' responsibility with a clinician, or 'hand over' responsibility to a clinician. Combinations of these preferences then fall under categories of preference for involvement in decision making (e.g. passive, shared, autonomous).

Edwards and Elwyn (2006) (89) conducted in-depth interviews with primary care patients about experiences of treatment decision making and demonstrated that a distinction exists between treatment decision-making processes (e.g. the analytical stages of decision making as described by Charles et al (83, 84), such as information exchange and deliberation) and who actually makes the decision.

Preference for involvement in treatment decision making

Preference for involvement in healthcare decisions appears to have increased in recent years. A recent review (90) of patient preference for involvement in treatment decision making for both psychiatric and non-psychiatric conditions located 115 studies, across which the majority of patients (63%) wanted some involvement. When divided into studies published before 2000 and those published between 2000-2007, the rates of desire for involvement in treatment decision making were 50% and 71% respectively. Although some of this increase may be a result of measurement differences over time, it may also reflect the growing shift towards more client centred care (as discussed in chapter 1). Preference for involvement does vary according to the way in which it is measured, the condition or illness for which the decision is made, and the type of decision being made, however studies have consistently found that individuals who are female, young and more educated are more likely to prefer involvement (90-93). Given that females are more likely to experience depression, and that depressive episodes are common in adolescence, preference for involvement of individuals diagnosed with MDD is an important consideration.

Evidence suggests that a significant proportion of adults diagnosed with MDD will want at least some involvement in treatment decision making (e.g. (91)), and some studies have shown that this is more the case for those with depression compared with other disorders (94-96). For example, in a study measuring preference for involvement in medical decision making (including treatment decision making), individuals with a diagnosis of depression were more likely to prefer an active role in making decisions than individuals with either severe or 'unsevere': hypertension, diabetes or heart disease (94).

The involvement of young people in their own mental health care

In terms of young peoples' preference for involvement in treatment decision making and related views about treatment options, little is known. Literature on the involvement of young people in mental health services has largely focussed on consultation with young people to inform service models and delivery. Three literature reviews were located that looked at the involvement of young people in mental health services (97-99). All three reviews found only a small number of studies, and all related only to involvement in areas such as policy development, service planning, implementation and evaluation. Although two of the reviews concluded that young people do indeed wish to be involved in making decisions about their care (97, 98), the studies they refer to have only considered decisions at a broader level than individual treatment decision making (e.g. service delivery).

Further literature searches for the current study were conducted and no additional studies were found specifically measuring the preferences of young people for involvement in treatment decision making with regard to their own mental health issues. However, one study was located, which demonstrated that young people are not without opinions with regard to the sort of interventions they prefer for the treatment of their own depression. Jaycox et al (2006) (100) assessed 444 young people aged between 13 and 21 years who were identified as suffering from depression in a screening process for a large randomised control trial. Participants were asked what treatment option they would choose for depression if they had a choice of antidepressant medication, counselling or watchful waiting. Participants were also given likely outcomes in terms of the absolute risk of improving within certain time frames (e.g. "Taking medication daily for 6–9 months, with a 60–75% chance of getting better within 6 weeks"; (100), p.200). Counselling was the most preferred treatment option, with 50% of young people reporting that they would choose this option, followed by watchful waiting (28%) and antidepressant medication (22%). These data are similar to those in the adult literature. For example, when asked to choose between antidepressant medication and psychological therapies, approximately two thirds of adults will choose psychological therapy (e.g. (101, 102)).

Beliefs about treatment options for depression and help seeking

Beliefs about treatment options for depression may shed some further light on preferences for involvement in treatment decision making. Preferences for treatment options as demonstrated above may be related to pre-existing beliefs about the potential risks and benefits of these options. These preferences in turn may influence whether or not a young person wants to be involved in making a decision about treatment. The majority of studies in this area look at beliefs about antidepressant medication. Studies investigating beliefs about treatment for depression in the general population have found that negative views about antidepressant medication are prevalent (e.g. (103, 104)) and may be related to factors such as educational history, exposure to depression, and age (105, 106).

Beliefs of adults in the general population are important to consider due to the caregiver role that such adults may fulfil for young people diagnosed with MDD. In looking at this issue specifically, Stevens et al (2009) (107) administered a questionnaire about attitudes towards psychological therapies to 501 caregivers of children at community mental health clinics in the United States. Almost all of the children (93%) were currently receiving counselling and 22% were taking antidepressant medication; however, depression was not necessarily the main presenting problem for all children. A 'depression' subset of this sample (n=287), which was comprised of caregivers who either had a child taking antidepressant medication or felt that their child was depressed, were also asked about their attitudes towards antidepressant medication. Although caregivers perceived both counselling and antidepressant medication to be beneficial, counselling was seen to carry few risks, whereas antidepressant medication was perceived as risky.

In relation to adults diagnosed with MDD themselves, a small number of studies have investigated beliefs and attitudes about various treatment options. Aikens et al (2008) (105) assessed 165 adults with a diagnosis of MDD about their beliefs about treatment for depression. Participants were being seen at primary care and psychiatric clinics as part of the baseline phase of a trial of antidepressant medication and psychotherapy. Those who perceived a need for antidepressant medication were more likely to have a longer duration of symptoms, and to attribute their depressive symptoms to a chemical imbalance. Conversely, those who believed that antidepressant medication was harmful were more likely to have not previously taken antidepressant medication, to attribute their depressive symptoms to 'random events', and to report themselves as having an 'unclear understanding' of depression.

In a similar study, Brown et al (2005) (108) investigated the beliefs of 192 adults patients at family practice clinics. Participants had been prescribed an antidepressant medication for depression or had switched antidepressant medication in the past two weeks and were undertaking baseline assessments for an observational study, part of which involved a questionnaire. Although 58.6% of participants endorsed items about the necessity of their antidepressant medication (e.g. 'My medicine protects me from becoming worse'), 49.2% also expressed concern about their medication (e.g. 'I sometimes worry about the long-term effects of my medicine'). Participants were also asked about their beliefs of medications in general, and 50.5% of participants expressed concern about the overuse of medication (e.g. 'Doctors use too many medicines') and 22.4% believed that medication could be harmful (e.g. 'Most medicines are addictive).

Whether or not individuals seek treatment in the first place may also be related to beliefs about depression and treatment options. This is important in terms of treatment decision making, because choosing not to seek help is as a decision in itself. Help seeking behaviours of young people (in general, not specific to those diagnosed with depressive disorder) are likely to be complex and be influenced by access to services and trust in health care professionals, but also by health information gained from sources other than health care professionals (109). Two studies highlight the relevance of beliefs in terms of help seeking behaviours specifically related to depression. In the first study, Cooper-Patrick et al (1997) (110) conducted three focus groups in order to elicit accounts of experiences and beliefs in relation to treatment for depression: one each with 'white' (n=8) and 'black' (n=8) adults who had a recent depressive episode; and one with clinicians who had experience treating clients diagnosed with depressive MDD (n=7; four GPs and three social workers). Depressed adult participants were divided according to ethnicity in order to compare responses between these two groups. Participants were asked to comment on what they felt were important factors related to accepting a diagnosis of depression, seeking help and receiving treatment for depression. In comparison to clinicians, participants who had experienced depressive episodes spoke more about spirituality, social support and life experiences as being important in terms of making decisions about, and engaging in, treatment. Clinicians, on the other hand, spoke more about coordination and referral issues; access to care; and different attributes of treatment options (e.g. positive, neutral and negative comments about different types of medication and psychological therapies). Participants identifying as black were also more likely than those identifying as white to talk about issues such as spirituality and stigma.

A second study related to this issue was located, in this instance with young adults. van Voorhees et al (2005) (68) investigated the beliefs and attitudes of 10,962 individuals aged 16-29 years who met the cut-off score for depression on an Internet screening program in the United States. 26% of participants reported that they did not intend to accept the diagnosis of depression. Factors associated with this reluctance to accept a diagnosis of depression included disagreeing about the effectiveness of antidepressant medication, disagreeing that there is a biological aetiology of depression, and feeling that you would be embarrassed if friends knew that you had been diagnosed with depression. In addition to these beliefs, experiences of past treatment and low severity of depressive symptoms also predicted the likelihood of not accepting a diagnosis of depression. It is likely that such reluctance would have a significant impact on the decision about whether or not to engage in treatment.

In addition to influencing help seeking, there is evidence to suggest that negative beliefs and concerns about medication increases the likelihood of poorer adherence (111, 112). Choosing not to adhere to a treatment option, or choosing not to engage in a service, are decisions that are likely to occur outside the clinical encounter. Negative beliefs, or concerns about treatment options, may make it more difficult to make a decision, and it is probable that such beliefs are not raised in consultation with clinicians (113-115). The decision-making style of the clinician in itself may also influence beliefs and adherence to antidepressant medication (116). On the other hand, feeling involved (e.g. in the decision-making process) increases the likelihood of feeling satisfied (117) and improvement in depression severity (118). Being able to express and discuss beliefs about depression and treatment options, and therefore being more involved in the decision-making process, is likely to increase feelings of satisfaction. For young people diagnosed with depression, relationships with adults such as clinicians can impact help seeking, engagement and adherence (119). Interactions that allow for sharing of information, including client beliefs, and discussion about this information are likely to be important. It is necessary to consider the relevance and influence of client beliefs on the treatment decision-making process, and the relationships associated with this process. Interactions between clinicians and clients when making such decisions, that is, experiences and beliefs around treatment decision making, are therefore essential to investigate.

Treatment decision making for depression

There is a growing body of qualitative research looking at experiences of adults diagnosed with MDD, including a recent meta-ethnography that synthesised 16 studies exploring experiences of taking antidepressant medication (120). However, only one study included in the meta-ethnography looked specifically at the experiences and beliefs about treatment decision making for depression. One additional study was located in a search conducted for the purposes of this thesis. As with the above research, both of these studies were conducted with adult participants.

Simon et al (2006) (87) interviewed 40 adults aged 18 to 70 years, who were diagnosed with MDD, about their perceptions of the treatment decision-making process. Findings highlighted the important role that GPs played for participants in terms of being the first point of professional contact on their help-seeking journey. GPs were also the main professional source of information about depression and related treatment options, however participants reported receiving little information and instead sought information elsewhere (e.g. on the internet). Participants also reported barriers to seeking and receiving care that impact upon treatment decision making, including stigma, attitudes towards depression and related treatment options, and concerns about side effects of antidepressant medication. Lastly, the study demonstrated the variation in participants' preference for involvement in the decision-making process.

Using a slightly different design, Garfield et al (2004) (121) interviewed 51 adults aged 19 to 61 years, who were being treated for depression in primary care and had recently been prescribed an antidepressant medication. A follow up interview was conducted three months later, and participants were asked about their experiences of treatment decision making for the initiation of antidepressant medication. Similar to the results from Simon et al (2006) (87), information was an important part of the decision-making process, and yet participants felt that they did not receive enough information. Additionally, they felt that it was difficult to remember all of the information that they did receive in consultations with their doctors. Types of information that were reported to be valued but sometimes missing included information about side effects, concerns about dependency, how long medication takes to work and the minimum and maximum dosage range. Another key finding was how preference for involvement in decision-making processes varied between participants but also across time.

Although there were no studies located looking specifically at experiences and beliefs about treatment decision making for *young people* diagnosed with depression, one related study was found. Wisdom and colleagues conducted a qualitative study exploring both how young people aged 14–19 years make sense of being depressed (122) and how they recognise and seek help for depression (123). The ways in which young people viewed themselves, including a desire to feel normal, connected and autonomous, along with their own stigmatising beliefs, made it difficult to recognise depressive experiences and seek appropriate care. Once young people accessed services, if they felt that clinicians were compassionate and provided them with information and treatment choices then this helped them to feel positive about the encounter. Conversely, if young people felt judged and were not provided with adequate information or treatment choice, then they were more likely to feel dissatisfied and disengage from treatment. The authors described specific issues related to this age group, including: 1) struggling with identity in terms of being diagnosed with depression, at an age where young people are already struggling to develop their own identity overall; 2) that accessing care independently can be difficult if young people are still being treated under the care of their parents or guardians; and 3) that making a decision about whether or not to take antidepressant medication was a difficult decision for young people and clinicians did not always address their concerns. Again, this research highlighted potential barriers to care.

Can young people be involved in making decisions about their own care?

In addition to considering how young people can be involved in treatment decision making for depression, or if they want to be involved, it is also important to consider the *capacity* of young people diagnosed with depressive disorders to be involved given both their age and clinical condition. Laws and policy regarding age of consent will vary according to geographical location. There is little research investigating the decisional capacity of young people diagnosed with depressive disorders specifically, however there have been recent calls for adolescents (particularly those aged 14 years and older) to be deemed competent to provide informed consent for participation in research studies (e.g. (124-127)). In one study with paediatric outpatients and inpatients, competency to consent to treatment was established and level of competency was not related to psychiatric symptomatology (128). Furthermore, studies assessing treatment decisional competency in adults diagnosed with depression demonstrate that despite some impairment, most individuals are competent and do not differ greatly from non-psychiatric control populations (e.g. (129-132)). However, decision making for young people diagnosed with depressive disorders is likely to be complex, and the point at which adult input is required needs to be assessed on an individual basis (133-135).

Summary

Regardless of whether or not young people have the capacity to be involved in all aspects of their own care, the importance of engaging young people once they reach a service (whether it be primary care or specialist mental health services) is clear. How to engage young people in the context of their pre-existing beliefs and attitudes, preference for treatment options and preference for involvement is poorly understood. It is unclear whether or not the growing endorsement for young people to be involved in their own care has actually eventuated at an individual level. The dearth of research in this area precludes not only a full understanding of this complex and dynamic scenario, but also of how to improve the decision-making process in order to promote and facilitate satisfaction, engagement and adherence. Perspectives of clients, caregivers and clinicians are likely to differ (136). In order to address this gap in our knowledge, interviews with these three groups were conducted to explore experiences and beliefs of treatment decision making for young people diagnosed with MDD. Chapter 3 presents the methodology of the study, and then the data are presented in chapters 4 and 5.

Chapter 3: Research methodology and methods

Introduction

The first aim of this study was to investigate the experiences and beliefs of clients, caregivers and clinicians about treatment decision making for young people diagnosed with MDD. This topic was considered to be important because it is a key stage in the treatment provided by services, and because there is a lack of understanding of how these decision-making processes occur. Due to the paucity of the data in the area, a descriptive account is of interest in and of itself, but also serves to provide the foundation upon which research into improving decision making can be developed. This chapter describes the study's research methodology for semi-structured interviews with clients, caregivers and clinicians. Interviews were chosen because they afford a dynamic way in which to explore and obtain rich descriptions of experiences of events (e.g. making decisions) and beliefs about these events (137). Also, unlike other approaches such as questionnaires, responses can be clarified and explored further, with any new topics raised by interviewees also delved into.

Theoretical framework and data analysis

As opposed to an essentialist or reductionist view where the task of the researcher is to uncover an ultimate 'truth', social constructionism is an epistemological framework that instead acknowledges the active roles that researchers and participants alike play in creating data (see (138, 139)). As such, data are seen as constructed and influenced by social encounters (e.g. an interview). Social constructionism assumes that there are multiple subjective truths, rather than one single truth or, for example, a natural, underlying pattern to 'uncover' (140). This approach acknowledges the subjective and interconnected nature of experiences and the accounts that are created of those experiences. These assumptions were adopted for the current study and so the accounts offered by participants in the interview were considered to be socially constructed explanations of their experiences. Unlike a quantitative approach that values 'representative' samples, the current project instead sought to encompass a *diverse* sample of participants, with varied accounts and realities. Additionally, the project was guided by research questions and aims rather than seeking to confirm or disconfirm a hypothesis or hypotheses. The interview schedule was designed to impose as little upon the interviewee as possible, and the dialogue between the interviewer and interviewee were treated as equally relevant data (i.e. the transcripts include verbatim representations of the discourse from both parties, see (141)). The aim was to elicit the ways in which participants made sense of their own experiences and beliefs, however the socially constructed setting of the 'interview' in and of itself was not ignored.

The methodology employed for the first phase was thematic analysis. This flexible type of qualitative research is appropriate to use within numerous epistemological frameworks, including a social constructionist approach (142). Previously, the term 'thematic analysis' has been used to refer to a number of different methodological approaches. Braun and Clarke (2006, (142)) have made attempts to delineate thematic analysis as an approach with more uniform standards by providing clear, thorough descriptions of both processes (see table 1) and quality criteria (see table 2). These served to guide the development and implementation of the current project. Accordingly, therefore, the flexibility of this approach was coupled with methodological rigour and transparency.

Table 1. Phases of thematic analysis ((142):87).

Phase	Description of the process
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collecting data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of

	each theme, and the overall story of the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Table 2. A 15-point checklist of criteria for good thematic analysis ((142):96).

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tape for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all (sic) each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with

		the epistemological position of the analysis.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.

Ethics approval

Ethics approval was obtained from the relevant local committee (Melbourne Health Research and Ethics Committee reference number 2008.19; see Appendix A). Parental or guardian consent was obtained for participants aged less than 18 years old.

Setting

Participants were recruited between August 2008 and May 2009. Clients and caregivers were recruited from two services: Orygen Youth Health (a specialist youth mental health service for young people aged 15-24 living in the north western metropolitan area of Melbourne, Australia) and headspace Barwon (an enhanced general practice service for young people aged 12-25 living in the satellite city of Geelong, 75kms south-west of Melbourne). Clinicians were recruited from these same services, and also from other services, including private practice, public child and adolescent mental health services and general practice. This purposive sampling targeted a variety of services where young people diagnosed with depressive disorders are seen, and allowed for the inclusion of perspectives from a clinical psychologist working at a clinic that was adolescent specific but not mental health specific, two clinical psychologists working privately and a general practitioner working in a generalist primary care setting (rather than with a mental health focus). All participants were interviewed at the relevant service.

Participant selection: clients and caregivers

A purposive sample (143) was recruited in order to obtain descriptions of the experiences and beliefs of young people and caregivers who had experienced and preferred different involvement styles (e.g. autonomous, shared and paternalistic) in relation to treatment decision making for young people diagnosed with MDD. The project was presented to clinicians from each service (see above) at staff and clinical review meetings, after which clinicians were asked to provide information about the study to clients and caregivers who met the inclusion criteria. Interviews were conducted until a diverse range of experiences and views had been covered, including experiences with school based services, primary care services, and both public and private specialist mental health services. Additionally, interviews were conducted until rich descriptions of passive, shared and autonomous involvement were obtained, from a variety of clients and caregivers, both in terms of the experiences of, and preference for, such involvement. Time was taken to review interview data as recruitment proceeded in order to ensure that the collection of data ceased only once all these domains had been covered. Ten clients and five caregivers were recruited in all. Fewer caregivers were recruited because their experiences and views were more homogenous and saturation was achieved sooner. Saturation is the point at which a qualitative researcher believes that no new themes are arising in the interviews (144). The purposive sampling method employed guided saturation for this study. Recruitment continued until participants had described different combinations of preference for involvement (e.g. wanted to share information with the clinician but did not want to make the final decision) and no new themes were apparent. These variations in experiences of, and preferences for, different types of involvement occurred not only across participants, but also within participants, as experiences and preferences varied over time.

Participant selection: clinicians

All clinicians from the relevant clinics (i.e. those who saw clients diagnosed with MDD but not psychotic disorders) at OYH and headspace Barwon were approached to participate in the study. This was done at team meetings with the initial visit including a brief presentation of the study and subsequent visits including reminders about the study. Interviews were conducted until a variety of professions were represented and no new themes were seen in the data, as with the client and caregiver recruitment. 22 clinicians participated in total.

Inclusion Criteria

In summary, inclusion criteria were:

- Young people aged 12-24 years old who had received treatment for a MDD whilst aged between 12 and 18 years old; or

- Any caregiver of a young person aged 12-18 years old, where the young person had been in receipt of treatment for MDD; or
- Any clinician who had been involved in treatment decision making for young people aged 12-18 diagnosed with MDD; and
- Sufficient language skills and intellectual capacity to provide informed consent and participate and not currently experiencing a psychotic episode.

Data collection

The interview probes were based on a previously published focus group schedule (145) and modified to meet the aims of the project. Probes were also altered slightly for each participant group (see table 3). They were designed to elicit descriptions of experiences and views in relation to treatment decision making (guided by social constructionism, as discussed above). The probes used were a combination of very broad, non-directive questions (e.g. 'How are decisions typically made?') and more specific questions (e.g. 'How do you present the risks and benefits of treatment options?'). Rather than following the probes verbatim, interviewees were initially asked to describe their experiences of treatment decision making and were then afforded the opportunity to further expand on these experiences in their own way. The interviewer was then free to ask for clarification or to encourage participants to elaborate further on their accounts. The probes were used at appropriate time points as the interviewees described their experiences, or to facilitate dialogue if the interviewee was slow to generate discussion, and again at the end of each interview to address any topics that had not already been covered. The interviews were audio recorded and transcribed using an orthographic (verbatim) style, and field notes were taken during each interview. Transcripts were checked for accuracy by independent parties. One clinician did not consent to the interview being recorded, and the interviewer took detailed notes instead, recording the conversation verbatim. Interviews lasted between 13 and 108 minutes (mean 39 minutes; SD 17).

Table 3. Interview probes for clients, caregivers and clinicians.

	Clients
Experiences	What different types of service experiences have you had?
	What types of decisions have you made/your clinicians made about treatment options for you?
	What options were presented to you?
	How were these options presented to you?
	How involved were you in making these decisions?
	How involved were your caregivers/parents?
	Were you informed of the possible risks and benefits of each treatment option?
	Have you ever disagreed about a treatment decision?
Beliefs	Do you wish the decision-making process was different? If yes, how so?
	How important is everyone's input into the decision-making process?
	How important are client, caregiver and clinician values?
	Who should weigh up the risks?
	Pros/cons of being involved in the decision-making process?
	Any barriers (e.g. in the system) to being involved?
	Anything that could improve decision-making process?
	What constitutes true involvement for you?
	Caregivers
Experiences	What different types of service experiences has your child had?
	What types of decisions has your child made/your made about treatment options for them?
	What options were presented?
	How were these options presented to you?
	How involved were you in making these decisions?
	How involved was your child?
	Were you informed of the possible risks and benefits of each treatment option?
	Have you ever disagreed about a treatment decision?
Beliefs	Do you wish the decision-making process was different? If yes, how so?
	How important is everyone's input into the decision-making process?
	How important are client, caregiver and clinician values?
	Who should weigh up the risks?
	Pros/cons of being involved in the decision-making process?
	Any barriers (e.g. in the system) to being involved?
	Anything that could improve decision-making process?
	What constitutes true involvement for you?
	Clinicians
Experiences	What different types of experiences (e.g. different clients you've seen,

	different services you have worked at) have you had?
	What types of decisions have you made/your clients made about treatment options?
	What options do your clients have?
	How do you present these options?
	How involved were you in making these decisions?
	How involved were your clients? Caregivers?
	Do you inform your clients/their caregivers of the possible risks and benefits of each treatment option?
	Have you ever disagreed about a treatment decision?
Beliefs	Do you wish the decision-making process was different? If yes, how so?
	How important is everyone's input into the decision-making process?
	How important are client, caregiver and clinician values?
	Who should weigh up the risks?
	Pros/cons of your clients/caregivers being involved in the decision-making process?
	Any barriers (e.g. in the system) to being involved?
	Anything that could improve decision-making process?
	What constitutes true involvement for you?

Data analysis

Analysis was undertaken in accordance with Braun and Clarke's (2006) description of thematic analysis (142). The analysis was theoretically driven in that main topics were decided before the interviews were conducted (and the interview probes were based on these topics, for example 'experiences of involvement in treatment decision making'), however the analysis was also inductive to an extent in that new topics were also derived from the data. Within each topic, more specific coding of themes was undertaken. Initial data coding occurred during transcription, followed by a secondary coding process conducted after all interviews had been transcribed. Themes were then compared within and across groups (clients, caregivers and clinicians). Theme and coding matrices were used to organize data items and sets and to generate a thematic map. The interviewer kept a reflective journal, which consisted of thoughts and feelings about the experience and content of the interview, as well as any initial thoughts about limitations or findings of the data. In doing so, and using the field notes taken during each interview, analysis could begin as data collection was occurring (as recommended by (143)) and consideration was given to the way in which the interviewer was influencing and interpreting the interviewees' responses. When analysing accounts of involvement, themes were informed by Charles et al's (1999) (84) description of decision making approaches and analytical stages of decision making, as well as the distinction drawn by Elwyn and Edwards (2006) (89) between the decision-making process and who actually makes the final decision (both described in chapter 2). Once analysed, the data were summarised in a report sent to participants inviting feedback in order to facilitate member validation, however no significant changes were made as a result of this process. Presentations were also made to the two main clinical services involved (OYH and headspace Barwon). Member validation, or member checking, is one way in which to increase the validity of qualitative research and involves asking participants to consider the validity of interpretations made by the researcher (144).

It soon became apparent once data collection commenced that the ways in which clients and caregivers described their experiences and beliefs was different to how clinicians did. Clinicians employed shared, professional terminology; they were more general in their descriptions in that they were referring to a large number of experiences of treatment decision making; and they also spoke about experiences and beliefs as being very similar, possibly because of the relative control they had to influence treatment decision making based on their beliefs. In contrast, clients and caregivers used more lay language; were more narrative in that they recounted specific stories rather than providing general accounts; spoke about a smaller number of treatment decision making experiences; and often spoke about beliefs that were different to the experiences they reported. The forthcoming analysis chapters, chapters 4 and 5, are therefore divided into service users (i.e. clients and caregivers) and service providers (i.e. clinicians).

Chapter 4: Interviews with service users about their experiences of, and beliefs about, treatment decision making

Introduction

This chapter presents the data from interviews conducted with service users. That is, clients aged 12-25 years old who experienced treatment decision making for MDD when they were between the ages of 12 and 18 years, and caregivers of such young people, but not necessarily of the young people interviewed for the project. The data from service providers, namely, clinicians who are involved in treatment decision making for such young people, will be discussed in chapter 5. As discussed in chapter 3, the interview probes were semi-structured and focused on themes related to experiences and beliefs about treatment decision making for MDD.

Participants

Of the ten clients who participated, 5/10 were male, 8/10 had a self reported comorbid mental disorder (anxiety disorders, borderline personality disorder, substance use disorder and/or Asperger's disorder) and their ages ranged between 15 and 24 years old (mean age 20.3 years; SD 3.1). All caregivers were female, aged between 40 and 55 years old (mean age 47.2 years; SD 6.1), and caring for their own offspring (not necessarily the clients participating in this study).

Results of interview data

Results are summarised in table 1.

Table 1. Summary of results from clients and caregivers related to experiences, beliefs and barriers to involvement.

		Clients	**Caregivers**
Experiences	Client involvement	• Varied according to client, clinician and service • Didn't always match preference • Most clients experienced different types of involvement • Less involved in certain settings (e.g. detoxification units, inpatient units) • Satisfaction of level of involvement varied	• Usually encouraged involvement of their offspring • Did so to promote engagement in service and personal development

	Caregiver involvement	• Many clients did not have caregivers involved • Clients who did not have caregivers involved described finding decision making challenging due to a lack of support • Clients who did have caregivers involved described at least one negative experience each where caregiver involvement was detrimental to decision making	• Experiences relatively homogenous • Felt involvement was usually limited to practical tasks • At times felt removed from clinical encounters, including treatment decision making • Caregivers asked for information about their child but not always given the information they wanted • Satisfaction of level of involvement varied and was influenced by characteristics of the young person and of the caregiver themselves • Many caregivers found confidentiality policies based on age problematic
	Clinician involvement	• All clients wanted some clinician involvement • Some clients wanted only specific clinicians involved (e.g. case manager but not doctor) • All but one client wanted clinician involvement to be of a collaborative nature • Most clients wanted to weigh up the potential risks and benefits of treatment options with clinicians	• Most caregivers wanted to trust clinicians as experts • Most caregivers wanted to be trusted as those who knew the most about their children • Caregivers reported either themselves or the clinician making the final decision • Trust in clinicians was dependant on perceived quality of care
	Information	• Provision of information varied across clients, clinicians, services, and also within clients across time • Information received was lacking or poor • Many clients sought information elsewhere • Some clients felt reluctant or unable to ask for more information • Information valued as important for decision-making • Clients wanted honest information about treatment options and likely outcomes to facilitate realistic expectations	• Provision of information was poor • Lack of information compounded feelings of exclusion and confusion • Some caregivers received information via their child • Some caregivers sought information elsewhere
Beliefs	Desire for involvement	• Desire for involvement varied both within and across clients • Most clients wanted a collaborative style • Trust, age, severity of symptoms and levels of support influenced preference for involvement	• All caregivers wanted some involvement • Degree of preferred involvement varied, including preference for who makes the final decision

		• Clients distinguished between decision making process and making the final decision	
	Importance of involvement	• Client involvement important for engagement process, adherence to treatment, safety, autonomy and empowerment • Consideration of personal characteristics, values and preferences was important to clients • Having the final say was perceived as a basic right	• Caregiver involvement important because of knowledge about offspring and continuity of care compared with limited time with clinicians • Client involvement important but extent of preference for client involvement varied
	Negative aspects of involvement	• One client sited immaturity and another felt that young people were not qualified	• One caregiver felt unable to be involved when experiencing her own mental distress
	Improving the decision-making process	• Suggestions influenced by experiences • Advocates on inpatient unit • Plan for therapy from the start • Wanted to be 'taken seriously' • Meaningful information that drew on existing personal knowledge • Interactive fact sheets	• Information, particularly about mental disorders
Barriers	Barriers to involvement	• System level barriers e.g. lack of time in consultations • Relationship barriers e.g. lack of communication or trust • Personal barriers e.g. age	• Service barriers e.g. confidentiality policies • Relationship barriers e.g. exclusion by clinicians and offspring • Personal barriers e.g. own mental health issues

Experiences of treatment decision making

Client involvement

Experiences of involvement in the decision-making process varied across clients, as well as across different services and clinicians. Clients' experiences of involvement did not always match their preferred level of involvement. Most clients wanted some form of collaborative involvement, whereby they would be involved in the decision-making processes (e.g. exchanging information; as described by Charles et al 1999; (84)) with their clinician, even if they weren't involved in the final decision. Yet it was common for the same client to experience both collaborative and paternalistic models (e.g. where involvement of clients was passive in that they were involved at a very minimal level).

For example, client 06 reported seeing many professionals, during which time she experienced varying degrees of involvement in treatment decision making. One psychiatrist carried out an assessment, informed her of his diagnosis, advised her that there were two treatment options that "some people (find) helpful", and told her to "come back to him if it didn't work". Not only was she uninvolved in the treatment decision-making process, but she was also not given any referral details and so did not carry through with this suggestion for treatment. Several years later, however, she saw a GP who she felt involved her considerably in the treatment decision-making process. She was able to voice her concerns about medication with this GP, and when the GP recommended medication to the client, she was told that it was her choice whether or not she wanted to take it. The GP also gave the client reasons why she felt medication was necessary, addressed the client's concerns about medication specifically (e.g. told her that she did not have to take them for ever) and gave the client relevant information, such as how long she would have to take the medication. Client 06 felt that the information was meaningful to her because it "drew on things I already had knowledge (of)" rather than, for example, "exactly what they (do) on a molecular level… because she explained it in that way… I was kind of okay with it". Another way in which client 06 felt involved in this instance was that she and the GP were working towards the same aim: "I was there overall because I (had feelings of wanting) to hurt myself and didn't want to hurt myself".

An example of an account of paternalistic involvement comes from client 01, who described very passive experiences of treatment decision making where his input and information sharing was minimal:

> "The doctors used me to ascertain my medical history because I was the only one who could remember all of the drugs that I had been on, um, and that was as far as my involvement went in the process, and as for information… nuh"

Rather than feeling as if he was part of the decision-making process, this client reported that he "would be sitting in the corner and they (clinician and caregiver) would be talking about me".

Client 04, who was comfortable with researching treatment options in his own time, described a collaborative approach with his psychiatrist in regard to decision making about medication that also involved some autonomous activities. Along with open discussions between them during appointments, they also both took on tasks related to the decision-making process:

> “She gave me a list of two or three different medications and said that these would probably be one of these would probably be what you’d be on… and she said go home and do some research on them if you want and tell me what you would like to be on if you do choose to go on medication”

Clients reported less involvement in decision making when treated on an inpatient unit, in detoxification units and forensic services. In these contexts they described not only having decisions made for them, but also a lack of shared information exchange or deliberation (84). One example of this was provided by client 01 who described his experiences at inpatient units as “horrible” and like being in a “dictatorship”:

> “Sometimes you don’t even know where the decisions are coming from… they just like get made and you have to live with the consequences of those decisions… I’ve been in there before and like had a nurse bring a cup of medication out to me… and I wasn’t taking medication the day before when I came in, all of a sudden there was this huge cup of medication in front of me. I hadn’t even seen a doctor”

Some participants were accepting of this decrease in involvement, for example because they felt too unwell to be involved, whereas others were not, as in the above example.

This also had ramifications for behaviours such as help seeking. Client 03 described two negative experiences when seeking help from GPs that have affected his help seeking behaviour since. In the first consultation he sought help for depression and believed that he was obtaining a referral for a counsellor. When the referral letter turned up in the post, it was instead for a dietician.

> “I think he took one look at me and thought alright I know how to fix this and like just blanked out on everything else I was saying… at that point in time I could care less about how much I weighed (laughter) like there were bigger problems to take care of and when I left I thought he knew exactly what I was talking about, he said alright we’ll get you a referral we’ll get you a counsellor, I was like okay that’s good”

The second time he sought help, the GP told him that it was too late for him to provide assistance and that he should attend the accident and emergency department of his local hospital. He did that and was discharged alone at 3am in the morning with no treatment plan and no way to get home. Client 03 explained the impact that it had on his future help seeking, several years after the initial attempts to seek treatment:

> "They were the two times I went to doctors for help and I don't think it's something I'll be doing again in a hurry… even today I struggle going to the doctors for anything, like I'm supposed to go and get a prescription refilled and it's been probably a month that I've been putting it off, and I'm pretty sure it's because of that, just because that went so wrong, that I'm sort of real hesitant to even go back there again"

Caregivers reported actively encouraging their sons and daughters to be involved in the decision-making process. They generally saw this as important, not only for their engagement in the service, but also for their development as individuals in terms of maturation. Caregiver 03 said:

> "I feel you know at fifteen and sixteen… they have to start taking some responsibility for themselves, they have to do that break away from mum bit, that's the whole teenage thing"

Two caregivers added caveats; one felt that her son should feel as if he was involved, but ultimately that she should decide what was best for him, and another felt that her son should be involved in so far as providing information and being informed, but that the clinician should make the final decision.

Caregiver involvement

Most caregivers had similar experiences to each other in terms of the ways in which they were involved both in the care of their offspring and also in the decision-making processes. Caregivers reported having essential roles in terms of practical support such as facilitating service use (e.g. driving their children to appointments) and managing medication (e.g. filling prescriptions for medication), however they reported being quite removed from treatment overall, including from both the decision-making process itself and also making decisions about treatment. All caregivers reported having been asked by clinicians for information about their child, in line with a passive involvement model (as defined by Charles et al 1999; (84)), but few were consulted fully about treatment decisions.

Whether or not this was a concern to the caregiver differed, and this was influenced both by their appraisal of their child's capacity to engage in treatment and make decisions, and also by their level of trust in the treating clinician and/or team. For example, when caregiver 02's son was started on medication, "I wasn't asked for my opinion but that didn't worry me because I thought, these people are supposed to know what they're doing". It was also influenced by caregivers' perceptions of their own competence with regards to knowledge of treatment options; for example, one caregiver who was a nurse and researched medications thoroughly, felt that it would be beneficial for her to be involved, whilst another caregiver who was diagnosed with Bipolar Disorder said that at times she wanted to be involved because of her knowledge based on experience, whereas at other times she couldn't be involved because she was unwell herself. Many caregivers also spoke of the difficulties they had experienced with age-of-consent policies at services, such as caregiver 03:

> "Because at the age of sixteen they're sort of classed… almost like an adult… I find that hard, because she's not an adult, she's not an adult until she's eighteen, and until that time I'm responsible for her, so if I'm responsible for her… I need to have information on what's happening within her treatment"

Caregivers reported that this lack of information impacted on their ability to provide the care that they wanted.

In terms of caregiver involvement from the perspective of clients, four clients had been living in foster care or under custody orders from early ages. Any involvement from parents or other caregivers such as case workers was very limited, and at times that lack of support made decision making difficult: client 08 described feeling alone in the decision-making process because she was "making (my) own decisions bringing (myself) up". This sense of needing to be self-reliant was often spoken about in relation to clients' perception of involvement being a basic right (as discussed below in 'Importance of being involved'). Many of the clients who did have caregiver involvement reported at least one negative experience. Client 03, for example, described attending an appointment with his mother:

> "Yeah I talked to (the psychologist) for a while and after it was done (my mother) got up and stormed out again… and it kind of dawned on me that any form of criticism levelled at her by these people she couldn't handle… so at that point I realised that if I'm ever going to do it (seek treatment) I'm going to have to do it by myself"

However, all clients felt that caregivers should be involved to some degree, including client 03, and there was a general consensus that caregivers should play a *supportive* role rather than a *decision-making* role. Client 06 felt that in supporting her, her caregivers could also provide a different perspective on her experiences:

> "I don't see them playing a role at all in making the decisions but it was important for me to have them there… for them to know that um I was doing something for myself finally… so that the psychiatrist could better understand what was wrong with me because I knew that you know hearing it only from my perspective was not necessarily going to give a whole picture, so I think that having my parents there on a level (where) we were equals was quite beneficial, but not with them having a capacity for making decisions"

Having her parents present was not only about "information sharing" for client 06, but also "knowing that they actually care".

Clinician involvement

When asked about the involvement of clinicians, some clients felt that it was important for clinicians to be involved in the decision-making process, whereas others said that it depended on the clinician (e.g. one client was happy for his case manager to be involved, but didn't want his doctor involved), but nobody advocated for a model where clinicians' input was excluded. All clients wanted clinicians' input to be of a collaborative nature except for client 03, who said that he wanted the clinician to set the agenda for treatment. He felt that if it were left up to him, then he wouldn't feel confident in his choices and may miss opportunities for recovery given the time limitations of the service. An example of the desire for a collaborative approach was client 05 who wanted her clinician to provide information to her, but also for her clinician to consider her past experiences and wishes, and to follow up and monitor her in order to demonstrate that they 'care'.

Interviewees were also asked directly whom they thought should weigh up the potential risks and benefits of treatment options. All responses except for two focused on the client and the clinician doing this together, or the client doing this after the clinician had explained the potential risks and benefits or offering their advice. Clients 01 and 03 also felt that caregivers should be involved in this ‘weighing up’ process, however client 03 qualified this by saying that it should be dependent on the age of the client and also that the information given to clients should be ‘watered down’ so as not to deter them from seeking help.

Most caregivers felt a need to be able to trust the experience and knowledge of the clinicians (as “experts”), whilst at the same time acknowledging that they themselves were the people who “know (their) kids, know what (they’re) like” [caregiver 03]. So although some caregivers were willing to trust clinicians implicitly (even if they had reservations), others wanted clinicians to act more as providers of information and for caregivers themselves to have the final say when making decisions. Caregivers reported mixed feelings about the quality of care provided by different clinicians, and this impacted on the level of trust they felt for each clinician.

Information

The level of information provided to clients varied across clients, clinicians, services, and also within clients across time. Generally, clients described the information they received as lacking or poor. Many clients sought information elsewhere, including other clinicians (e.g. pharmacist), the Internet, and asking friends and family members. One client [client 04] even attended a conference on mental health to better inform himself. Some clients felt reluctant or unable to ask for more information from their clinician, particularly if the rapport was compromised. Yet information was seen as an important factor in the decision-making process, especially in terms of feeling comfortable with the decision. The type of information desired by clients overall was summarized well by client 10, who felt that it was important to know about “alternative stuff” (treatment options), to have “realistic expectations”, good information about cognitive therapy and medication, and to be provided with honest information about potential risks (mainly side effects).

Caregivers reported receiving even less information, and this compounded their feelings of exclusion (e.g. lack of awareness of what was going on during clinical sessions) and confusion (e.g. coming to terms with the experiences, diagnoses and treatment options for their child). Some caregivers received information from their child who shared items such as fact sheets with them, and others initiated their own research (usually on the internet).

Beliefs about treatment decision making

Desire for involvement

The majority of clients preferred a collaborative style approach (whereby both the doctor and client worked together to make the decision about treatment), although desire for involvement varied both within and across clients. Additionally, views about who should be involved (e.g. clients, clinicians and/or caregivers) and their roles (e.g. decision makers, providers of information) varied within the different preferences for involvement.

A distinction was often drawn between being involved in the decision-making process (e.g. discussing the options) and making the final decision (89). For example, client 02 was happy to be quite passive in the decision-making process (e.g. not be involved in information sharing or discussing the potential risks and benefits of treatment options), but he wanted to be the one to make the decision. Client 03, the only participant who thought that young people should be involved as *little* as possible in the decision-making process, also described an experience where he ceased medication without the involvement of his clinicians or caregiver in order to illustrate that the decision was ultimately his. There was more variability reported in preference for involvement in the decision-making processes rather, whereas most clients wanted to make the final decision in the majority of examples they provided.

Preference for involvement was not static, however, and most clients reported their preference for involvement changing over time. There were issues described by clients as relating to broader changes in preference for involvement, such as wanting more involvement as they got older. The severity of the symptoms they experienced was also influential, in that several clients said that as they felt better they felt more able to be involved. The degree to which clients felt supported by those around them was also reported as impacting on their preference for involvement.

Relationships with others also played a key part in preference for involvement on more case-by-case basis (i.e. as opposed to broader changes in preference over time). If there was a certain level of trust in clinicians and/or caregivers (e.g. good rapport, a feeling of mutual respect), then some clients were willing for their own involvement to be less prominent. Feeling as if they were being heard, being treated as an equal, not being talked down to, and feeling that the clinician was caring for them were important to clients. Client 06's account of a "really good" GP included some of these aspects:

> "I had a really good G-P that I really trusted… she recommended this psychiatrist to me… I think she's the first female G-P that I really started seeing… she was really accepting and quite understanding and she'd listen, she didn't just shrug off some of my problems as being something tiny or anything like that… I've been to a lot of G-Ps over the years and a lot of them are you know just (smacks hands twice) I don't know, she was just a really good G-P (laughter)… when it came to medical issues and stuff like that she was always really open minded and willing to look into something further and stuff like that"

All caregivers wanted some involvement, although the degree to which they wanted to be involved varied. One caregiver said that she would listen to the opinions of her son and the clinicians, but then she would always make the final decision. She even went so far as to say that if the clinician didn't agree with her that she would take her son to a different service. She also reported that she often went to her general practitioner already having made her mind up about the treatment decision outcome, and this included asking for (and subsequently receiving a prescription for) antidepressant medication for her son. Another caregiver held contrasting views and felt that clinicians should always be the ones to make decisions about treatment and she said that she just had to trust that the right decision was being made, even if she (or her son) didn't agree with the outcome. The remaining three caregivers wanted to play equal roles in collaboration with their child and the relevant clinicians.

Reasons for wanting involvement

All but one of the clients advocated for significant client involvement; as mentioned above, client 03 did not think that young people should be involved in certain decision-making processes, such as setting the agenda for psychological therapy. For others, there were a variety of reasons given about why it was important to be involved in treatment decision making. These included the engagement process, adherence to treatment, safety, autonomy and empowerment. As discussed earlier, negative experiences were also reported to influence help seeking. Client 01 felt that the level of involvement "impacts (my) willingness to seek treatment" both at the time and in the future, and his experiences of not being involved made it difficult for him to want to subsequently seek help or agree with decisions. Several interviewees also thought that their positive experiences of involvement had impacted on their adherence to medication. Although he generally adhered to his medication regime, client 01 felt that if he was more involved by being provided with more information, then "I probably would have been more happier to take it (antidepressant medication)". For others who had been non-adherent in the past, improvements in the decision-making process meant that they were more willing to take medication.

Feeling empowered and autonomous was important in and of itself for some clients, and for others this was also important for safety (e.g. being able to recognize side effects and knowing what to do about them). Client 10 believed that:

> "Young people need to feel control and they need to sort of feel empowered and I think they should be informed about… the drug and everything like that so yeah I think they should be pretty involved in making that decision to go on the medication"

Without involvement, client 05 felt like "things (are) out of my power or out of my control", but when she did experience a collaborative approach, this opened up a dialogue between the clinician and herself:

> "I know I was really concerned about being safe about it too… I was able to ask questions without feeling judged, like is it okay if I take the Mirtazapine at night

> after I've had a few drinks, you know, and how does it work with alcohol and these kind of things, and instead of someone saying no you shouldn't really drink when you're taking it, it was more like well if you drink while you're taking it, it probably doesn't have the same beneficial effects, so explaining it in that way without being judging was really helpful"

The way in which treatment options related to personal characteristics, values and preferences were common themes among clients.

Having the final say was seen as a given, a basic or human right: "because you know they're (young people) human they should be able to make decisions" [client 10]; "doctors throw in suggestions and that but in the end no one can make me go anywhere really" [client 07]. The importance of being involved in the decision to even seek treatment (i.e. treatment decision making in terms of weighing up whether to get treatment or not) was highlighted by some clients. Client 04 had two experiences of seeking help: one that involved being told by his parent that he was going to see a clinician whereby he refused to attend further sessions and failed to engage, and another where he was asked if he would like to "do something" about feeling depressed, after which he agreed to attend and engaged well.

All but one caregiver felt that their involvement was important because they knew their son or daughter in a different way to their clinicians. Also, their care for their child remained constant, whereas involvement with services and clinicians was less frequent and changed over time. As caregiver 03 put it: "they see a psychologist what, once a week, once a fortnight, once a month in some cases. I'm the one doing the ongoing care." Caregivers also thought that it was important to involve the young person as well, although the extent to which they felt this should be done varied.

Negative aspects of being involved

When asked, only two clients could think of negative aspects of being involved in the decision-making process. Client 09 felt that some young people might be too immature to be involved and client 03 felt that "if you knew what you were doing you wouldn't be in therapy", and that for people with a "mental illness", information should be kept to a minimum. The only negative aspect of being involved from the caregivers' perspectives was reported by caregiver 02 who felt unable to be involved when she was experiencing mental distress herself (as discussed above).

Improving treatment decision making

Suggestions from clients for how to improve the treatment decision making varied and were influenced by the experiences that each client had. For example, client 01 had negative experiences at an inpatient unit, so he felt that there should be advocates placed on the ward in order to support the decision-making choices of the client. One client (03) who had expressed concern about making the most of therapy sessions said that he would have liked a more structured plan about therapy from the beginning, because early on he "didn't really know where it was all heading". He said that without a clear plan it was "hard to come in every week sometimes when you don't know what's coming next" and now that he was nearing discharge from the outpatient service he would like to have a clearer idea about how far he had progressed in relation to where he "should be" at. For other clients, "being taken seriously" (05) as a young person was key to improving the decision-making process. As one client put it (01): "some services, like, you could be there as a patient and they would still want you to be twenty five with a bachelors' degree before they would take your opinion on anything".

The majority of clients felt that more information was needed in order to improve the decision-making process, and it was important for them that the information drew on existing personal knowledge so that it was meaningful. Client 09 wanted more information in the form of fact sheets "but ones that you've gotta fill out and stuff"; that they were interactive was important to him. Client 05 felt that more information would have helped her to avoid a lot of the negative experiences she had when seeking help during her teenage years; when asked what information she would have liked, she said that it would be "amazing if I could see on a piece of paper options for treatment my god that would just be insane… that would be mind blowing to discuss what I think would work best with my personality". This response was made without prior discussion of SDM or DAs. Caregivers also felt that more information would have improved their experiences, particularly in relation to information about mental disorders.

Barriers to involvement in treatment decision making

Clients spoke about barriers to involvement in the decision-making process in three different contexts: at a system level, at a relationship level with clinicians and at a personal level. In terms of system-level barriers, a lack of time for questions during consultations was raised for clients who were treated in general practice and inpatient units. Barriers at a relationship level included miscommunication or a lack of communication with their clinicians, and breaches in trust (clients not trusting the clinician and/or clients not feeling trusted by their clinician) as issues. Perhaps surprisingly, symptoms of depression were only described by two respondents as being a barrier to being involved in the decision-making process (05 and 08), and the only other personal barrier that was reported was being young, where one client (01) likened the lack of involvement when he was young (aged 12-13) to his negative experiences at an inpatient unit: "I wasn't involved then… a lot of the times I didn't even like consult with people making the decisions, it was a lot like um being an inpatient in my own life". For caregivers, the main barriers related to service settings and clinicians, although caregivers also reported instances where their child had excluded them from treatment decision making. Caregivers spoke about age ranges not necessarily matching developmental stages, and how this made it difficult to respect the confidentiality policies of services.

Discussion

The most striking finding from these data is the variability in experiences of and desire for involvement in treatment decision making, both within and across clients, clinicians and services. Yet involvement, at some level, in the decision-making process was important to all clients for a broad range of reasons. This complements results from research into preferences for involvement in adults with mental disorders (93, 146, 147), and it would be of benefit to further investigate the preferences for involvement that young people diagnosed with MDD have across a larger range of services to further understand how generalizable these findings are. Particularly given that young people (e.g. (92)) and adults diagnosed with MDD (e.g. (94)) have demonstrated strong preferences for involvement.

Despite showing a strong desire to be involved in the decision-making process, all clients wanted at least some involvement from their clinicians, which supports a collaborative model rather than an autonomous model (84). It also demonstrates that client preferences for involvement do not always fit the three main models of involvement (e.g. paternalistic, shared and autonomous), but might involve components of each. Therefore, a more flexible understanding of involvement that incorporates more complex combinations of preferences is necessary (88, 89).

The desire for involvement of caregivers varied across clients, and is likely to be related to the existing role that caregivers play in the young person's life. Caregivers, on the other hand, wanted to be more involved in treatment decision making (mostly decision-making processes, although one caregiver wanted to make any decisions). However, in their experience they mainly fulfilled practical roles instead.

Clients' accounts of what constituted true involvement for them focused on factors related to key aspects of the client-clinician relationship, such as engagement and adherence, as well as client centered goals such as autonomy and empowerment. This supports the notion that conceptualizations of involvement should acknowledge and consider the views and feelings of clients (and caregivers) about their relationships with clinicians (85, 148). In line with recent calls promoting SDM for mental disorders (149, 150), these data support a focus on involvement in decision-making processes for young people diagnosed with MDD. These data also endorse the proposition that the emphasis should be on the decision-making processes rather than who actually makes the decision (89).

The provision of information also varied across clinicians and services, yet most clients and caregivers voiced a desire for more information. This is in line with previous research investigating the experiences and preferences of adults and adolescents receiving treatment for depression (87, 123). For clients it was important that this information accounted for their values and preferences. Some clients felt unable to ask for information, even though they didn't think that they had sufficient information to be involved in the decision-making process or understand why a treatment was being offered and/or feel satisfied with the decision-making process.

There are several reasons why informative resources that promote the inclusion of young people in decision-making processes are difficult to produce and may not be available. Reasons may include: a lack of evidence to base information on and the need to update resources according to the latest evidence; challenges with dissemination (e.g. translating evidence into readily accessible and understandable resources); and barriers to implementation (e.g. enlisting the support of organizations and clinicians). Information resources need time for ongoing development and, therefore, ongoing financial commitments from services. While potentially costly, they would provide a systematic way to ensure the opportunity of involvement of each client. Given the significant problems with help seeking in this population (69, 151), there is an onus on service providers to employ tactics that maximise engagement and adherence to the chosen treatment option. Past negative treatment experiences have been highlighted elsewhere (68) as a key factor related to accepting a diagnosis of MDD and, therefore, impacting on help-seeking behaviour, which was echoed in the findings of this study. The need to choose treatments that are preference based and clinically effective in collaboration with the young person upon initial engagement in a service is twofold. Firstly, with the hope that the treatment will work first time round; and secondly, if this is not achieved, that the young person will be willing to remain engaged and pursue further treatment options.

Significant barriers were discussed by clients, both in terms of access to services at all and also in terms of being involved in the decision-making process once gaining access to a service. Barriers at an individual-, clinician- and service- level were reported, demonstrating the complex process that young people are faced with when making treatment decisions. Acknowledging the specific needs of treatment decision making for depression (87), and allowing these needs to guide the decision-making processes (86) may be required to overcome some of these barriers.

Caregivers found barriers in gaining access to services for their children, but also barriers to being involved in their care once accepted into services. The issue of the age of their children and associated confidentiality policies was the biggest concern reported by caregivers. Whilst such policies are unlikely to change, the use of DAs (152) may be one way in which to either involve caregivers in the decision-making process (if so desired by the client) or communicate to caregivers the rationale for the decision made so that they can at least understand.

The experiences of the clients highlighted gaps in the decision-making process, and clients offered ways in which to improve such processes. Information that was interactive and meaningful (i.e. perceived as relevant to themselves) was a priority for clients, as was feeling as if they were respected and taken seriously by their clinicians. This priority, in combination with clients' desires to have their personal characteristics, values and preferences considered, clearly supports the use of DAs and SDM. Given that preference for involvement is likely to change over time, having tools available to use on a repeated basis as decisions are revisited seems warranted. Understanding treatment options both for themselves and also to explain to caregivers if appropriate, was important for clients in order to navigate the complex process of seeking help and engaging with services.

There are several limitations to the current study. Although the study aimed to obtain a rich description of experiences and beliefs based on a purposive sample, the small sample size minimizes the generalisability of the findings. While the participants were recruited from only two services, they had all experienced treatment decision making at other services and therefore data were obtained for experiences at general practice, enhanced general practice, the public mental health system and private practitioners. It is acknowledged, however, that there are likely to be characteristics unique to this sample that may not be present in the broader population. Current clients of the services were recruited, which meant that recruitment was difficult, as the clinical needs of the young people had to be prioritized. Efforts were made, however, to review the interview data as they were being collected to ensure that different types of experiences and beliefs were being addressed. Most young people and caregivers were interviewed as they were being discharged from the service, which meant that they could reflect on their time at the service as well as experiences at services prior to attending their current service.

It is possible that the clients who agreed to participate did so because they have more extreme experiences or stronger opinions about treatment decision making. However, this was not reflected in the data (i.e. not all experiences were extreme and not all participants had strong opinions). Only one person coded the data, which means that interpretations were not directly checked by independent raters for comparison in order to increase reliability. Instead of this, the coding process was described and justified to the three researchers supervising the project (all of whom have previously published qualitative research). Another limitation is that participants were asked to recall events that they had experienced over several years. In line with the social constructionist approach taken, however, the focus was on participants' accounts and interpretations of their experiences rather than what actually happened. Concepts such as involvement can be very subjective and different parties (e.g. clinician and client) may describe an encounter involving treatment decision making in very different ways. How young people and their caregivers make sense of such encounters can help us to understand and improve treatment decision making.

Chapter 5: Interviews with service providers about their experiences of, and beliefs about, treatment decision making

Introduction

This chapter presents the data from interviews conducted with clinicians (service providers). The same interview probes were used as those in the interviews with service users, however rather than being asked to talk about each specific experience with a service (as service users were), clinicians were asked to talk generally about their experiences and beliefs, using case examples where appropriate.

Participants

Of the twenty-two clinicians who participated, their ages ranged between 25 and 54 years old (mean age 36.9; SD 9.6) and 13 (40.9%) were female. There were ten clinical psychologists (eight working in the public mental health system and two working in private practice); five psychiatrists; four general practitioners (GPs); one mental health nurse; one youth worker; and one youth outreach worker. Clinicians had been working in their respective professions for between one and 30 years (mean 10.7; SD 9); and had been working specifically with young people for between one and 25 years (mean 8.5; SD 7.5).

Results of interview data

Results are summarised in table 1.

Table 1. Summary of results from clinicians related to experiences, beliefs and barriers to involvement.

Approach to treatment decision making
Decision-making model • Vast majority of clinicians employ a collaborative approach to decision-making processes either some, or all, of the time • Ultimate decision rests with the client, but clinicians have professional responsibilities
Who should weigh up the potential risks and benefits of different treatment options? • Clinicians present treatment options to clients and discuss the potential risks and benefits of treatment options • Most clinicians support a collaborative approach to considering potential risks and

benefits of treatment options • Small number of clinicians felt that either they should do it themselves or that clients should do it with their support • Clinicians role in weighing up risks and benefits ranged from supportive to directive, and included provision of information as a key task • Some clinicians made a distinction about the decision-making process and who actually makes the decision
Client values and preferences • Values and preferences important part of treatment decision making, including cultural and religious values, and relevant individual characteristics • Clinicians have opinions about the merits of different treatment options and explain the rationale for their choice to clients, particularly when disagreements arise • Clinicians make some decisions before being discussed with clients
Asking explicitly about preference for involvement • None of the clinicians ask clients explicitly about their preferred level of involvement in treatment decision making
Exceptions to decision making approaches taken by clinicians
• Four main circumstances leading to a more paternalistic style of treatment decision making: depression severity and associated decline in functioning; perceived risk levels (i.e. to risk to self or others); perceived client preference for involvement; age/developmental stage of the client • These situations involved a shift in dynamics rather than employing a strictly paternalistic approach • Several clinicians felt that the client should still have the final decision unless they were being treated involuntarily • Caregiver involvement necessary for younger clients
Reasons for involving clients
• Therapeutic in and of itself • To facilitate engagement of the client • The “right thing to do” • Developmental stage/age • To help young people develop a sense of autonomy • “Higher success rate” with treatment • Affording clients a “sense of control” • Adherence and therefore longer lasting benefits of treatment • To promote future help seeking
Caregiver involvement
• Optional and based on the preference of the client • Encouraged but not mandatory

- Policy at some services to never insist on caregiver involvement
- "Ideal" or "essential"; but only with client consent
- More of less caregiver involvement based on age/maturity of client; depression severity and risk issues; capacity to make decisions
- Some clients do not have caregivers
- Usually involves practical assistance and provision of collateral information rather than sharing decision
- Providing information to caregivers seen as important
- Potential negative outcomes

Conceptualising involvement

What constitutes true involvement?

- "Joint understanding"
- Engagement
- Insight
- Willingness to be there
- Having an opinion; feeling comfortable to openly criticise experiences of treatment
- Freedom for "mutual agreement and disagreement"
- "Two way conversation"
- "Equal conversation"
- Respect for choices
- Competency
- Comprehension
- Level of articulateness

Information provision

General

- Topics typically covered (e.g. depression, therapy, medication)
- Information sourcing and provision (e.g. fact sheets, websites)
- Reasons for varying the content or format of information (e.g. younger clients)

Describing potential risks and benefits of treatment options

- Potential benefits of CBT: effectiveness in general and in terms of relapse prevention; that it can be tailored to the client
- Potential risks of CBT: disengaging from therapy; poor connection with therapist; feeling worse before feeling better; gaining insight may cause distress
- Potential benefits of medication: Likely to help faster than psychological therapy and might help to do therapy but would not "cure anything"; not a "magic bullet"; would not work straight away; evidence favours combination of CBT and medication;
- Potential risks of medication: important to discuss to avoid non-adherence, so clients could monitor seek treatment for side effects, and because it's a clinician's duty of care; different levels of information provided; increased risk of suicidality.

Tailoring information

- Information simplified for younger clients; those with lower levels of comprehension/literacy skills or cognitive impairment
- Information provision varied according to clinician

Information formats

- Information mostly conveyed orally
- Some clinicians felt that written information was useful; others did not; some felt web based tools helped engage young people
- Psychologists assumed psychiatrists used fact sheets; psychiatrists did not report consistent use of fact sheets

Negative aspects of client involvement

- Few negative aspects reported
- If client decided not to engage in, or disengage from, treatment; if a client did not comprehend/process information sufficient to make a decision; if the family does not support the young person's decision and this causes conflict or stress; potential burden

Disagreements

Disagreements with clients

- Some clinicians reported no disagreements; others reported minor disagreements (e.g. "little bumps"); others reported more significant disagreements (e.g. non-attendance)
- Responses to disagreements included "actively exploring" reasons and/or unresolved questions; presentation and/or representation of information and/or clinician rationale
- Ultimately up to client

Disagreements with caregivers

- Majority involved caregivers either wanting, not wanting, or not being told about medication prescribed to clients
- Responses to disagreements included involving caregivers earlier in the process; further exploring and understanding the perspective of the caregiver; and restating the rationale or justification for their position

Barriers and facilitators to involving clients and caregivers in treatment decision making

Client and caregiver level barriers

- Depression severity; risk to self and/or others; non-attendance; poor engagement; age and/or capacity; stigma; perceptions of paternalism and coerciveness, and experiences of not being involved; concerns about confidentiality

Clinician level barriers

- Reluctance to talk about sexual side effects; disagreements between professionals; style and approach of individual clinicians; disorganisation; underestimation of clients' ability to comprehend information; failure to share information

Service level barriers

- Time limitations, including wait lists and high case loads; decisions already being made before clinician sees client (e.g. treatment initiated by another clinician before seeing

client); limited treatment options; lack of available services; lack of readily available resources (e.g. fact sheets)
Broader level barriers • Lack of evidence in the area; restriction of government funding to seeing caregivers
Facilitators Adequate time; culture of the team; treating voluntary clients; having referral options; professional culture; general shift in healthcare culture towards collaborative approaches/informed clients
How to improve treatment decision making
• Better information resources (e.g. fact sheets) that are up-to-date, relevant to young people, able to be given to caregivers, readily available, balanced, not overwhelming, available on the Internet and interactive; giving structure to existing conversations (e.g. about treatment); time to think about decisions; being clear about limitations of the service; development of guidelines around involvement and capacity for involvement; training for clinicians; more time

Approach to treatment decision making

Decision-making model

The vast majority of clinicians reported employing a collaborative approach to decision-making processes either some, or all, of the time. Several clinicians also said that standard assessment tools used by the service helped to facilitate collaboration:

> “(Using the assessment tools of the service and creating a mental health care plan) we’re sharing dialogue and stepping through presenting problems and maybe unpresented (sic) problems… so that is taking the person with you so that you come to the conclusion to summarise… what the major issues might be such as depression… and then the (treatment) plan” [Clinician 23; male GP]

Clinicians who didn’t use these assessment tools also reported collaborative approaches, for example clinician 14 (female private psychologist) who said that she would present clients with information, give them her recommendations “and then allow them to make the decision together and talk it through”. Clinician 11 felt that ideally the decision-making process would involve an informed client and informed caregivers “and you’d make a joint decision together”, however although most clinicians endorsed a collaborative approach to decision-making process (as described by Charles et al 1999; (84)), they usually advocated for the decision to be made by the client.

For example, clinician 12 (female psychiatrist) said about her approach to treatment decision making:

> "It'd be collaborative usually, it would all be kind of discussed and the different options would be put forward and then we kind of talk about, you know, the benefits and the disadvantages of the different options and then they would kind of choose a preference"

Ultimately, the decision was seen as belonging to the client; that, for example, "the young person has to say 'yay' to (treatment options)" (clinician 05; male psychologist). This was described both in terms of psychological therapy and medication:

> "How the client uses the therapy is left up to them by default, whether or not the client comes to therapy is their decision and whether or not they engage with other parts of the service, for example group and stuff, that is also their decision in principle" [Clinician 09; female psychologist]

> "It always ends with the client, if they don't want medication or aren't interested in hearing about it then it's not really discussed with them, it's not made important" [Clinician 03; female psychologist]

Who should weigh up the potential risks and benefits of different treatment options?

During the treatment decision-making processes, clinicians reported presenting treatment options to clients and discussing the potential risks and benefits of treatment options:

> "You often present people with the evidence, and that is for the treatment of depression, the combination of medication and therapy, often people find works best, but that's not to say that you're not going to get better on just therapy, and then the risks would be the side effects, I guess in that, you know, not every medication works for everyone and sometimes you have to try a different medication and so on" [Clinician 08; female psychologist]

The majority of clinicians believed that a collaborative approach to weighing up the potential risks and benefits of treatment options was most ideal. Other clinicians felt that clients should do it with their support, and still others felt that they themselves should take on the task. There was variation in reasons for these responses, however, and as with the decision making models described above, for some clinicians there was also a distinction made here about the decision-making process and who actually makes the decision.

Clinicians also referenced their professional obligations. For example, clinician 01 (female psychologist) believed that the potential risks and benefits of treatment options should be considered by the client, caregiver and clinician "all together… (but) responsibility lies with us". Clinician 06 (male psychiatrist) agreed that a collaborative approach should be taken when weighing up potential risks and benefits, but he felt that some clients "with severe depression (who) really need medication so… I put it to them that the stakes are too high and we need to try everything". In a similar vein, clinician 16 (female GP) was happy to leave the weighing up to clients, but if she believed that they weren't giving themselves the "best chances of recovery" then she would tell them so. Clinician 13 (female psychologist) endorsed a collaborative approach, but also with exceptions: "it's (influenced by) what development stage young people are at, and how much they can weigh up a choice and a consequence".

Clinicians also spoke about their role in the 'weighing up' process, which varied from supportive to directive. Clinician 12 (female Psychiatrist), for example, felt that "if you're saying somebody has capacity to make a decision, they should be able to weigh them up themselves, but they need the information to do it". Playing the role of the educator was also reported by clinician 29 (female youth outreach worker) who said "I think the clinician obviously needs to inform the young person and educate them of options and the young person should make the main decision, but with the assistance of people around them".

Rather than just be a provider of information, other clinicians believed that they should play a more directive role in weighing up the potential risks and benefits of treatment options. For example, clinician 20 (female mental health nurse) wanted to "drive it… I know what would be helpful and what would not be helpful I guess, and what would be too risky not to do… so I guess I do have to take responsibility for influencing a lot of the end outcome." Clinician 14 (female private psychologist) went further and said that she felt it was an ethical obligation to provide effective treatment. She also believed that some young people lacked the capacity to undertake this ‘weighing up’ process:

> “Given the latest information about brain development with kids I don’t think kids are really able to weigh up the long term pros and cons… I think they can definitely say yeah this isn’t working for me, this is working for me, I don’t like her, I do like her, and I think they should be given every right to say that I want to stop therapy at the moment… but I don’t think they currently have the kind of ability to see the long term impact of whether or not they engage in things at that time… I think that then falls to their caregiver, because it’s the caregiver who’s going to make them return in many ways”

This interviewee was the only clinician to suggest that caregivers should play the primary role of weighing up the potential risks and benefits of different treatment options. One last unique response was clinician 19 (male GP) who refuted the proposition that there were potential risks of treatment and therefore felt that there was nothing to weigh up.

Client values and preferences

Values and preferences were also depicted as part of treatment decision making, including cultural and religious values, but also relevant individual characteristics. For example, clinician 09 (female psychologist) believed that she could use her existing knowledge to consider the relative benefits of treatment options, and she used the example of considering whether or not a medication might have the potential to cause weight gain for a client with a history of an eating disorder. Clinician 13 (female private psychologist) felt that considering client values and preferences was good clinical practice, and clinician 16 (female GP) said that doing so allowed her to find the “best fit” of treatment for the client.

Clinicians also reported having opinions about the merits of different treatment options for clients, and many clinicians said that they would explain the rationale for their choice to clients, particularly if there were any disagreements. In describing these processes, clinicians demonstrated that although they believed that the ultimate decision rested with the clients, they did make attempts to influence these decisions.

Clinicians also acknowledged that some decisions were made before they were discussed with clients. For example, some clinicians said that they might think medication is suitable for a client and influence the decision-making process accordingly (e.g. promoting the potential benefits and minimising the potential risks). Clinician 10 (female psychiatrist) said that she would "sell" medication to clients in this case, but that ultimately the decision was still theirs. Conversely, other examples focused on clients for whom clinicians considered medication to be unsuitable (e.g. if the level of symptoms experienced was not severe enough) and therefore would not present it as an option. An exception to this was Clinician 06 (male psychiatrist) who said that if a client requested an antidepressant medication then he would prescribe one because they are "quite safe".

Asking explicitly about preference for involvement

None of the clinicians reported asking clients explicitly about their preferred level of involvement in treatment decision making. Clinician 17 (female GP) believed that asking explicitly about involvement wasn't her "style" and that she prefers to "forge ahead and see what happens", all the while paying attention to non-verbal signs of desire for involvement:

> "It's not always about verbal cues, it's about non verbal cues… so it's body language, you can usually tell how involved they want to be just by what they're saying you know, the other cues, I use other cues… so I'm trying to get a feel for their decisions not just by what they're telling me"

Clinician 16 (female GP) chooses not to ask explicitly about involvement because in her experience clients' preference for involvement changes over time, so there is no one time when she could ask that question and get a representative answer. Improvement in depressive symptoms was one example she gave of why willingness to be involved may change over time. Instead, she reported gauging preference for involvement using questions such as "what are your feelings about the different ways we could go forward with this". Similarly, clinician 20 (female mental health nurse) reported using questions such as "what pace would you like to go at", and clinician 22 (male youth worker) informs his clients "that they're in control of what happens to them here… if they see me and they decide they don't want to see me again and they want to tell me to F off then tell me to F off".

Exceptions to decision making approaches taken by clinicians

As described above, almost all clinicians described their usual approach to treatment decision making as collaborative in some way. Despite this, clinicians also described situations in which they would not follow their usual approach. There were four main circumstances described, which all lead to a more paternalistic style. These included: the severity of depressive symptoms experienced by the client and associated decline in functioning; perceived risk levels (i.e. to risk to self or others); perceived client preference for involvement; and the age or developmental stage of the client.

Less commonly discussed situations included being treated on the inpatient unit; being treated involuntarily; cultural background of the client; a perceived biological aetiology (as opposed to a more reactive depression or a perception by the clinician that the depression is due to personality factors); specific comorbid disorders with related comprehension issues (e.g. Asperger's, psychotic disorders); and the clinician believing that the client needed medication in general, for example clinician 06 (male psychiatrist) who, for people he feels need medication, he will tell them that there is "no question in (his) mind" that they should take it.

When clinicians described situations where they would not employ a collaborative approach, they spoke about a shift in dynamics rather than taking over entirely or employing a strictly paternalistic approach. Clinicians spoke about this shift as if it were on a continuum rather than a categorical change, for example clinician 05 (male psychologist) spoke about a range of issues that would culminate in him adjusting the continuum of involvement:

> "Certainly, with people where their functioning is really deteriorating, their supports are lacking, their engagement is not great, all of these sorts of risk factors, in many ways our level of directiveness (sic) will increase, so as their deterioration worsens, our getting a little bit directive increases"

For clinician 16 (female GP), she felt more adamant that if there were significant risk issues "I have to be far more controlling than that… (I) need to ensure that the risk is managed". Similarly, clinician 13 (female psychologist) believed that this increased control was necessary:

> "If somebody's acutely unwell and they're going to end their life and they're at risk, you know, they need to be contained and treated, and so they're not going to have as much say over what is going to happen to them if the mental health act has to be elicited… it is about other people stepping up to make sure that there's safety"

However, when clinicians spoke about a decrease in client involvement, it was usually in terms of increased 'encouragement' (e.g. clinician 03; female psychologist), 'pushing harder' (e.g. clinician 08; female psychologist) or more strongly 'recommending' treatment (e.g. clinician 01; female psychologist). It was also usually about promoting medication rather than psychological therapies or other treatment options:

> "Generally when it comes to antidepressants we really, at the end of the day, put all the options (to the client), we might make some recommendations and I guess… how hard we kind of push the recommendations depend on how severely the young person's depressed"

Several clinicians felt that the client should still have the final decision unless they were being treated involuntarily. Advocating for clients having the final say was seen in the interview data from clinician 08 (female psychologist), who was also an example of a clinician who cited client preference as a reason for less client involvement in decision making:

> "There are times… where, you know, they're given the options and they go 'well, I don't know, you're the doctor' and so the doctor makes the decision, so it's more about (having) given the options, so I think when you make the decision for someone, you end up being a bit more pushy with treatment, it comes after the process of giving all the options and inviting them… to kind of give their opinion and guide you"

For this clinician, the act of making the decision on behalf of the client did not preclude her from providing the client with treatment options and asking their opinion, as she would with clients when using a more collaborative approach. Clinician 09 (female psychologist) also believed that making decisions for clients should be a "stop gap measure just when somebody's feeling really overwhelmed". For example, in situations where the client doesn't want to be involved, clinician 09 said:

> "The treating team would probably make the decision for somebody as a temporary measure more than anything else, so, for example, if somebody is saying 'I'll just do what you tell me to do because I'm just feeling so distressed that I just don't want to make the decision' that is, in effect, a decision anyway"

Clinician 11 (male psychiatrist) believed that situations like these were like being given the "green light" from clients to make decisions for them, and clinician 15 (female private psychologist) would make suggestions rather than decisions, and check in with the client to see if she could get them to agree or disagree about the proposal. Clinician 10 (female psychiatrist) reported making decisions for clients she considered to be overwhelmed, however she also felt that she was "presuming or assuming that (they are too overwhelmed to be involved), that might not be true".

In relation to the age of the client, several clinicians believed that caregiver involvement was necessary for younger clients and that, for example, caregivers should be involved for the "very young ones" (clinician 16; female GP). For clinician 12 (female psychiatrist), her perception of the client's maturity was more important, and she felt that there was a "big difference" between a 12 year old and a 17 year old. Similarly, clinician 13 (female psychologist) reported that she would afford caregivers more "say" for 12-14 year olds, but that 16-18 year olds "would have a lot more participation in their treatment decisions".

Reasons for involving clients

Involving clients in decision-making processes (and in making actual decisions) was seen as important to clinicians for several reasons. Several psychologists believed that feeling involved was therapeutic in and of itself, that it could help to facilitate engagement of the client, and that it was the "right thing to do" (e.g. clinician 11; male psychologist). As clinician 04 (male psychologist) put it:

> "I mean, it helps with the treatment itself, I think, when you have someone involved in making their own decision because then the engagement and the whole treatment and the whole therapy… there's an exponential increase in the level of engagement in the treatment because the person feels involved… which you could argue has a flow on effect to how effective the treatment is, then as a separate point you've just got the basic human respect side of it that rather than

> dishing out treatments that should be taken… it's an issue of human respect basically"

For clinician 09 (female psychologist), this was also relevant because of the age of the clients:

> "I also think that a lot of the people who come along here are used to being controlled and that can be one of the key parts of the difficulties that they have, so giving somebody a different experience of actually making their own decisions can help them feel less controlled and more empowered, which interestingly I think sits at odds with the experience of depression, so that in itself I think can be a therapeutic process"

Clinician 12 (female psychologist) agreed that young people need to develop a sense of autonomy because they often "feel imposed on by lots of different people… and we don't want to fit into another category of people imposing our views on them". Other reported benefits of involving clients included having a "higher success rate" with treatment (e.g. clinician 18; male GP); affording clients a "sense of control" (e.g. clinician 08; female psychologist); adherence and therefore longer lasting benefits of treatment (e.g. clinician 16; female GP); and creating a positive experience of treatment in order to promote future help seeking (e.g. clinician 15; female private psychologist).

Potential negative outcomes of not involving clients as reported by clinicians included non-adherence to medication and disengagement from treatment overall. For example, clinician 20 (female mental health nurse) felt that if clients aren't involved then:

> "They don't come back… (it) doesn't engage young people at all, it just makes them more mute and more angry and more cross and more pissed off with you and they don't come (back), so it's pointless, and also if they don't have some sense of ownership about what they're doing and some responsibility about taking some part of that process then it's my stuff, not theirs and it doesn't go anywhere"

Caregiver involvement

Caregiver involvement, for the majority of clinicians, was presented as optional and based on the preference of the client. Several clinicians (particularly those from headspace) reported that it was the policy of their service to treat the young person as the client and never insist that caregivers be involved. Clinicians from other services spoke about encouraging caregiver involvement, in some cases saying that it was "ideal" or "essential" (e.g. clinician 08 and 03; female psychologists), but only with the consent of the clients themselves.

Clinician 17 (female GP) described how she would usually broach the idea of involving caregivers, using questions such as "are you going to tell your mum" or "would you like me to tell your mum". Client 18 (female GP) also described how she would ask clients about their preference for caregiver involvement in an ongoing way:

> "(We give) the client first say as to whether they want that (caregiver) in the room… more often than not the younger they are the more they want that person in the room… and at some stage we also double check when they want that person to leave, or I might simply ask them to leave because we're getting into more delicate questioning"

Clinicians 02 (male psychologist) and 15 (female private psychologist) also believed it was important to convey to the client that the process of involving caregivers was an open one and that they could either be present at, or informed about, any discussion between the clinician and caregiver. Affording clients responsibility for their own care was seen as important for their developmental stage:

> "Part of growing up and going through adolescence is individuation and being able to make decisions for yourself and even if those aren't good decisions (it's important) that they're allowed to make those decisions and the process of trial and error" [Clinician 14; female private psychologist]

Within this overarching model of client directed involvement of caregivers, several clinicians reported making a decision together with the client and then presenting this decision to the caregiver. Clinician 02 (male psychologist) reported that most caregivers were supportive if the decision was explained to them and clinician 09 (female psychologist) would ask them what they thought of the decision. Clinician 10 (female psychiatrist) followed this same process but said that presenting decisions as "*fait accompli*" to caregivers could be problematic.

Clinicians reported situations in which they would involve caregivers more or less than usual. Some clinicians were more inclined to involve caregivers for younger clients; others felt that age was less important than factors such as maturity and how involved caregivers were in the lives of the client in general. Reasons for involving caregivers included if there were risk issues with the client, if the client was severely depressed, lacked capacity to make decisions, was younger or less mature.

Several clinicians noted that some clients did not have caregivers who were involved, some were homeless and some were custodians of the State. For example, clinician 08 (female psychologist) said that involvement of caregivers was not determined by the age of the client, but rather:

> "Whether they're living independently and about how independent they are already from their family and if they're living with their partner in their own place, it's more to do with that. I think when they're living at home with their family, the family are automatically involved, so often you'll involve them."

Only two clinicians provided reasons for not involving caregivers aside from clients not giving permission. Both were in relation to caregivers being overly controlling, for example clinician 02 (male psychologist) said that he would not involve caregivers if they were "really over involved and really controlling and critical".

The sense that caregivers may not always be sources of support for clients was echoed in concerns raised by clinicians about caregiver involvement. Aside from being "controlling" (as mentioned above), clinician 02 (male psychologist) felt that caregiver involvement could be problematic in situations where he perceived that problems experienced by the client were due to the family environment in the first instance. Although clinician 16 (female GP) said that she had positive experiences of "concerned mums who are sensitive to the need for the young person and GP to talk alone", she also reported that some of her clients were "independently seeking assistance, very often in the absence of a competent carer". For example, she has had clients from "very disturbed home situations where there might be abuse at home, so the so-called carer is sometimes the perpetrator… these young people have grown up very, very early". Considering the client's perspective was important to clinician 14 who said that in her experience "I've found that kids are very loyal to their parents regardless of the way in which the parents behave”.

In terms of the way in which caregivers could be involved, clinicians commonly cited practical assistance such as driving clients to appointments; facilitating engagement; taking care of medication in the home; and providing collateral information such as developmental history, current functioning and risk levels, which was valued by clinicians: “In fact the carer can often give a really useful perspective, an additional perspective (about) what’s going on” (clinician 16; female GP). Clinician 19 (male GP) also believed that meeting caregivers could shed light on the dynamics between them and the client: “my knowledge of the family is sort of useful to me in talking to the patient and their relationship with their family and actually who’s caring for who”.

Potential negative outcomes of involving caregivers were spoken about in terms of their own behaviour and that of caregivers. Clinicians reported caregivers wanting a “quick fix” (clinician 17; female GP); not believing that the client was capable of taking on the responsibility of decision making and therefore causing “confusion and stress” (clinician 13; female psychologist); wanting medication prescribed when the clinician did not; not wanting medication prescribed when the clinician did; having concerns about treatment because of their own experiences with mental health services or treatment; having different caregivers disagree with one another, particularly if separated or divorced; and caregivers making “just completely critical comments… sometimes it just becomes so bad you just have to stop it… sometimes parents have walked out” (clinician 20; female mental health nurse); and caregivers saying things perceived to be unsupportive by clinicians, for example:

> “Look, the majority of it’s been terrible experience with carers to be honest, most parents, unless they have had depression in the family… just don’t understand why, how their son or their daughter can be depressed and basically just tell them just to snap out of it, cheer up, you know, all of the worst things you can say to someone who’s depressed basically, it comes from a good place but basically a lot of the times they just end up alienating their children further from actually feeling like they’re supported” [Clinician 22; male youth worker]

One clinician also believed that his role could become blurred when involving caregivers because he did not offer family therapy (clinician 05; male psychologist) and another wanted to avoid the client feeling as if he and the caregivers were "siding with" each other, because "you run the risk of alienating the patient" (clinician 11; male psychiatrist).

Despite seeing difficult or troubled families, positive aspects of involving caregivers were also cited, including that "even difficult communication" between caregivers and clients can "foster better relationships" (clinician 05; male psychologist); that discussing issues with caregivers can demonstrate to them that there is indeed a problem (e.g. clinician 11; male psychiatrist) and help to build trust. As part of building trust with caregivers, clinician 21 (female youth outreach worker) felt that information was an important part of this: "I find that when I explain (information to caregivers), if I'm providing them with the information then they are very good. But if I'm not informing them, then they get their back up". Clinician 20 (female mental health nurse) believed that the involvement of caregivers afforded an opportunity to promote communication and improved relations between clients and caregivers:

> "We talk about 'if things were going to be different, if things were going to change, what would people around you… what might they need to know, what might that look like, how might they support you, how could they be helpful, and so we have that conversation… and so the client and carer have that conversation together about well, when you say this it doesn't…"

Clinician 17 (female GP) also reported seeing "kids from terrific families, mums and dads who are more than competent and compassionate and (who listen) to that young person".

Conceptualising involvement

As the interviews were conducted, a theme not covered by the interview probes was identified in several interviews conducted with clinicians, that is, how involvement was conceptualised by participants. After conducting the first ten interviews (all of which were with clinicians), a question was added to the interview probes for clinicians, clients and caregivers: 'What constitutes true involvement for you?'. As such, the responses in this section are not representative of the group as a whole. Nevertheless, responses are included as they highlight the variation in the perceived notion of involvement and what that might mean for various clients and caregivers.

For clinician 11 (male psychiatrist), true involvement was a step beyond merely agreeing about something (e.g. treatment choice). For him, it was necessary for there to be a "joint understanding" between him and the client, and a prerequisite for this understanding was good engagement. Engagement was important because it meant that the client would listen and trust his judgement, but ultimately he felt that in order to achieve true involvement, "they have to weigh up their own decision making". Engagement was also a key factor for clinician 15 (female private psychologist), who believed that involvement meant that the client was engaged not only with her but also with the service, had some insight into their own problems and a willingness to be there. That the client had an opinion and felt comfortable enough to openly criticise their experiences of treatment was important to her, because she believed otherwise "they're already making decisions themselves". Being able to have "mutual agreement and disagreement" was also important for clinician 20 (female mental health nurse):

> "Well, I guess it's having a two way conversation, it's around allowing the space, the freedom for mutual agreement and disagreement, no, I think that sucks, (or) okay fine, or to have that kind of equal balance conversation I suppose"

Clinician 20 also felt it was important that she didn't fall into the role of parent or teacher, that she didn't tell her clients what to do. She believed that in order to involve clients she would offer to have "(an equal) conversation around what fits and what doesn't" and that she would "respect their decisions" even if that meant that they didn't want to attend appointments. Client 17 (female GP) also raised engagement and insight, but then added competency, comprehension and level of articulateness as indicators that the client was engaged:

> "How well the person's engaged, how articulate they are, how much they understand what you're saying, what they're saying back to you, so the language they're using, the words they're using, you know, trying to get them to repeat back to you what you sort of said to them… how insightful do they seem to be, how competent do they seem to be"

Having the client make a decision constituted involvement for clinician 21 (female youth outreach worker), but she also felt that she played a part in this process, and this required her to ask "them what they feel they need… so it's about giving them the option (of different treatments) and then them picking what it is they need". This is in line with the bi-directional conversation discussed above by clinicians 15 and 20, and the mutual understanding spoken of by clinician 11.

Information provision

In terms of the type of information provided to clients, clinicians raised several topics that they typically covered (e.g. depression, therapy, medication); various ways in which they obtained and provided information (e.g. fact sheets, websites); and situations in which they might vary the content or format of information (e.g. younger clients).

By discussing the topic of depression with clients, clinicians tried to promote optimism by saying, for example, that "most people get better from their depression" and that there are effective treatment options "just gets to normalise the experience for them as well as them not feeling so isolated" (clinician 01; female psychologist). Many clinicians said that they would provide a description of the disorder, either characterising it as a syndrome (e.g. clinician 06; male psychiatrist) or an illness (e.g. clinician 10; female psychiatrist). Several clinicians reported that they would describe depression as common and treatable. Clinician 12 (female psychiatrist) also believed that it was important to describe their impression of the client's experiences and then "get feedback on whether that's, if that sounds reasonable (and) from there you'd go into the different treatment options".

Describing potential risks and benefits of treatment options

When describing the potential benefits of psychological therapy, clinicians spoke about the effectiveness of CBT (e.g. clinician 05; male psychologist); that CBT could prevent relapse (e.g. clinician 06; male psychiatrist); and that CBT could be tailored to the client in order to help them achieve personalised treatment goals (e.g. clinician 01; female psychologist). In terms of the potential risks or downsides of therapy, clinicians spoke about disengaging from therapy (e.g. clinician 15; female psychologist); having a poor connection with the therapist (e.g. clinician 18; male GP); that clients may feel worse before they feel better; and that insight into their problems may cause distress (e.g. clinician 01; female psychologist). Clinician 05 (male psychologist) said that he doesn't talk about any potential risks of CBT because they are "negligible", but that he does say to clients "look, you might feel crap after session sometimes (and) that we might wrap things up a bit early on". Clinician 16 (female GP) also felt that there were few risks of psychological therapy, but that she encourages clients who are psychotic or have a history of abuse to think about whether or not it is the right time to commence therapy: "if they're going through a really difficult, stressful phase of life, it's probably not the time to be addressing abuse issues".

The potential risks and benefits of medication were spoken about in more detail than the potential outcomes of therapy. In terms of benefits, key messages reported by clinicians included that medication wouldn't "cure anything" (e.g. clinician 19; male GP) and was not a "magic bullet" (e.g. clinician 05; male psychologist); that it would not work straight away (although the timeframe mentioned by different clinicians differed slightly); that it was likely to help improve depression symptoms faster than psychological therapy (e.g. clinician 07; male psychiatrist); that "the evidence favours a combination of medication and individual therapy" (e.g. clinician 06; male psychiatrist); that it might help to "get them in a bit of a better place to do therapy" (e.g. clinician 02; male psychologist); and that they should still participate in psychological therapy (e.g. clinician 15; female private psychologist). Clinician 07 (male psychiatrist) was "keen not to oversell medication" because the evidence says "they're not always effective" and that he would feel uneasy if "everything's gonna be pinned on the (effectiveness of the) medication". Several clinicians reported informing clients that medication would be effective in approximately 70% of young people (e.g. clinician 06; male psychiatrist). Clinician 14 (female private psychologist) also cited evidence in her information provision, for example:

> "I would say that medication is one option for treatment with depression and go back to that evidence base of the evidence suggests that it certainly plays a role, that current recommendations are not first line treatment, but that doesn't mean

> that it can't play a part… depending on the level of the kid I sometimes explain how it works, and say that it can take between three to eight weeks to work, that you have to be kind of closely monitored, it doesn't mean that there's anything wrong with you, you're not dependant… often I like to give a handout if I can on medication… I usually talk about side effects as well and just say sometimes it can make you feel nauseous"

On the other hand, clinician 04 (male psychologist) said that when he and the treating team presented medication to clients "if anything there might be more emphasis on the potential benefits than the potential risks (because) we are often coming from the angle of already thinking that it would be useful for the client". When informing their clients about the potential benefits of medication, clinician 15 (female private psychologist) believed that it was important to get clients to think about "what it's actually going to provide… is it actually going to help that much". Similarly, clinician 20 (female mental health nurse) said that she found it helpful to ask clients about their existing knowledge, for example "what do you know about medication, do you know what's in it, what idea have you got, why do you think it might be helpful".

The potential risks of taking medication, including side effects, was the most common topic clinicians reported talking with clients about. Clinicians felt that it was important to talk about side effects for various reasons, including that if you didn't clients would "stop it as soon as they start to get a side effect" (clinician 17; female GP); so that clients could look out for them too (e.g. clinician 05; male psychologist); because it was a clinician's duty of care (e.g. clinician 13; female psychologist); and so that clients could seek medical attention if they experienced a side effect (e.g. clinician 15; female private psychologist). However, levels of enthusiasm for communicating possible side effects to clients did vary. Clinician 22 (male youth worker), for example, believed that it was "absolutely essential" to let clients know of potential risks because "it's part of treatment… if I was going there I would want all the information, there's no difference between me wanting it and a fourteen year old wanting it… they should be given all the information". Likewise, clinician 04 (male psychologist) thought that communication about side effects was important for monitoring, so that both the clinician and client could look out for side effects, and to let clients know that they would be asked about side effects at each appointment. Clinician 18 (male GP), on the other hand, felt that there was:

> "…a two edged sword there, it's a bit like getting people to read the drug inserts in medication, if they read them half the people wouldn't touch the drugs and I suppose one thing we want to do is to make a reasonable clinical decision here in my own head as to what the issue is and what the best way to approach it is without putting the person off by saying well, look, do you realise… it's a bit like a surgical consent form, did you realise you could bleed to death, I could lacerate your spleen, or whatever, you don't want to put them off and particularly in a group that is very quickly disengaged"

In his experience, clinician 02 (male psychologist) said that medical staff might describe side effects, "but they're not really emphasising (them) a huge amount, I suppose we could explain it more clearly… it's not really like a clear policy" and that if a client raised any concerns about medication that they would usually provide them with a fact sheet on antidepressant medication. Reasons for minimising the amount of discussion about side effects included that it would take too much time and be a bit "alarming" (e.g. clinician 06; male psychiatrist) for the client.

Although it was not a topic covered specifically by the interview probes, several clinicians raised the issue of the increased risk of suicidality for young people taking selective serotonin reuptake inhibitors (SSRIs). For example, when clinician 01 (female psychologist) was describing the way in which she would communicate information to clients about the potential risks of antidepressant medication, she said that she would tell them about side effects, what to expect, and:

> "…particularly alert them to the risks around agitation and… generally tell them about the fact that there might be a risk of increased suicidal thoughts and agitation and that the young person, if experiencing those things, is to call us straight away and we review it"

For clinician 10 (female psychiatrist) it was also important to her to inform the client of this risk to let the person know that "this is why we watch more closely" and for "medico legal, well no, I mean it's good clinical (practice) but I've really been aware of medico legal sort of issues around it as well". Other clinicians did not raise this issue, and although reported talking to clients about side effects, also said that they would present SSRIs to clients as, for example, "the commonest, it's the safest, it's the easiest to prescribe, it's for the least amount of side effects" (e.g. clinician 17; female GP).

Tailoring information

Clinicians raised several situations where they would change the content or delivery of information for clients. Clinicians reported simplifying information for younger clients; clients with lower levels of comprehension or literacy skills; and clients with some type of cognitive impairment. The amount of information provided varied according to clinician; for example, clinician 17 (female GP) said that she gives clients "as much information as I think that they can take in", whereas clinician 16 (female GP) reported keeping information simple because she believed "we give them too much information… I think providing relevant information enables a decision rather than confusing the matter (with too much information), particularly when people are depressed and their decision-making processes might be impaired".

Information formats

In terms of the format that clinicians reported providing clients with information, the majority of clinicians said that they just conveyed information orally. Some clinicians felt that written information was useful (e.g. clinician 16, female GP, who believed that "most of what you say in a consultation is forgotten the minute the person walks out"), whereas others did not, such as clinician 18 (male GP), who said that "paper resources I don't think are particularly useful in this age group, they usually end up out on the street". Clinician 16 (female GP) also believed that web based tools helped to engage young people. Several psychologists said that they didn't use fact sheets but assumed that their psychiatrist colleagues did. Psychiatrists reported different ways in which they used or did not use fact sheets. Clinician 06 (male psychiatrist) said that he referred clients to the inserts in medication packets instead of using fact sheets; clinician 07 (male psychiatrist) said that he used verbal information instead of fact sheets; clinician 11 (male psychiatrist) said that he used fact sheets when prescribing medication for the first time and gives the client "a couple of minutes to have a look" but he couldn't remember which ones; clinician 12 (female psychiatrist) said that she didn't use fact sheets unless a client was refusing medication and she thought that they should take it, in which case she would use either OYH fact sheets or ones from the UK Royal College of Psychiatrists because she wanted to "avoid them looking up stuff on any old internet site". Lastly, clinician 10 (female psychiatrist) said:

> "I wish I could say I always give them written information… if I'm being good I'll get something form one of the websites about SSRIs like that SANE website or something because I find the packet inserts are useless because they're just full of intense kind of technical information so I'll try and get something very general from a consumer website"

In general, clinicians reported using fact sheets from public or not-for-profit organisations and services, such as Orygen, headspace, *beyondblue*, the Black Dog Institute, Reachout, SANE and MIMS handouts. One clinician (clinician 02; male psychologist) said that he sometimes used pharmaceutical company fact sheets but the Orygen ones were more useful because "it just keeps it simple". Accessibility of fact sheets varied, with some clinicians reporting that they didn't hand out fact sheets as often as they felt they should because they didn't have them in their office (e.g. clinician 10; female psychiatrist) and others reporting that fact sheets were freely available in their office or the waiting room of their service (e.g. clinician 13; female psychologist).

Clinicians sourced their own information from websites, the MIMS and medical colleagues, for example clinician 03 (female psychologist) said:

> "The resources that I have actually really just come from hearing the psychiatrists talk and doing a bit of reading about medication a while ago but I think I've sort of got my head around different types of medications and the general information clients would need to know"

Similarly, clinician 09 (female psychologist) said that rather than using fact sheets or guidelines, she uses "basic, general information I've kind of gleaned rather than anything formal really". Personal resources used by clinician 17 (female GP) included websites, ongoing education and conversations with peer group psychiatrists.

Negative aspects of client involvement

The majority of interviewees did not report any negative aspects of involving clients (potential negative aspects of involving caregivers are reported separately, see above), however several clinicians had either experienced downsides of involving clients or could see situations where there might be negative outcomes. Three responses focussed on the potential for the client to disengage or not take up a treatment option that could offer some benefit. For example, client 11 (male psychiatrist) believed that informing clients of the potential risks of medication might make them not want to take it:

> “They say they don’t want to take it so you just have to then either explore the reasons or sort of again say this is why I think you should, but if that’s what they say, then that’s what they say… I guess it’s better for them to be informed rather than in three days time feel sick as a dog and go alright I’m never taking this again because the doctor didn’t tell me it was going to happen… I mean that does happen”

Ultimately, he felt that the disclosure of such information was important but that there was a need to “balance” what was discussed because he couldn’t tell them about “all of the side effects”. Making sure that the client had understood information was a concern for clinician 09 (female psychologist), who reported “situations where it feels like it hasn’t worked”, where she doubted the “intellectual capacity” of the client and where it had taken a “long time to… try and explain the different options to somebody”. Alongside this, clinician 12 (female psychiatrist) believed that it was a challenge to involve clients when she had to manage a variety of stakeholders: “there’s just so many different people, it’s hard to juggle everybody”, particularly when caregivers were not supportive of clients. Clinician 13 (female psychologist) also spoke of difficulties related to affording autonomy to clients when their caregivers were not supportive of this:

> “If young people don’t have a lot of freedom or flexibility because of religious values, or you know, very punitive parenting styles, it can be a miss fit if you’re encouraging young people to really start to be more active thinkers and actively involved if they cannot take that back to their environment, and in trying to do that it causes more stress and harm for them. I think that’s potentially a risk”

Clinician 13 also spoke of the client needing to be ready and mentally well enough to be involved:

> “If someone’s acutely depressed, suicidal, very anhedonic (sic) and slowed, you wouldn’t want to task them with too much because they’re already feeling quite burdened and overwhelmed”

This potential negative outcome was reported as being temporary, however, and the clinician felt that affording the client "relief from their symptoms" would result in them being able to be involved in the long term. Whether or not the client wanted to be involved was raised by clinician 01 (female psychologist), who reported experiences of clients becoming "anxious about the fact that you're in a position of 'expert' and you won't take up that role". Still, she felt that once young people experienced involvement then this was generally a "liberating" experience for them.

Disagreements

Clinicians were asked about any disagreements they had experienced, either with clients or caregivers, and how they dealt with such disagreements. Clinicians recounted specific examples of disagreements as well as speaking generally about disagreements they had encountered.

Disagreements with clients

Several clinicians reported not experiencing any disagreements with clients because the approach taken to treatment was based on the preferences of the client. Others said that there were minor disagreements, for example clinician 08 (female psychologist) described facing "little bumps" along the way so that "you're constantly negotiating about their treatment". More significant disagreements were also described, including non-attendance and reluctance to engage in other services (e.g. group programs, drug and alcohol services).

Responses to these disagreements included clinicians trying to understand and "actively explore" (e.g. clinician 02; male psychologist) reasons for decisions made by clients; to present information about treatment options in more detail; to provide more encouragement; to reiterate their position; and to explore any unanswered questions. Ultimately, however, clinicians said that it was up to the client and they could not force clients to agree with them. For example, clinician 11 (male psychiatrist) said:

> "I tend to just put my views across and my points across but at the end of the day it's their decision so it's (about) trying to keep them informed… (sometimes) they've got some things that they haven't told you or some questions that haven't come out and if you can answer those you can get over the barrier… that's the

> best way to go… it's (about) trying to get your point across, not in a forceful way, but just making sure that they've thought through the risks and the benefits and they're properly informed"

Leaving the final decision up to the client was also endorsed by clinician 10 (female psychiatrist) who believed that "there's not enough evidence that (medication is) an essential part of the treatment for me to really het up about it". She said that instead she would try other approaches. She also felt that it was important to allow space for discussion of concerns about medication and time to think about treatment options in order to avoid disengagement. Initially she would:

> "print off sheets for them on the medications… and give them time to read it… they will go away and read about it and come back and then tell me what their problems with it were and what were their concerns and then revisit the decision"

If they still chose to decline medication, and she still believed that they should take it, she would make a mutually agreeable time to revisit the decision "so that I'm not harassing her and she's not avoiding me".

However, disagreements were not all about medication. Some clinicians recounted instances where clients had not wanted to engage in therapy, or parts of therapy, despite the clinician feeling that it was a good idea. For example, clinician 09 (female psychologist) described her experiences of a client:

> "(She) couldn't see the relevance of discussing relationships (and) coming along to therapy, and the thing I pointed out to this person was that the thing that she constantly brings to therapy is how she feels sadder when she has contact with her family (and) from my sense that would probably mean there's a relationship between her relationship with her family and her mental state, so I said we don't have to talk about that stuff, but to be honest with you, I don't know how much things are going to improve if we don't talk about it, I think it does put a ceiling on how much things can improve but we can leave that alone"

Rather than forcing the client to discuss things that she did not want to, the clinician instead respected her wishes "because it feels like any other option is just a recipe for disengagement". Similarly, clinician 14 (female private psychologist) said that she suggested taking a break for any of her clients who did not wish to engage in therapy, and offering for them to return to her at a later stage or to try a different therapist. Clinician 19 (male GP) felt there was little to gain from going against the wishes of clients because they would not change their mind.

Disagreements with caregivers

In relation to disagreements with caregivers, the majority were regarding caregivers either wanting, not wanting, or not being told about medication prescribed to clients. For example, clinician 11 (male psychiatrist) said he thought that:

> "probably everybody's made mistakes about starting (a medication) and thinking that's the right thing to do and then having a carer coming (and saying) well why was I not informed about this or whatever"

Ways in which clinicians responded to, or managed, these disagreements included: involving caregivers earlier in the process; further exploring and understanding the perspective of the caregiver; and restating the rationale or justification for their position. For example, when clinician 08 (female psychologist) experiences disagreements, she feels that "it's about everyone putting their position forward on something and kind of just figuring out what's best". Clinician 01 (female psychologist) described an example where caregivers of one client, who was depressed and anxious, wouldn't accept that their daughter was "experiencing mental health difficulties". In response, the clinician said that she "had to work really hard with the parents (and provide) psychoeducation".

Barriers and facilitators to involving clients and caregivers in treatment decision making

Clinicians spoke of perceived barriers to clients being involved in the decision-making process that occur at four different levels: at a client and caregiver level, a clinician level, a service level, and at a broader level, for example barriers within the community.

Client and caregiver level barriers

As noted above in the section 'exceptions to decision making approaches taken by clinicians', clinicians stated they would be more likely not to involve clients in the case of severe depression or risk, and when asked specifically about barriers this again emerged as a theme. Several clinicians raised the experience of depressive symptoms as a barrier to clients being involved in treatment decision making, in that such symptoms impact upon motivation, apathy and engagement in general. The severity of these symptoms was said to vary and therefore have different levels of impact on the ability of clients to be involved.

> "Especially when a client is really unwell and not really motivated to attend anyway, it does feel like the decisions are much more left with you, because they're not wanting to involve themselves in those decisions" (Clinician 3; female psychologist)

At the more severe end, the level of risk (e.g. suicidal ideation and behaviours) assigned to clients was something that clinicians considered in terms of the point at which they believed they had to take more control and make decisions for clients. Clinicians felt that this was their responsibility to do so; however, they acknowledged that this had an impact on their relationship with their clients. Clinician 3 (female psychologist) said that in these circumstances "I think it's still helpful to give them opportunity to have their say and make some of the decisions (where possible)". Non-attendance was a specific concern for two clinicians, which clinician 14 (female private psychologist) related to symptoms of depression:

> "Getting kids in to see you and that sort of stuff is actually quite hard… if you're getting kids that have been dragged (in) to see you… that's a really tough scenario… when they're angry it's much harder to be collaborative because they just don't want a part in any of it… anger and aggression and agitation is a symptom of depression in this sort of age group"

Poor engagement was also seen as a key barrier by several clinicians; as clinician 1 (female psychologist) described it: without involvement "it's almost impossible to make a decisions, for the young person or for us, to make a decision". For clinician 22 (male youth worker), in his experience getting the client to "give it a shot" was the engagement-related barrier; "one once we get them in here and engage them then they tend to keep coming back".

The age range of the clients was raised as a barrier by psychiatrists, one of whom said that it was an "awkward" age in terms of the legal guidelines around capacity to consent to treatment (clinician 07; male psychiatrist). That the guidelines for capacity were based on age rather than developmental stage was a concern for clinician 12 (female psychiatrist). She felt that in practice she was required to weigh up the autonomy of the client with her own duty of care, but that autonomy took precedent:

> "Autonomy takes precedent, so somebody's right to make a decision about their own health takes precedent over your duty of care, but then you carry a certain risk"

Clinician 11 (male psychiatrist) said that in his experience 15-year-olds could sometimes be like "rabbit(s) in the headlights" when it came to involvement.

Barriers were also raised relating to preconceived perceptions held by clients about mental health services. These included stigma about mental disorders and mental health services, perceptions of paternalism and coerciveness, and experiences of not being involved that have led clients to not expect to be involved, for example:

> "Some (clients) look at you sometimes and go what do you think and if they're not used to having that conversation or they don't quite know what to expect because it's all quite new for them… it's quite difficult… you hope you've made them feel comfortable enough to express an opinion and have a conversation but sometimes that doesn't happen" (Clinician 11; male psychiatrist)

Clinician 16 (female GP) believed that there were preconceived ideas that acted as barriers and were specific to GPs. In her experience she found that clients held perceptions that:

> "The doctor is… just going give me drug, they're you know not interested in me, they're busy, they haven't got time... I can't see my family doctor for this because they've looked after all my family and this is confidential and I'm not necessarily convinced that the confidentiality is going to work"

Concerns about confidentiality were also raised more broadly as a barrier to clients being involved in treatment decision-making and disclosing information in general. Less commonly raised barriers included clients' mistrust of adults; a need for clinicians to "push" for treatment because of the nature of adolescent depression; having clients who are unwilling to make decisions; and behavioural issues. Only one caregiver-level barrier was raised, which was that parental conflict could preclude the involvement of the client (clinician 11; male psychiatrist).

Clinician level barriers

There were fewer barriers reported by clinicians in terms of their own behaviours and there was less consistency across clinicians than seen in client and caregiver barriers. Clinician 01 (female psychologist) felt that clinicians were reluctant to talk about sexual side effects; clinician 03 (female psychologist) felt that disagreements between professionals (e.g. between case managers and medical staff) could make it difficult for clients to be involved in treatment decision-making; clinicians 04 (male psychologist) and 21 (female youth outreach worker) believed that involvement could depend on the differing styles and approaches of individual clinicians; clinician 10 (female psychiatrist) felt that her own disorganisation (e.g. not having fact sheets printed out and ready to be given to clients) and an underestimation by clinicians in general of clients' ability to comprehend information were barriers; clinician 16 (female GP) acknowledged that the presentation of information influenced decisions made by clients and therefore could potentially act as a barrier to true involvement; and lastly, clinician 21 felt that clinicians' failure to share information (e.g. not reading clinical notes) could hinder the way in which clients were involved because there may be discrepancies between what the client thinks clinicians know and what they actually do.

Service level barriers

Clinicians commonly reported two service level barriers: time limitations and the fact that some decisions were already made before they saw clients. Time limitations were discussed in relation to the length of appointments (e.g. not enough time to discuss all of the potential risks and benefits of treatment options); the number of government subsidised appointments with private psychologists; and the duration of care restrictions for clients in the public health system, particularly for clients who have already had a past episode of care:

> "It probably feels more urgent to get the work done and to see some improvements, and perhaps personally I take a little bit more control in those situations in terms of directing treatment… they're obviously still involved in the decision-making process but it probably comes a little bit more from me those times" (Clinician 03; female psychologist)

Related concerns included having a waiting list for their service (and therefore if a client did not engage then they were discharged), and having high caseloads resulting in time pressures and less frequent appointments.

Clinicians also believed that it was difficult to involve their clients in some decisions because these decisions had already been made before seeing them. This involved decisions having been made at the same service but by other clinicians (e.g. entry or assessment teams, acute services and inpatient units) and also decisions having been made by other services (e.g. in general practice). For example, clinician 06 (male psychiatrist) estimated that 70% of his clients had already had treatment initiated by a clinician either within or outside of his service before seeing him. Clinician 22 (male youth worker) reported that because approximately 90% of clients had seen a GP before him, that decisions about medication and referrals to psychologists had already been made.

Several clinicians also felt that the treatment options they could offer clients were limited. For example, clinician 08 (female psychologist) felt that the time limitations reduced the options, because ongoing therapy was not possible; clinician 09 (female psychologist) believed that the service determined the type of psychological therapy she could provide despite her being trained in other approaches; and clinician 15 (female private psychologist) reported that there was a limit to the amount of case management she could provide a client with because she was a private psychologist (i.e. she does not have a related crisis team or 24 hour care service). Clinician 13 (female psychologist) felt that there was "still an enormous bias towards talking to families and not to young people" in the "acute health setting". Lastly, a lack of resources, both in terms of available services and information resources such as fact sheets, were identified by several clinicians as barriers to involving clients in fully informed treatment decision-making.

Broader level barriers

Clinicians raised a small number of barriers that were of a more general nature, rather than related specifically to clients, carers or services. Two clinicians felt that a lack of evidence in the area prevented them from being able to provide sufficient information to clients, for example:

> “I don’t get the sense we really explain to patients as much as we should about how long they need to take (medication) for, probably because the answer is we don’t know, because no one does any of those really long term studies” [Clinician 02; male psychologist]

For psychologists working privately, or for GPs referring clients to private psychologists, the restrictions of the government subsidy program for private psychologists in Australia (Medicare ‘Better Access for Mental Health’) acted as a barrier. Firstly, at the time of the interviews the maximum number of subsidised sessions to 12 per client in any 12-month period. Secondly, the subsidy was only available for appointments with the client, i.e. clinicians cannot see caregivers alone. As clinicians explained, this meant that if the clinician wanted to see the caregiver about issues related to the client, they needed to do so with the client present (which in turn may mean that, for example, the client had to miss school for an appointment that they are not participating in). The client also then missed out on a session that they could otherwise use for their own therapy. Alternatively, if the caregiver had approval to be seen under the same subsidy, they could attend as a client themselves, but this was not possible at youth services (due to age related criteria) and it also meant that the caregiver had one less subsidised appointment for their own therapy. Clinicians report these issues acting as a barrier to the caregiver being involved, but also that the involvement of the client in treatment decision-making is hindered because the options for care are limited. One clinician (20; female mental health nurse) also reported that if she had to see clients under the Mental Health Act then this would act as a barrier to involving clients; however, she said that she is not required to see such clients at her service.

Facilitators

When discussing barriers to involving clients in treatment decision-making, several clinicians also volunteered facilitators, or factors that make it possible, to involve clients in such decision-making. Having adequate time was the most common response, including having the “space to flesh (pros and cons) out more” (clinician 09; female psychologist); “the luxury of having the time to do what I see as best practice, and not all GPs have that time" (clinician 17; female GP); and long appointment times (clinician 18; male GP). The culture of the team within which clinicians worked was also a facilitator, for example that the clinic supported collaboration with clients (clinician 06; male psychiatrist); being able to raise issues in clinical review settings, and not having concerns about the client trivialised, and therefore feeling more supported to involve clients (clinician 21; female youth outreach worker); not having to see clients being treated involuntarily and having referral options if treatment is not working with her (clinician 20; female mental health nurse); working in a profession where clients tend to be "a bit more open" than, for example, with medical doctors (clinician 22; male youth worker); and what clinician 10 (female psychiatrist) saw as a general shift in healthcare culture towards a more collaborative approach with more informed clients.

How to improve treatment decision making

The most common response from clinicians when asked what they thought would improve treatment decision making, was to have better information resources (e.g. fact sheets):

> "I don't know if there's any sort of information that we could hand to them that they could read… so that they could go home and read and think about, that might be helpful to them, we don't use anything like that" (Clinician 03, female psychologist)

Clinicians valued having fact sheets that were up-to-date, relevant to young people, able to be given to caregivers and readily available. Suggestions for fact sheets included that they be balanced, unbiased (e.g. "not driven by litigation and drug companies"; clinician 16, female GP), not overwhelming, to have simple messages, to be available on the Internet, and to be interactive; "anything you can do interactively, like getting (clients) to write things in and you write things in is good" (clinician 10, female psychiatrist). Interactive "self reports" were also important to clinician 13 (female psychologist):

> "I'm a big believer in, as part of the assessment process, having self reports that people fill out, and in the self report having some scripts, or some inclusion about ideas for treatment themselves, so what do you think is going to make a difference, and have you had any experience of something making a difference before, so that you get that from the outset"

Giving structure to existing conversations (e.g. of doing or not doing treatment) was suggested by clinician 02: "formally going through what might be the pros and cons would be helpful". Having the information available in written format was valued in order to allow clients the time to process the information:

> "I think time is the main thing, to make sure that all of the issues have been explored, I think that's a big one, and having things written… on paper, because sometimes it can all be verbal and then you can lose track of it, anyone can" (Clinician 04, male psychologist)

Information was also desired for ongoing treatment decision-making, for example clinician 09 (female psychologist) suggested that fact sheets and a protocol for "any kind of change in treatment… or a change in medication… that people are given a fact sheet (and told) 'go away and think about this for a week'". Having time to think about decisions was also important to clinician 04 (male psychologist), who believed that it was necessary to have "more checking that the young person's okay with it… giving it a bit longer to seep in" and to clinician 11 (male psychiatrist) who felt that "people only take in twenty five per cent of what you're saying anyway" and that by providing "useful educational stuff" the client would have "something to go away with and read and… a green light to come back and say I've experienced this (side effect)".

There was some concern from clinician 16 (female GP) that "providing overwhelming amounts of information and causing confusion" would be unhelpful for clients, particularly already anxious clients, however clinician 04 (male psychologist), for example, didn't feel that information would overwhelm clients and that information about treatment options (e.g. medication, psychological therapy) should be presented "upfront":

> "Probably a little bit more options presented upfront about the different, you know, the different medication options, I think that's a good point… the different options should be presented immediately, and I think there's a bit of an overestimation of how much that will overwhelm the client, I think they can often handle it… if it's done in that slow way… the psychiatrist can still express which one they think will be best… I think that could be done as well (with) psychological therapy"

Being upfront about what the service could and could not provide (e.g. continuing care but not an outreach service) was a concern for clinician 05 (male psychologist), and giving clients realistic expectations in general was endorsed by several clinicians.

Examples of resources (other than fact sheets) that were suggested include guidelines, specifically formal guidelines about involvement and the capacity for involvement, and training for clinicians, for example "in the soft engagement side of things with kids" (clinician 22, youth worker). Lastly, time was seen as a key factor in how to improve treatment decision-making. For example, clinician 08 (female psychologist) said "we are always under time constraints to get people in and get them out again", and clinician 18 (male GP) said that time was "crucial" for helping clients to feel heard: "these kids don't feel they're being listened to or taken seriously by either their peers or their parents… so listening, which inevitably takes time, is crucial". As a GP who is not paid a salary but rather per appointment, he also felt that finding ways to finance longer appointments was necessary in order to be able to improve treatment decision-making practices. Despite all of these recommendations for ways in which to improve the decision-making process, when clinicians were asked if they ever wished the process was different, they all responded by saying 'no'.

Discussion

Clinicians endorsed, and reported employing in the majority of cases, a collaborative approach to treatment decision making for young people diagnosed with MDD. In the process of making decisions many clinicians felt that it was an ideal situation to have the client, caregiver and clinician weigh up the potential risks and benefits of different treatment options. Ultimately, however, it was felt that the client themselves had the final say when it came to accepting or declining both psychological therapies and antidepressant medication. This highlights not only the differentiation made by clinicians about the process of decision making and who actually makes the decision (89), but also the similarity in beliefs of clinicians when compared with the variety of perspectives presented by clients (as discussed in chapter 4). The variation seen in descriptions of involvement also highlights that roles taken on by clients, caregivers and clinicians are more complex than the categories of autonomous, shared and paternalistic styles (88).

Many clinicians felt that considering the values and preferences of clients and their caregivers was important, however values and preferences were not asked about routinely; instead, they were discussed and addressed as the need arose (e.g. if raised by the client). Client preference for involvement was also not routinely asked about. Both the routine consideration of individual characteristics, values and preferences, and explicitly asking about preference for involvement are key steps in models of SDM, the dominant framework for collaborative treatment decision making (84, 89, 153).

Several circumstances or situations were described in which clinicians would limit the amount of involvement afforded to clients. In line with experiences reported by clients, these situations included clients' age and when clients had more severe depressive symptoms and higher levels of risk. However, clinicians added to this perceived client preference for involvement. Given that clinicians did not report asking explicitly about client preference for involvement, it is possible that discrepancies may arise between perceived and actual client preference for involvement. This may be reflected in the fact that some clients were accepting of having reduced levels of involvement whereas others were not. Considering the limited ways in which clients *can* be involved, even when clinicians feel that full involvement is not possible, it may be beneficial to maintain involvement of clients in terms of maintaining rapport throughout these compromised situations. In doing so, affording clients control over some aspects of their treatment (e.g. type of medication to take or psychological therapies to engage in) may compensate from being excluded from deciding about larger decisions (e.g. being treated as an inpatient rather than in the community).

Despite this variation in how clients were actually involved in the decision-making process, clinicians felt that using a collaborative approach with clients was important. They believed that involvement was therapeutic in itself, that it promoted autonomy and that it was important for clients developmentally. They also predicted that if they failed to employ a collaborative approach and involve clients in the treatment decision-making process, that clients would be non-adherent and/or disengage. Again, this is supported by the client data, where young people reported not taking medication and disengaging from services after failing to be involved by clinicians.

Along with talking about the importance of involving clients, many clinicians also believed that caregiver involvement was ideal. Ultimately, however, they said that it was optional and based on the preferences of the client. Clinicians said that it was best for caregivers to agree with decisions, but that they were not necessarily decision makers. Rather, they were seen as important contributors to practical aspects, such as looking after medication. Despite caregivers reporting wanting more involvement than this, the clinicians' description of caregiver involvement is consistent with the experiences that caregivers reported. It is also consistent with clients descriptions in that clients who had caregivers involved in their lives generally reported wanting caregivers to play a supportive role, rather than act as decision makers. Such a role may not match the desired level of involvement and definition of involvement as viewed by caregivers.

Clinicians were asked to define what they believed to be true involvement. Responses focused on aspects of the client-clinician relationship such as engagement, and having the client feel comfortable enough to explicitly decline treatment options. Clients also felt that relationship related factors such as engagement and trust were critical. Taken together, these responses further support the notion that involvement should be considered not only as concrete behaviours (e.g. sharing information, talking about this information), but also in terms of the feelings that each person has for the others involved in the treatment decision-making processes (85, 148).

One of these decision-making processes addressed directly in the interview probes was the provision of information. Clinicians stated that they provided clients and caregivers with information about depression, the relevant treatment options, and the potential risks and benefits of these treatment options. The amount of information, as well as the content and format of such information, described by clinicians varied. Clinicians also spoke about tailoring the content and amount of information provided to clients depending on individual characteristics and perceived needs (e.g. literacy levels, depression severity). Information was mainly disseminated orally rather than in written format. Some non-medical clinicians reported on relying upon medical staff to hand out fact sheets, yet medical clinicians did not use fact sheets routinely or often. This matches clients' accounts of not always receiving information and having to look elsewhere for it.

A small number of negative aspects related to involving clients in decision-making processes were highlighted by some clinicians, including the possibility of overwhelming clients when they were unwell. Although one caregiver felt this about herself, neither clients nor caregivers reported this as an issue for clients.

Clinicians also spoke about times when they had disagreed with clients or caregivers and the ways in which they had dealt with such disagreements. The main approach adopted was to explore reasons behind disagreements (e.g. the reasons for a client refusing medication) and restate their rationale and justification for their own position. Again, clinicians felt that ultimately the final decision rested with clients and that they could not force voluntary clients to engage in treatment.

Indeed, many clinicians saw engaging clients as a key barrier to involving clients, saying that they could not involve them if they were not attending sessions and willing to be seen by the service. Severity of depressive symptoms, level of perceived risk and the age or developmental stage of the clients were also seen as significant barriers by clinicians. Along with these client-level barriers, clinicians also spoke about clinician-level barriers (e.g. clinician style), service-level barriers (e.g. lack of time in appointments) and broader-level barriers (e.g. lack of evidence). In contrast, several clinicians reported that having long appointments, working within a team that supported a collaborative approach and not treating involuntary clients acted as facilitators to involving clients. Clients reported very similar barriers, with particular emphasis on these same clinician-level and system-level barriers, whereas caregivers focussed instead on the service-level barriers such as age-related confidentiality policies.

Lastly, several suggestions were made for how to improve the treatment decision-making process for young people diagnosed with MDD. Aside from increased time, clinicians showed a strong desire for more informative resources for both clients and caregivers. Fact sheets that were up to date, relevant to young people, able to be given to caregivers, readily available, balanced, web based and interactive were valued. Such requests were very similar to those desired by clients and caregivers, and suggest that informative tools such as DAs may be useful for this population, satisfying the needs of clients, caregivers and clinicians.

In addition to the limitations discussed in chapter 4, a limitation of the current study is that participants were not discussing the same instances. An alternative approach, for example, may have been to interview a client, caregiver and clinician about the same instance of treatment decision making. In doing so, more direct comparisons could be made about the similarities or variations in accounts. However, it is anticipated that recruitment of such a sample would have been more difficult and resulted in a smaller numbers of participants. Instead, the approach taken in the current study was to sacrifice this triangulation for a broader range of perspectives about a larger number of situations. Rather than attest to the accuracy of accounts, this study has instead sought to consider variations in experiences of involvement. Also, consideration of beliefs from a broader range of participants has been possible. This was important given the aim of the study was to obtain rich descriptions of a variety of experiences and beliefs, something that is lacking in this area of research.

Overall, interview data from both service users and service providers has demonstrated that some type of collaborative approach to treatment decision making for young people diagnosed with MDD is seen as the ideal model. The main collaborative approach described by participants was not necessarily about always sharing the actual decision. Instead, the focus was on engaging in a shared decision-making process where possible, which included the provision of information about potential risks and benefits of treatment options and consideration of the preferences of the young person for involvement in making the decision, usually allowing the client to make the final choice (88, 89). This was flexible, however, and sensitive to client-related factors that (mainly clinicians) believed should determine the level of involvement afforded to clients. Having the opportunity to share some involvement where possible may lead to higher levels of satisfaction and engagement for clients who are denied their preferred level of involvement. When considering the three main models of involvement (84), the preferred model by the majority of all participants was most in line with SDM. Given that SDM is most often facilitated with the use of informative, evidence-based decision making tools called DAs, this approach also has the potential to fulfil the desire of all participant groups for more informative resources. Chapter 6 will describe SDM and DAs, and consider the current evidence for such interventions in mental health.

Chapter 6: Literature review of shared decision making in mental health

Shared decision-making (SDM)

The purpose of this chapter is to review the evidence for SDM, with specific consideration to mental health and youth mental health. Before doing so, a brief description of SDM will be offered.

Incorporating tenets of evidence based medicine and patient centred care, SDM is an approach to healthcare decision making that lies between a paternalistic model (whereby the clinician makes the decision for the client) and an autonomous model (whereby the client makes the decision for themselves, consulting the clinician only to obtain information or treatment). The most common model of SDM is that described by Charles and colleagues (83), which involves three major steps: 1) two parties (e.g. doctor and patient) provide each other with relevant information; 2) these same two parties deliberate on the decision by discussing the treatment options and preference for each option; and 3) a treatment option is selected that is consistent with patient preferences and values. The emphasis should not be on who actually makes the decision, but that the process involves the sharing of relevant information (89). Elwyn and colleagues (2001) detail six steps within this framework: 1) problem definition (e.g. stating that there is a health problem that requires a decision to be made); 2) equipoise (e.g. stating that there is more than one legitimate option); 3) options and information about options (risk communication); 4) enabling patients to explore their concerns and queries; 5) decision making; and 6) reviewing arrangements (154). Box 1 describes the process of SDM, using the example of a young adult experiencing moderate depression. In 2010, the *Salzburg Statement of Shared Decision Making* (155) was signed by 58 representatives from 18 countries calling on patients, clinicians, policymakers, researchers and other professions to ensure that the 'ethical imperative' to provide quality, evidence based information and involve patients in decision making regarding their own treatment and care is realised. Part of the rationale for promoting SDM (e.g. (156)) is the strong evidence for the effectiveness of decision-making tools called DAs in improving outcomes related to the decision-making process.

Box 1. An example of the processes involved in SDM.

The following is an example of what steps might be taken if employing a SDM model to treatment decision making about treatment for depression with an 18-year old female presenting with moderate depression (adapted from (83, 157)):

- Discuss what depression is
- State that there is more than one suitable treatment option (i.e. psychotherapy, prescription of different types of antidepressant medication)
- Ask the client about her preferred level of involvement and desire for carer involvement
- Discuss preferred information format (fact sheets or decision aids if available, verbal, websites etc.)
- Discuss the potential risks and benefits of each treatment option (including other available resources and treatment options from other professionals, e.g. psychological therapies)
- Explore ideas, fears and expectations of the problem and possible treatments
- Check with the client about her understanding of the information and reactions to this
- Make, discuss or defer the decision/s
- Arrange follow-up

Decision aids

Decision aids (DAs) are evidence-based tools that provide information about the potential risks and benefits of treatment options (or other health related choices such as screening tests) and are designed to elicit patient preferences in relation to these options. In doing so, they are also designed to facilitate the exchange of information and increase the amount of information shared between the clinician and client. The International Patient Decision Aid Standards (IPDAS) describe criteria for assessing the quality of DAs (158) and there is a valid and reliable tool for doing so (the IPDAS instrument, or IPDASi; (159)). DAs should include information from the following three categories: 1. A general description of the disorder and treatment options; 2. A clear presentation of the evidence concerning the potential risks and benefits of each treatment option; and 3. A section that encourages the client to work through their individual characteristics (e.g. risk factors, available resources for support), values and preferences with regard to these potential options. DAs are not designed to exclude the input of the clinician. Ideally both parties should use the DA together (with the inclusion of carers as necessary), and the DA should act to facilitate discussion between the clinician and client about the evidence.

Evidence for SDM in general medicine

The majority of studies investigating SDM to date have tested the effectiveness of DAs as a means of facilitating SDM. Evidence for the benefits of DAs varies according to the type of decision under consideration, the quality of the DA and the way in which the DA is evaluated. A recently updated Cochrane review concluded that DAs increased clients' knowledge, reduced decisional conflict (both in terms of feeling uninformed or feeling unclear about personal values), reduced the proportion of clients who were passive in the decision-making process and reduced the proportion of clients who remained undecided (152). Due to the limited consistency of the ways in which outcomes were measured across studies, more work is needed to provide evidence about the effect of DAs on treatment adherence and healthcare outcomes, and several large studies are underway in the USA and Europe. Additionally, the existence and dissemination of DAs not guarantee uptake in clinical practice, and current knowledge about effective implementation strategies for SDM interventions is limited (160).

SDM and mental health

As discussed in chapter 1, clinical guidelines and other advisory documents advocate for the inclusion of people with mental disorders in decisions about their own care. There have been increasing calls in the literature to support a SDM model for mental health (e.g. (161-163)), including an editorial that describes SDM as an ethical imperative (149), and this advocacy of SDM has also extended to the area of youth mental health (e.g. (150, 164)). In order to assess the evidence to support this enthusiasm, a review of the literature was conducted. Studies were included from the following groups:

1. Studies measuring levels of SDM behaviours;

2. Studies testing the effectiveness of SDM interventions, including DAs, using high-level methodological approaches (e.g. randomised controlled trials or controlled trials) or other methodologies; and:
3. Studies testing the effectiveness of interventions on SDM behaviours, namely involvement in treatment decision making and/or treatment preference ('SDM-related interventions').

For all studies the following inclusion/exclusion criteria were also relevant:

1. Of primary interest were studies that related to young people diagnosed with MDD, however due to the anticipated lack of research in the area, all mental health areas and age groups were considered.
2. Studies were excluded if they were not in English or if they did not present data for the outcomes of interest (e.g. measured patient involvement but did not report on it).

Search strategy

A search strategy was developed with key terms for both mental disorders and shared decision making (see table 1). The search strategy was run in Medline, PubMed, and the Cochrane Library in 2008 (including articles from 1950 and onwards) and again in 2011 in order to update the search. Key journals (e.g. Patient Education and Counselling) were also searched individually (all available articles until 2011) and ancestry searches were performed on key papers. Titles and abstracts were screened, and papers initially included were then read in full in order to determine whether or not they met the inclusion criteria. The number of articles excluded at each stage was not recorded.

Table 1. Example of search strategy (Medline EBSCO)

S1	MM Substance-Related Disorders
S2	MM Alcohol-Related Disorders+
S3	MM Amphetamine-Related Disorders
S4	MM Cocaine-Related Disorders
S5	MM Marijuana Abuse
S6	MM Neonatal Abstinence Syndrome
S7	MM Opioid-Related Disorders+

S8	MM Psychoses, Substance-Induced
S9	MM Phencyclidine Abuse
S10	MM Substance Abuse, Intravenous
S11	MM Substance Withdrawal Syndrome+
S12	MM Self-Injurious Behavior+
S13	TI (self poisoning or self inflicted or self destructive or automutilation) or AB (self poisoning or self inflicted or self destructive or automutilation)
S14	TI suicidal or AB suicidal
S15	MH Bipolar Disorder+
S16	MH Psychotic Disorders+
S17	MH Delusions
S18	MH Hallucinations
S19	MH Paranoid Disorders
S20	MH Schizophrenia+
S21	MM Eating Disorders
S22	MM Anorexia Nervosa
S23	MM Bulimia Nervosa
S24	MM Anxiety
S25	MM Anxiety Disorders+
S26	MM Depression
S27	MM Depressive Disorder
S28	MM Depressive Disorder, Major
S29	MM Dysthymic Disorder
S30	MM Mood Disorders
S31	MM Somatoform Disorders
S32	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29 or S30 or S31 or S32
S33	TI shared decision making or AB shared decision making
S34	TI patient sensitive decision making or AB patient sensitive decision making
S35	TI patient preference or AB patient preference
S36	TI patient choice or AB patient choice
S37	TI decision making or AB decision making
S38	TI patient decision aid or AB patient decision aid
S39	TI decision support or AB decision support
S40	TI decision support tool or AB decision support tool

S41	TI patient decision or AB patient decision
S42	TI collaborative AB collaborative
S43	TI decision aid or AB decision aid
S44	TI treatment choice or AB treatment choice
S45	TI patient centered care or AB patient centered care
S46	S33 or S34 or S35 or S36 or S37 or S38 or S39 or S40 or S41 or S42 or S43 or S44 or S45
S47	S32 and S46

Existing level of SDM related behaviours in mental health care

Levels of SDM behaviours have been investigated for mental health areas in two ways; by asking patients or clinicians about their experiences and practices, and by recording clinical consultations and using rating scales to measure SDM behaviours. Studies include those explicitly assessing for levels of SDM as a whole, as well as studies assessing levels of the separate components of SDM, meaning one or more of the following: 1) the provision of information; 2) offering treatment choice to patients; and/or 3) patient involvement in the decision-making process. Here, we first consider the subjective reporting of overall SDM behaviours before presenting results from studies that have measured such behaviours objectively.

Subjective measures of SDM related behaviours

In order to investigate clinicians' self-report of SDM behaviours, Hamann and colleagues (165) surveyed a convenience sample of 352 psychiatrists attending a German psychiatric conference. Two questionnaires were administered; 181/352 (51.4%) completed a questionnaire that focussed on the influence of patient characteristics on SDM behaviours and 171/352 (48.6%) completed a questionnaire that focussed on the influence of different decision topics on SDM behaviours. All psychiatrists were also asked about their beliefs concerning SDM for patients diagnosed with schizophrenia in general. Factor analysis confirmed distinct patient characteristics and decision topics that influenced the likelihood of employing SDM behaviours. Psychiatrists were unlikely to employ a SDM approach for patients with 'impaired decisional capacity' (e.g. high levels of psychopathology, low levels of education), were more likely to use SDM for patients with 'negative attitudes towards treatment' (e.g. poor therapeutic alliance, poor compliance), and were very likely to use SDM for 'ideal patients' (e.g. well informed about treatment options, generally accepting of antipsychotic medication). Psychiatrists were unlikely to employ a SDM approach for 'medical and legal decisions' (e.g. decisions about hospitalisation, prescription of antipsychotic medication), yet likely to do so for 'psychosocial decisions' (e.g. decisions about psychotherapy, future housing and work). The majority of respondents reported employing a SDM style of consultation for patients diagnosed with schizophrenia (173/352, 51%), followed by a paternalistic style (151/352, 44%) and then informed choice (18/352, 5%). There was no association between reported communication style and psychiatrist characteristics.

Complementing this study of SDM behaviours from the clinicians' perspective are studies that have investigated patients' experiences of SDM behaviours. Measuring performance indicators as stipulated by the National Institute for Clinical Excellence guidelines for the prescription of antipsychotic medication, Olofinjana and Taylor (166) interviewed 30 patients diagnosed with psychotic disorders at eight acute, adult wards in London, UK. Very few patients reported receiving any information (7/30 or 23% received a pamphlet and 1/30 or 3% received information from their pharmacist) and an audit of all patients' medical records revealed no notes to indicate that any patient had been informed about the potential risks or benefits of taking antipsychotic medication (although one file noted that the patient had refused an information sheet on the topic, it was not noted whether the information had been conveyed verbally instead). In terms of patients being afforded a choice of medication, 27/30 (90%) reported being given no choice, two patients (7%) said that they were given a choice between oral and depot forms of medication and one patient (3%) reported having free choice. Contribution to choice was also measured, and again the majority of patients felt that they had not been involved in the decision at all (26/30 or 87%), while one patient (3%) felt partly involved and three patients (10%) felt that they were unrestricted in their contribution (despite who made the actual choice).

A cross-sectional, correlational study was conducted using the Control Preferences Scale (CPS) and Perceived Coercion Scale (PCS) to assess both preferred and actual participation in decision making about medication in 84 (data available on these scales for 83) outpatients with 'serious mental illness' in the US (167). The CPS was modified to include three communication styles to choose from: active, collaborative and passive. Agreement between preferred and received style was an additional item, which revealed that 26/83 (31.3%) patients felt that there had been a disagreement. The rates of actual communication style received are as follows: 8/83 (9.6%) active, 58/83 (69.9%) collaborative and 17/83 (20.5%) passive. The PCS assesses coercion on a scale of 0 (no perceived coercion) to 25 (very high levels of perceived coercion); the mean score for this sample was 6.5 (SD 0.61), with a range of 0-14, indicating low to moderate levels of perceived coercion.

Objective measures of SDM related behaviours

The most commonly used instrument to measure SDM behaviours is the OPTION scale, developed by Elwyn and colleagues (168). The OPTION scale is designed for use with transcripts of audio recordings of consultations where decisions are made. There are two versions of the scale (153), with different scoring systems, however they both involve 12 items that comprise the SDM process and the scores can be converted so that the two versions are comparable (see table 2 for OPTION scale items). Three studies were located using the OPTION scale to assess transcripts of consultations involving mental-health-related treatment decision making.

The first published study measuring levels of SDM for mental disorders using the OPTION scale investigated this in patients (n=20) diagnosed with MDD in primary care teaching practices associated with a University Hospital in Freiburg, Germany (169). Between one and four consultations were provided per clinician (n=9) and the mean length of consultations was 16 minutes and 6 seconds. The consultations were timed according to Elwyn and colleagues' (2001) (154) six stages of SDM (as described above). The vast majority of time was spent on problem definition (mean = 763s), with the remaining sections receiving comparatively less time ('equipoise' mean = 1s; 'options and information about options' = 50s; 'enabling patients to explore their concerns and queries' = 48s; 'decision making' = 60s; 'reviewing of arrangements' = 31s). Although there was variability both across and within clinicians for

OPTION items, overall very low levels of SDM behaviours were demonstrated (see table 2). The satisfaction of patients was not measured. Limitations of this study include a poor response rate of GPs (60 general practices were approached and 9 GPs agreed to participate; total number of GPs approached not reported) and low number of consultations contributed per GP (range =1-4; mean =2.22).

Table 2. OPTION scale items and mean (SD) raw scores (0-4[a]).

OPTION Scale Items	**Loh et al**	**Goossensen et al**	**Goss et al**[c]
Mean length of consultation	*16m 6s*	*13m*	*40m*
1. The clinician identifies a problem(s) needing a decision making process	0.8 (0.6)	2.46 (-)[b]	1.9 (-)
2. The clinician states that there is more than one way to deal with an identified problem	0.5 (0.66)	1.66 (-)	0.61 (-)
3. The clinician lists 'options' including the choice of 'no action' if feasible	0.0 (0.0)	0.10 (-)	0.0 (-)
4. The clinician explains the pros and cons of options to the patient	0.6 (0.87)	1.80 (-)	1.41 (-)
5. The clinician checks the patient's preferred information format	0.3 (0.38)	1.46 (-)	1.22 (-)
6. The clinician explores the patient's expectations (or ideas) about how the problem(s) are to be managed	1.0 (0.6)	1.30 (-)	1.25 (-)
7. The clinician explores the patient's concerns (fears) about how problem(s) are to be managed	0.8 (0.41)	1.18 (-)	0.85 (-)
8. The clinician checks that the patient has understood the information	0.1 (0.15)	1.56 (-)	1.34 (-)
9. The clinician provides opportunities for the patient to ask questions	1.1 (0.15)	3.44 (-)	1.04 (-)
10. The clinician asks for the patient's preferred level of involvement in decision making	0.1 (0.18)	0.20 (-)	0.14 (-)
11. An opportunity for deferring a decision is provided	0.8 (0.73)	2.87 (-)	1.66 (-)
12. Arrangements are made to review the decision (or the deferment)	0.1 (0.93)	2.44 (-)	1.39 (-)
Mean of mean scores	*0.6 (0.47)*	*(-)*	*(-)*

[a] *0 = Behaviour not observed; 1 = A minimal attempt is made to exhibit the behaviour; 2 = The behaviour is observed and a minimum skill level achieved; 3 = The behaviour is exhibited to a good standard; 4 = The behaviour is exhibited to a very high standard.*

[b] (-) = Not reported

[c] NB: Calculated based on raw data reported in article

The second published study in this area was conducted at a psychiatric outpatient clinic at an academic hospital in Rotterdam, The Netherlands, with 8 psychiatrists and 61 patients with a range of non-psychotic disorders (170). Psychiatrists recruited patients until they had contributed eight sessions (with unique patients) where decision-making around treatment occurred. The mean length of consultations was 13m (SD=6), however the length of each SDM stage was not recorded. Although the mean scores for each OPTION item were higher than in the above study (see table 2), overall the scores demonstrated relatively low SDM behaviours, with only one item on average being performed to a 'good standard'. Associations between total OPTION scores and a) patient and psychiatrist characteristics and b) duration of consultations were investigated, however, the only significant association found was between OPTION scores and length of consultation (the longer the duration time, the higher the score). Additionally, patient satisfaction was measured via a questionnaire, however only 29/61 questionnaires were returned. Satisfaction scores were generally good, including satisfaction with behaviours that scored very low on the OPTION scale, however sample biases cannot be ruled out due to the low response rate of the questionnaire.

The third published study in this area examined SDM levels in a community mental health service in Verona, Italy, with 16 psychiatrists and 80 outpatients (171). Psychiatrists contributed between one and 11 consultations (mean = 5), and the mean length of consultations was 4,245 words per consultation transcript (SD 1,989), which the authors equate to a mean of approximately 40m (using a ratio of 10m per 1,000 words). The length of each stage of SDM was not recorded, although this estimate suggests longer consultation times than the previous two studies. In line with the above two studies, low levels of SDM behaviours were found (see table 2). The mean scores according to each psychiatrist were not reported, however the differences between individual psychiatrists were analysed and were significant both in terms of OPTION scores and length of consultations. Associations between total OPTION scores and the characteristics of patients and psychiatrists were investigated, however there were no significant factors (while significant associations were found between characteristics and individual OPTION item scores, they are not reported here for the sake of brevity). As with the above study (Goossensen et al, 2007), the total OPTION score showed a significant correlation with the length of the consultation (the longer the consultation time, the higher the score).

High-level evidence for SDM specific interventions

Given that existing levels of SDM behaviours are low, consideration of interventions that facilitate SDM is warranted. Two existing reviews on SDM in mental health were identified in the literature search; the first was a non-systematic review that included both SDM intervention trials and SDM-related intervention trials (172) and the second was a systematic Cochrane review that included only SDM specific randomized controlled trials (173), of which there were two. Two additional RCTs have since been published, resulting in four identified RCTs of SDM interventions for psychiatric populations. Details of included studies are summarised in table 3.

Table 3. Characteristics of included studies testing effectiveness of SDM intervention compared with treatment decision making as usual.

Study references	Methods	Participants	Interventions	Outcomes
Loh et al 2007 (174)	Cluster RCT (clinicians randomised)	N=263 intervention clients[a] (mean ages 50.4 (SD=16.3) to 48.8 (SD=17.5); 22.2-34.7% male)[b] and N=142 control clients (mean ages 40.8 (SD=13.2) to 41 (SD=13.7); 30.5-32.7% male), all diagnosed with moderate depression	Wed-based DA; training for clinicians (GPs)	Client involvement (Patients' Perceived Involvement in Care Scale and the Man-Son-Hing Scale (adapted)); client satisfaction (Client Satisfaction Questionnaire-8 Item); depression severity and other clinical outcomes (Brief Patient Health Questionnaire-Depression); treatment adherence (investigator-developed 5-point Likert scale items); timed duration of consultation.
Hamann et al 2006;	Cluster RCT (hospital	N=49 intervention	Paper-based DA; training for the	Psychopathology (Positive and Negative

2007 (175, 176)	wards randomised)	clients (mean age 35.5 (SD=11.9); 59% male) and N=58 control clients (mean age 39.6 (SD=10.8); 47% male), all diagnosed with schizophrenia or schizophreniform disorder	head nurses of the wards	Syndrome Scale for Schizophrenia); doctor's appraisal of relationship with client (Working Alliance Inventory); time spent with clients; therapies administered; client preference for decision making role (subscale of Autonomy Preference Index); client's appraisal of involvement in treatment decision making (Combined Outcome Measure for Risk communication And treatment Decision making Effectiveness); client satisfaction (Client Satisfaction Questionnaire-8 Item); client knowledge of disorder and treatment (investigator-developed multiple choice items). Additionally, the following were all measured using investigator-developed 5-point Likert scales: doctor's appraisal of client's "performance" in consultation; doctor satisfaction; nurse's appraisal of client's capacity to understand and process information.
Woltmann et al 2011 (177)	Cluster RCT (clinicians randomised)	N=40 intervention clients (mean age 47 (SD=9); 62%	Web-based decision support system (DA	Client satisfaction (investigator-developed 5-point Likert scale items); clinician

		male) and N=40 control clients (mean age 46 (SD=11); 70% male), all diagnosed with a 'severe mental illness' (e.g. schizophrenia)	completed by both client and clinician individually and with report of both available for discussion in consultation); brief orientation session for clinicians	satisfaction (investigator-developed 5-point Likert scale items); client knowledge of care plan (investigator-developed questions and prompts).
Joosten et al 2009 (178)	Cluster RCT (clinicians randomised)	N=111 intervention clients (mean age 40.8 (SD=10.6); 73.9% male) and N=109 control clients (mean age 40 (SD=11.1); 70.6% male); all diagnosed with a substance abuse disorder	Structured, three-month SDM intervention (including a decision support process using multiple tools but no single one DA, which spanned five consultations); training for clinicians	Substance use (European Addiction Severity Index); type and severity of substance dependence (Composite International Diagnostic Interview – Substance Abuse Module); quality of life (EuroQoL-5D; investigator-devised visual analogue scale item).

[a] The term 'client' is used here to differentiate between client and clinician participants.

[b] A range of means is offered here due to there being two groups each for both the intervention and control arms (pre- and post- use of the decision aid).

In a cluster RCT, general practitioners (GPs) were randomised to provide either a SDM intervention involving GP training and use of a web-based DA (n=17) or treatment decision making as usual (n=8), to adult primary care patients with recently diagnosed MDD (n=405) (174). The number of GPs per group was weighted according to the expected larger drop out rates of SDM intervention GPs who had to undertake 5 training sessions over 6 months. The majority of GPs were male (69.6%), had a mean age of 48.4 years (SD=8) and had a mean number of years professional experience of 13 (SD=7). Participants in all four groups (pre-intervention SDM, pre-intervention control, post-intervention SDM, post-intervention control) were predominantly female (65.3-77.8%), had mean ages of 40.8-50.4 years and had baseline depression scores of 13.7-14.7 on the Brief Patient Health Questionnaire – Depression, which indicates moderate depression severity. There were differences across groups in terms of age, educational history and relationship status, and so these factors were controlled for in the analyses. The main outcomes measured were patient involvement and participation, satisfaction, adherence, and depression severity and remission. The duration of consultations was also measured in order to see if the SDM intervention increased consultation time. All participants completed assessments after the appointment during which they made a decision about treatment and then again 6-8 weeks later. The SDM intervention significantly increased patient involvement and satisfaction without increasing the duration of consultations; however, the SDM intervention had no impact on level of depression severity.

A second study investigated SDM with the use of a paper-based DA for adult inpatients diagnosed with schizophrenia in a multisite, cluster RCT involving twelve psychiatric wards across two hospitals (175, 176). In order to ensure that only intervention group participants had access to the DA and SDM trained staff, six wards were randomised to receive the SDM intervention and the remaining six acted as control wards. Although randomisation occurred at the ward level, patients within each ward were considered the participants and analysis was conducted at the individual level. The head nurse of each SDM intervention ward was trained in how to help participants use the DA and distributed the DA to each participant (n=49). Within 24 hours of assisting the participant to use the DA, a 'planning talk' was held with the participant and their doctor, and discussion during this talk was facilitated by the completed DA. Those participants in the control group (n=58) continued with treatment decision making as usual. The mean age of participants was 35.5 years (SD=11.9) in the SDM intervention group and 39.6 (SD=10.8) in the control group, 59% of the intervention group was male compared with 47% in the control group. Outcome measures included positive and negative psychotic symptoms, therapeutic alliance, patient satisfaction, drug attitude inventory and additional measures related to decision making (e.g. decision making preference) and details of treatment plans (e.g. number of medication switches). All participants were assessed at baseline and then again at discharge; the SDM intervention group were also assessed immediately after the planning talk. The intervention demonstrated that SDM was feasible for this population, and significantly increased patients' knowledge about schizophrenia, uptake of psychoeducation, and feelings of involvement in consultations, again, without increasing consultation time. However, as with the first study, clinical symptom severity did not improve.

Another study with a similar population, but in a community setting, tested an electronic decision support system (EDSS) designed to facilitate SDM in a cluster RCT (177). 20 case managers at three urban community mental health settings were randomised to provide either the EDSS intervention or treatment decision making as usual to their respective clients (n=40 for each condition; total n=80) for their care plan. The main outcome measures were client and clinician satisfaction with the care plan, and client recall of care plan goals. These were assessed 3 days after the care plan session, and satisfaction was assessed on a purpose-designed questionnaire with items being rated on a scale of 1-5, where 5 indicated the highest level of satisfaction. Clinicians were required to complete a questionnaire for each participant rather than provide an overall score. Participants were mostly male (SDM group 62%; control group 70%), had a diagnosis of schizophrenia or schizoaffective disorder (SDM group 60%; control group 63%), and the mean ages were 47 (SD=9) in the SDM group and 46 (SD=11) in the control group. Clinicians delivering the SDM intervention were significantly more satisfied than those in the control group (mean summary score of 4 (SD=0.5) compared with 3.3 (SD=0.5); p=0.01), however there was no difference between participants in terms of satisfaction levels. Participants in the SDM group were able to recall significantly more information about their care plan than those in the control group (a mean proportion of 75% (SD=28) of plan goals compared with 57% (SD=32); p=0.02).

One final study involved a more structured, three-month SDM intervention and was tested in a cluster RCT with adults who had substance abuse disorders in the Netherlands (178). Clinicians (n=39) from three treatment centres were randomised to provide clients with either the SDM intervention (n=111) or treatment decision making as usual (n=109). Clinicians administering the SDM intervention were provided with an initial training day and then a booster session one month later. The SDM intervention protocol had five dedicated sessions, and involved a range of values clarification activities designed to facilitate information exchange between the clinician and client and to elicit client preferences around treatment options. Outcome measures included substance use severity and related functioning as measured by the European Addiction Severity Index (EuropASI), diagnosis as determined by the Composite International Diagnostic Interview – Substance Abuse Module (CIDI-SAM), and quality of life as measured by the European Quality of Life scale (EQ-5D). Participants were assessed at baseline and 3 months, unless they exited the study early in which case they undertook an exit assessment. Participants were mostly male (SDM=73.9%; control=70.6%) and had mean ages of 40.8 years (SD=10.6) in the SDM group and 40 years (SD=11.1) in the control group. The main type of substance abuse was alcohol abuse (SDM=53.6%; control=52.3%) and polysubstance abuse (SDM=26.4%; control=32.7%). At three months, all participants had reduced levels of substance use and addiction severity, and increased quality of life. Those in the SDM group had significantly improved ratings on the drug use and psychiatric problems subscales on the EuropASI. These data demonstrate an 'add-on' value of a SDM intervention compared with an already effective treatment as usual control condition.

Due to the small number of SDM-specific interventions tested using high-level methodological approaches, non-randomised SDM intervention studies will now be discussed, before consideration of SDM-related intervention trials assessing the effect of treatment preference and involvement of clients.

Non-randomised studies of DAs and SDM interventions

There have been a number of DAs and SDM interventions that have been described or evaluated in study designs other than RCTs. Deegan and colleagues (179-181) have developed an online, computer-based SDM program that operates out of the waiting room at a medication clinic for clients with 'serious mental illnesses'. A pilot study has been reported, which included both analysis of intervention uptake and focus groups with stakeholders. The program aimed to enhance the existing standard 15-minute consultation with medical staff that clients have at the service. The intervention involves a 30-minute session with a peer support worker assisting the client to use CommonGround, a web-based SDM program, prior to the medical appointment. This was done in the waiting room of the service and after completing CommonGround modules and surveys a report was generated for use in the medical consultation. This report included SDM related information, such as consideration of client preferences and values, and allowed this to be included in the session despite the short duration of the medical appointment. Focus groups were conducted with medical staff (n=4), clients (n=16), case managers (n=14) and peer staff (n=3) (181). These data showed that, from the perspective of the clients and staff, the intervention had increased efficiencies within the medical consultation and had increased the level of client involvement in treatment decision-making. At the time of the pilot testing, 189 clients had used the software, resulting in 662 reports (1-10 per person, depending on number of appointments). More recent service use data reveal that the software has since been used with 4,783 clients across 8 sites (180), confirming the feasibility of the intervention. A randomised controlled trial is underway, however results have not been reported.

Also in the US, the Dartmouth Decision Support Centre is an online hub of tools dedicated to supporting a variety of decisions faced by people with mental disorders (182). The tools available on the Centre have been developed with a generic software program that also allows for the development of further resources. As such, it allows for a continually expanding set of resources and also functions as a resource for researchers and service providers who wish to develop new decision support tools such as DAs. Additionally, the tools that have been developed cover not only specific DAs for treatment decision making, but also tools related to health and lifestyle decisions often faced by psychiatric populations such as smoking cessation and exercise plans. The Centre is part of a partnership dedicated specifically to SDM that exists between the academic-based *Dartmouth Psychiatric Research Center* and *Thresholds Rehabilitation*, a health care service providing psychiatric care in the US (183).

Using a slightly different approach, the Right Question Project for Mental Health (RQP-MH) developed an intervention designed to activate and empower patients from ethnic minorities to ask their healthcare provider questions that result in a more inclusive decision-making process (184, 185). The intervention was tested in a controlled clinical trial with participants from an intervention mental health service (n=141) and participants from a control mental health service (n=90) (184). Additionally, qualitative interviews with participants from the experimental site were conducted in order to further evaluate the intervention (185). The RQP-MH involved two, four-hour training workshops for clinicians, who also had access to ongoing consultation, and three educational sessions for clients that focussed on developing three core skills:

> (a) identification of important decisions and issues about their mental health care;
> (b) question formulation around these decisions and issues; and:
> (c) revision and refinement of questions to lead to more informed decision making about their mental health care and to facilitate communication with the provider so that the communication highlights their needs ((185) p.141).

Clients in the intervention group were predominantly female (78.7%), were mainly aged 35-49 years old (44.7%) and a large majority of clients identified as being Latino (83.0%). Clients in the control group were also predominantly female (83.3%) and Latino (75.6%), however there was a more even spread of age ranges represented. The primary outcome measures were changes in self-reported client 'activation' (e.g. taking action to improve your own mental health; as measured by the Patient Activation Scale) and empowerment (as measured by the Empowerment Scale), treatment attendance and retention in treatment, for which retention was considered to be four or more visits in the six month follow up period. Participants in the RQP-MH intervention group were more than twice as likely to remain engaged in treatment and had 29% higher attendance rates to appointments when compared with the control group. The intervention had a positive effect for self-rated participant activation, but not for empowerment.

Lastly, there have been two DA libraries that have been tested, both of which include one DA for depression. The first, 'Arriba-lib' in Germany, evaluated an electronic library of six DAs in primary care with 29 clinicians and 192 clients (186). Participants were asked to complete a questionnaire after the treatment decision-making consultation and partake in an interview two months later. There were high rates of client satisfaction and willingness to use the library in the future. There were also high rates of congruence between the preferred level of involvement in decision-making and perceived involvement, and 80.7% of clients implemented the decision outcome. Although these results are impressive, only a very small proportion of participants used the depression DA. An initial evaluation of a DA from the second DA library in Spain has demonstrated that the DA for hip or knee osteoarthritis reduced decisional conflict, however the depression DA is yet to be evaluated (187).

Evaluation of collaborative care models

Despite there only being four RCTs testing interventions specific to SDM and the use of DSTs, there have been a number of efforts in recent years that have taken a person-centred approach to interventions for depression and other mental disorders. Most collaborative care models (CCMs) in the US, for example, have incorporated patient-centred decision-making processes and have been demonstrated to improve clinical outcomes such as adherence to medication, depression severity, quality of life and client satisfaction (188). CCMs have largely been tested in adults and individual studies on adults will not be presented here; however, a small number of studies have been reported in young people diagnosed with MDD (146, 147, 189, 190). Of the three studies located, one did not involve client choice as part of the intervention (189) and so was not included in the current review.

A small uncontrolled, pre-test/post-test, pilot study was conducted testing a CCM based on an intervention designed for older adults and adapted for young people 12-18 years being seen in primary care (190). The 6-month intervention included client choice of treatment with input from caregivers, and was found to be acceptable to young people, their caregivers and physicians, and depression scores improved for the majority of participants.

The Youth Partners in Care (YPIC) study (146, 147) was a randomised controlled trial that compared a 6-month CCM intervention with usual care in five service settings that included managed care, public sector and academic medical clinics. 418 young people aged 13-21 (mean age 17.2 years; SD=2.1) were enrolled in the trial; 211 were randomised to the CCM intervention and 207 received usual care. 78% were female and all participants had current depressive symptoms; 42.6% had a diagnosable depressive disorder (42% MDD) and 57% had subthreshold depression. There were no significant differences between the groups at baseline. The intervention involved expert leader teams, case managers who supported primary care clinicians, CBT training, and professional development around depression evaluation and management. Additionally, as part of the CCM intervention, participants were informed about, and involved in, making decisions about treatment options. The primary outcome measure was depressive symptoms, and secondary outcome measures were mental health related quality of life and satisfaction with mental health care. Participants were followed up at 6-, 12- and 18-months. Similar to results of studies with adults, the 6-month intervention significantly improved depression severity, quality of life and client satisfaction when compared with treatment as usual. Although there was a trend for continued benefit of the intervention in terms of reduction of depressive symptoms at 18-months, statistical significance was not attained (p=0.06). There was also a trend in favour of the intervention group in terms of time to recovery (on average they recovered 27 days sooner than the control group), however this result also failed to reach statistical significance. The results from these studies offer insight into the effects of CCMs, although it is difficult to tease apart the contribution of the patient-centred elements. Therefore, the effects of the SDM-type behaviours and practices are unknown.

SDM components: effect of accounting for treatment preference

In terms of evidence for SDM-related behaviours, a number of RCTs of treatment interventions for depression have also considered the effect of affording clients treatment preference has been studied in. In a RCT of antidepressant medication compared with counselling in 31 general practices in the UK (101, 191), adult participants with mild-to-moderate depression who refused randomisation, but consented to research, were included in patient preference arms, which resulted in four arms: those randomised to medication (n=51); those randomised to counselling (n=52); those who chose medication (n=80); and those who chose counselling (n=140). Participants were mostly female (74-77% across groups), had a mean age of 36.4 (SD=10.1) to 38.1 (SD=12.7), and mainly had moderate levels of depression (62-78%). There were no significant differences between the groups at baseline, however for those who were offered treatment choice, the majority (63.6%) chose counselling over medication. The main outcome measure was response defined as a reduction of five or more points on the Beck Depression Inventory (BDI) and secondary measures included the Eysenck Personality Inventory, the SF-36 (a self-report measure of disability) and attitudes toward treatment, including measures of client satisfaction. Participants were followed up after 8 weeks of treatment and again at 12 months. There were no differences between any of the groups at 8 weeks, and 69% of all participants no longer met the inclusion criteria, which was assessed using the Research Diagnostic Criteria for major depression. Those who chose counselling attended more sessions than those who were randomised, however this did not result in better outcomes in terms of depression severity or satisfaction. At 12 months, 83% of participants who had a known outcome achieved remission. Those who chose counselling had significantly lower scores on the BDI than those who were randomised, with a mean difference in BDI scores of 4.6 (range of mean group differences=0-9.2).

In a large scale RCT involving 73 general practitioners from 24 general practices in the UK, 197 adults with depression or comorbid depression and anxiety disorders were randomised to receive usual care, CBT, or non-directive counselling (192-194). An additional 130 participants were randomly assigned to either CBT or non-directive counselling only, and a further 137 participants chose their treatment option. Of these 137 participants, 2 chose general practice contact only (i.e. no active treatment), 82 chose CBT and 54 chose non-directive counselling. Both psychotherapy interventions involved a minimum of six and maximum of 12 sessions. Primary outcome measures included depression as measured by the Beck Depression Inventory, other psychiatric symptoms, social functioning and satisfaction with treatment. Participants had a mean age of 37 years (SD=12.2), were predominantly female (75%) and most had been diagnosed with MDD (62%). Participants were followed up at 4- and 12-months. Both of the psychological interventions significantly reduced depressive symptoms (BDI mean scores 4-5 points lower for the intervention groups, described as clinically significant) when compared with usual care. By 12- months this difference no longer remained. There was no benefit at either time point for those who chose their treatment option when compared with those who were randomised. The only effect seen in the treatment preference groups was that those who chose non-directive counselling were more satisfied at 12-months than those who chose CBT.

In a single site RCT comparing medication (sertraline) (n=83) and placebo (n=83), as well as group CBT (n=61) and guided self-help (as a control condition for the CBT; n=59), a fifth arm was included whereby participants chose between the two active conditions (i.e. sertraline or group CBT; n=82) (195, 196). In doing so, preference was tested in a randomised sample, rather than in those who refused randomisation. All treatment arms were of 10 weeks duration. The study, conducted at a dedicated research centre in Germany, took referrals from primary care of adults with subthreshold or established MDD. The primary outcome measure was a global measure of efficacy based on z-converted scores from the Hamilton Rating Scale for Depression and the Inventory for Depressive Symptomatology. All randomised participants were also asked whether or not they had been allocated their treatment of choice. The mean age of participants was 46.4 years (SD=14.6), 68.2% were female, and the main diagnoses were dysthymic disorder with a current MDE (41.3%) and MDD (30.7%). After ten weeks of treatment, the active conditions were both significantly better than their respective control groups in terms of depression severity. Those in the patient choice arm achieved results in line with the active treatment groups, i.e. performed better than placebo but not better than those randomised to active treatments. At 12 months, a subgroup analysis was done on those randomised to the active treatment groups (sertraline and group CBT). Participants from these groups were divided according to whether or not they have received their preferred treatment option. Those who had preferred and received CBT scored on average eight points lower on the HAMD-17 than those who did not receive it, and those who preferred sertraline and received it scored on average 2.9 points lower on the HAMD-17 than those who did not receive it. Both results represented a statistically significant improvement in depression scores for those receiving preferred treatment compared to those who did not.

A RCT testing a CCM in older adult primary care patients diagnosed with MDD measured the treatment preference of all participants at baseline and compared this with the treatment they actually received (197). As part of the CCM, which was compared with usual care, "when possible" (p. 166) participant treatment experiences and preferences were accounted for. Participants were assessed at baseline, 3 months and 9 months, and main outcome measures included disease burden (Chronic Disease Score), attitudes and beliefs about depression, functioning (SF-36), depression severity (Hopkins Symptom Checklist – depression scale), disability (Sheehan Disability Scale), changes in health outcomes, treatment preference, treatment received and treatment preference match. The vast majority of participants were male (95-96%), had mean age scores of 55.2 (SD=13.4) – 64.4 (SD=11.1) years, and were diagnosed with MDD, dysthymia or both. After controlling for baseline depression scores, participants who received their preferred treatment had significantly improved depression scores at 3 months follow up. Not only was the difference statistically significant, but the mean difference in depression scores was also deemed to be clinically significant. At 9 months, however, the participants who did not receive their treatment preference had 'caught up', and had improved at the same rate as the preference-concordant group, meaning that there was no longer a significant difference in depression scores. Those in the CCM intervention group were more likely to receive their preferred treatment option.

Another study considered the effect of treatment preference concordance on therapeutic alliance (198). In a RCT with three treatment arms lasting 16 weeks each (supportive-expressive therapy (SE), sertraline and placebo), 75 adult participants diagnosed with MDD were asked to state their preference for treatment prior to randomisation. Other outcome measures included therapeutic alliance as measured by the California Psychotherapy Alliance Scale (CALPAS) and depression severity as measured by the Hamilton Rating

Scale for Depression (HRSD). Participants were assessed at baseline, 3 weeks, 5 weeks and 9 weeks. 53% of participants were female and the mean age was 40 years (SD=12.7). Participants who received preference-concordant psychotherapy had significant increases in therapeutic alliance over time, and those who preferred psychotherapy yet received medication or placebo had significant decreases in therapeutic alliance over time. For those participants who stated a preference for medication, there was no effect on therapeutic alliance regardless of what treatment arm they were randomised to.

SDM components: client involvement

In a study investigating the effect of client involvement in treatment decision-making, data were analysed from the Quality Improvement for Depression (QID) study, which aimed to test quality improvement strategies for treating depression in primary care (118). Data from 1706 participants were included; participants were predominantly women (74%), aged 18-50 (69%) and had mean baseline scores on the Center for Epidemiologic Studies – Depression (CES-D) scale of 48 (SD=21), on which a score >20 signifies a likely diagnosis of depression. Participants were asked to rate their level of involvement in treatment decision-making on a scale of one to five, with one equating to poor involvement and five equating to excellent involvement. Other outcome measures (assessed every six months for two years) included depression severity (as measured by the CES-D) and participant report of guideline concordant care. For each 1-point increase on the scale of participant involvement in treatment decision-making, the probability of receiving guideline concordant care and experiencing resolution of depressive symptoms significantly increased.

Swanson and colleagues (199) also examined data from the QID study with specific consideration of SDM and receipt of mental health care. Data from 1,317 participants diagnosed with MDD were included in this cross-sectional analysis, which is the number of participants who completed both a baseline and six-month follow-up questionnaire. The outcome measures of interest for this analysis included satisfaction with overall health care, satisfaction with mental health care and receipt of quality mental health care. SDM was measured using a self-rated five point Likert scale, ranging from poor to excellent, with three items: 1) involvement; 2) choice of treatment; and 3) explanations of your health problems. Additional outcomes included social support, health status, depression severity and alcohol use. The demographic details of participants were similar to the QID sample described above. Participants' mean rating of clinicians' SDM provision was 3.3 out of five, where a rating of five was a score of excellent. Both SDM and receipt of mental health care were significant predictors of client satisfaction at six months.

SDM in youth mental health

Although the current review highlights a lack of intervention studies in the area of youth mental health, several developing studies have been located and will be described here. In the United Kingdom, an implementation study of SDM in four Child and Adolescent Mental Health Services is underway ('Closing the Gap: Shared Decision Making in CAMHS'; (200)). Each site will have support to incorporate SDM practices in their respective service, with some flexibility allowed around the type of model employed in order to maximise the chances of successful implementation. The multifaceted and adaptable intervention will be evaluated in terms of impact on engagement (e.g. attrition rates), time to improvement, clinical outcomes, uptake of evidence-based treatment options, and satisfaction levels. Recruitment for the project is due for completion by the end of 2013. In a youth-led initiative, a Canadian organisation specialising in youth mental health, Mobilizing Minds (201), has commenced a 5 year national study that aims to develop a suite of resources to support the provision of information and treatment decision making in order to facilitate help-seeking, increased mental health literacy and SDM. The project is led by a range of stakeholders including young adults who are responsible for guiding all aspects of the study. The DAs and other resources resulting from the study will be disseminated nationally at the conclusion of the project. Another team from Canada have developed a package of resources called 'Med Ed', which include informative and practical tools designed to support decision making and facilitate involvement of young people in their own care (202). The package is yet to be evaluated. Lastly, in the United States a group of social workers and researchers have developed an evidence-informed framework for the foundation of YSDM

(164, 203). The framework emphasises the need to ensure that meaningful involvement occurs and accounts for the varying levels of involvement that caregivers have for this age range. From this framework, a number of tools designed to facilitate SDM have been developed and are currently being pilot tested.

Discussion

The current review considered the evidence for shared decision making in youth mental health and related areas. A limitation of the present review is that the number of articles included and excluded at each stage was not recorded. Another limitation is that the review was not systematic. Despite this, it adds to an existing systematic review (173) by reviewing including non-randomised trials and evidence for SDM behaviours.

The use of DAs to facilitate SDM in non-psychiatric care has been shown to improve knowledge, reduce decisional conflict, reduce levels of passive involvement and help people to make decisions rather than remain undecided. There has been a recent increase in calls for the consideration of SDM for mental health areas and the purpose of this review was to assess the current evidence for this. Existing levels of SDM were considered first, and subjective reports from psychiatrists suggested that they would employ a SDM-type approach approximately half of the time, but that they were unlikely to do so if they deemed the client to have impaired decisional capacity or if the decision was of either a medical or legal nature (165). Subjective reports from clients were somewhat mixed, with 70% of one client group reported having received a SDM-type approach (167), whereas another stated that they had received very little information, had been given no treatment choice nor been involved in treatment decision making (166). This second account is supported somewhat by objective assessments of consultations that revealed very low levels of SDM behaviours across three studies (169-171).

With the potential for improving such low levels, four cluster RCTs testing SDM interventions have been conducted for adults diagnosed with MDD (174), schizophrenia (175, 176), severe mental illness (177) and substance use disorders (178). All interventions demonstrated effectiveness for at least one key outcome, including increased involvement, knowledge, client or clinician satisfaction, and improved drug use and psychiatric problems. Inconsistencies with the outcomes measured mean that it is difficult to compare outcomes across studies or trials across disorders. It appears that clinician and client satisfaction, adherence to treatment, length of consultation, symptom severity and other factors related to decision making (e.g. level of perceived involvement, information retained from treatment decision making session) need to be measured more thoroughly and consistently in such trials in order to gain a thorough understanding of the effectiveness of SDM interventions. No studies were identified that tested a SDM intervention for youth depression or youth mental health in general.

Due to the small number of SDM-specific intervention studies found, non-randomised studies were also considered. Several programs have been developed and either evaluated or pilot tested, including two online decision support centres (179-182), two DA libraries (186, 187) and a training program to encourage clients to ask effective questions during clinical consultations (184, 185). Again, these programs show promise in the areas of increased involvement and satisfaction; however, they will need to be tested more thoroughly to demonstrate effectiveness for these outcomes.

Collaborative care models that afford clients involvement in treatment decision-making have been tested with young people diagnosed with MDD and are therefore particularly relevant to the current study. A small, uncontrolled pilot study demonstrated acceptability and improved depression scores (190), and a larger RCT demonstrated significantly improved depression scores, quality of life and satisfaction in the short-medium term (146, 147).

Giving clients what they want in terms of treatment preference for depression appears to have a different effect depending on what treatments are on offer. If counselling and antidepressant medication are options, then most clients will choose counselling and those who choose counselling are more likely to attend sessions and have improved therapeutic alliance, satisfaction and depression scores (101, 191, 195, 196). If clients are given a choice of different psychological therapies, then it is possible that satisfaction will be increased, but not other outcomes (192-194). Importantly, for clients who prefer psychological therapy but are only offered medication, it is likely that therapeutic alliance will be negatively affected, something not seen in clients who prefer medication but are only offered psychological therapy. Additionally, greater involvement by clients in their own treatment (including treatment decision making) increases the chances of receiving guideline-concordant care and being more satisfied (118, 197-199).

The majority of research in this area has been conducted with adults, yet the advocacy of SDM in the area of youth mental health has resulted in several large studies being undertaken (200-202). These studies are in their infancy and forthcoming results will offer some insight into the merit of this interest. Evidence from both adult populations and CCMs for young people diagnosed with MDD, however, appears promising for the potential effects of SDM for young people, particularly in the area of depression treatment decision making. Given that the majority of high quality evidence for SDM in mental health for adults is based on interventions that include a DA, and based on the interview data from chapters 4 and 5 (i.e. that clients, caregivers and clinicians want informative and interactive resources to support decision making), a DA for young people diagnosed with MDD was developed and this development process will now be presented in chapter 7.

Chapter 7: Development of a decision aid for young people aged 12-25 years with moderate to severe depression who are facing a decision about what treatment option is best for them

Introduction

Chapters 4 and 5 presented interview data from clients, caregivers and clinicians about their beliefs and experiences of treatment decision making for young people diagnosed with MDD. These data highlighted four important aspects of the decision-making process: 1) although a collaborative model was important to clients, caregivers and clinicians alike, experiences of this varied; 2) clients were not asked explicitly about their preference for involvement; 3) the caregiver's role in decision-making processes should be dependent on the preferences of the young person and existing caregiver involvement; 4) there is a significant gap in the availability of high quality, evidence-based, unbiased, youth friendly, interactive, web-based information resources to support the decision-making process. In response to this, the evidence for DAs that facilitate SDM, and other related literature, was reviewed in chapter 6. Although SDM for mental health is an emerging field, with a small number of new studies recently commenced in the field of youth mental health, there is no publicly available DA for young people diagnosed with MDD. Given the high prevalence rate and potential negative outcomes of experiencing depression in adolescence as discussed in chapter 1, a tool that facilitates engagement in evidence-based treatment was considered. This next phase of the current study aimed to develop a DA for young people diagnosed with MDD facing a decision about treatment options. This chapter is broken into two sections: phase one describes the initial development process of the DA, whereby the DA was prepared for field-testing; and phase two presents the results of the field-testing, which completes the development process.

Phase one: Developing the DA for field-testing

Theoretical framework of the DA

DAs have been developed on the basis of several relevant theories. Many DAs are based on more than one theory, and such an approach is necessary due to the complex nature of the decisions being addressed, as there is not one single theory that can account for all of the factors related to the decision-making scenario faced by clients (204). Such theories include decision analysis (205); theory of reasoned action (206) (which was later extended into the theory of planned behaviour (207)); conflict theory (conflict model of decision making) (208); expectancy value theory (expectancy value model) (209); and prospect theory (framing bias theory) (210) (see Box 1. for brief descriptions). These theories have influenced the development of a range of documents that have been designed to inform the development of DAs, including the *Ottawa Decision Support Framework* (ODSF) (211) and the related *Workbook on Developing and Evaluating Patient Decision Aids* (212) (described below), as well as the *International Patient Decision Aids Standards* (158) (IPDAS; discussed in chapter 6 and below) and the *'International Patient Decision Aids Standards instrument'* (159) (IPDASi). The IPDASi is a valid and reliable measure for assessing the quality of DAs based on the IPDAS. Given that this sets the bar in terms of standards of quality for DAs, it was used to guide the development of the current DA. The IPDASi also allows for the systematic incorporation of relevant theories (including those mentioned above). In addition to such theories, or where there is no theory to guide an area of DA development, empirical evidence is used. Many of the items in the IPDASi reflect an element of relevant theory that has informed the area of DAs. For example, prospect theory (210) purports that the way in which options are framed (e.g. in terms of relative gains or losses) influences the likelihood of individuals choosing certain options, and also the consistency in how individuals make choices. This is reflected in the IPDASi item 8 of the 'probabilities' section, which states that the DA should provide "balanced information about event or outcome probabilities to limit framing biases" ((159), p.e4705). Rather than use one single theoretical framework, the IPDASi was used as a way in which to incorporate all relevant theories and empirical evidence. The process for how the IPDASi items were used to develop this DA is described later in this chapter.

Box 1. Brief description of examples of theories relevant to the development of decision aids.

Decision analysis (205)

Decision analysis is an overarching term for a set of theoretically-based procedures related to the identification, representation and assessment of factors related to decision making. A common application of decision theory is the use of decision trees, which are comprised of decision nodes (e.g. available treatments); chance nodes (e.g. probability of potential outcomes); and end nodes (e.g. remission). In doing so, decision trees allow the decision maker to see a visual representation of the likely outcomes for each available choice.

Theory of reasoned action (206)

The theory of reasoned action purports that an individual's *attitudes* (e.g. an individual's attitudes towards antidepressant medication) and *subjective norms* (e.g. an individual's perceptions of what other people will think about antidepressant medication) will predict their *behavioural intention* (e.g. whether or not an individual intends to choose antidepressant medication as a treatment choice), which in turn results in whether or not they follow through with that behaviour (e.g. whether or not an individual takes antidepressant medication).

Conflict model of decision making (208)

Influenced by both social psychology and information processing, a conflict model of decision making focuses on the influence of psychological aspects, such as stress, on the processing of information and making decisions. The model proposes that the degree to which an individual feels stressed about a decision will determine how fully they engage in decision-making processes, which will consequently influence how satisfied or conflicted they feel about the decision made.

Expectancy value theory (expectancy value model) (209)

There are three main tenets of the expectancy value model: 1) that when confronted with a novel stimulus or information about that stimulus (e.g.

information about the potential benefits of CBT), a person will develop a belief about this stimulus (e.g. that CBT can help to overcome depressive symptoms); 2) that a person will then place a value on the related attributes of this belief (e.g. a reduction in depressive symptoms is valued highly by the person); and 3) that this results in an expectation of the person, which is based on such beliefs and values (e.g. the person expects to get better and feel good as a result because they value the prospect of experiencing less depressive symptoms). Expectancy value theory has been used to develop further theories, such as the theory of reasoned action, which in turn was used as the basis for the theory of planned behaviour.

Prospect theory (framing bias theory) (210)

Prospect theory focuses on the context in which information relevant to decision making (e.g. probability of positive and negative outcomes) is presented, particularly when the outcomes are unknown and there is some chance involved. One main principle of prospect theory is that potential negative outcomes (i.e. losses) are more influential on decision-makers than potential positive outcomes (i.e. gains). This theory is particularly relevant to treatment decision making and risk communication because of the different ways in which potential outcomes can be conveyed (e.g. relative risk vs. absolute risk).

Initial development process

Each of the main documents that have been developed to guide the construction of DAs (described above) was used to inform the content, design and formatting of the DA for youth depression as it was drafted in preparation for field-testing (see figure 1 for the development process overview). Before going on to describe the way in which these resources informed the development of the DA, each resource will first be described briefly.

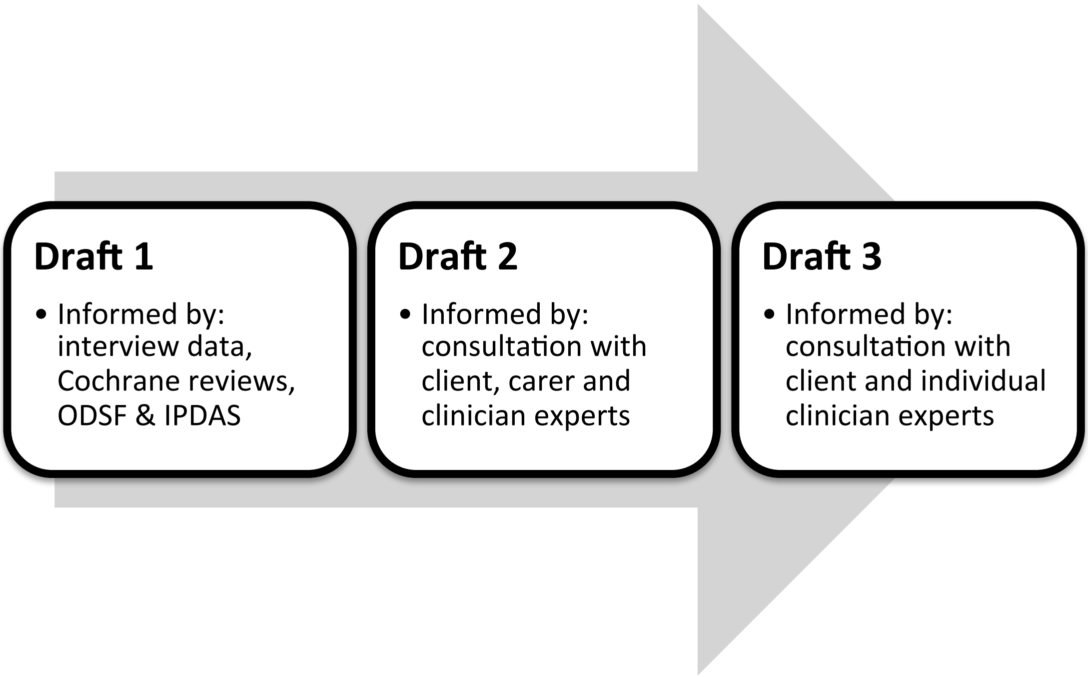


Figure 1. Overview of the development process of the decision aid.

Resource 1: The 'International Patient Decision Aids Standards' (IPDAS) and the 'International Patient Decision Aids Standards instrument' (IPDASi)

The IPDAS (158) have 49 items across two domains that are relevant to the development of the current DA: Content (n=23 for treatment decisions) and Development Process (n=26 for this type of DA). The IPDAS also have a domain for the effectiveness of DAs, and extra items for DAs that include personal stories, and those that are for individuals facing decisions about screening tests. These will not be discussed here. The IPDASi (159) is a measure that assesses the extent to which a DA meets the IPDAS criteria. The IPDASi has 47 items across 10 domains. In preparation for developing the DA, the author attended 'Designing decision support for shared decision making', a training workshop preparing participants to use the IPDASi, run by leading experts in the field, including authors of the IPDAS and IPDASi (held at Schiphol Airport, Amsterdam on Friday 3rd April 2009; hosted by Cardiff University and Decision Laboratory).

Resource 2: The 'Ottawa Decision Support Framework' (ODSF) and 'Workbook on Developing and Evaluating Patient Decision Aids' ('Workbook')

The ODSF is an "evidence-based, practical, mid-range theory for guiding patients making health or social decisions" ((211), no page number). It describes a range of principles that should guide the development of DAs, with three specific steps about how to implement these principles. Two of the three steps of the ODSF were relevant to the development stage of the current DA: 1) identifying decision support needs; and 2) providing decision support that is tailored to the needs of clients. The third step, evaluation of the DA, was outside the scope of the current project, although some evaluation measures from this step were used for the field-testing (see below). The *Workbook* is a guide to developing decision support tools that follows the principles of the ODSF.

Resource 3: Interview data

Interview data from clients, carers and clinicians about their experiences and beliefs about treatment decision making for young people diagnosed with MDD (as presented in chapters 4 and 5) formed the basis of the original content and design of the DA.

Resource 4: Systematic Reviews

A search of the literature was conducted to locate systematic reviews and meta-analyses of studies testing the effectiveness of relevant treatment options (as described in clinical guidelines, i.e. SSRIs and CBT). Additionally, results of unpublished updates of existing Cochrane systematic reviews (e.g.(41)) and new Cochrane reviews (e.g. (213)) were discussed with the review authors in order to locate any relevant new papers. As a result, it was confirmed that the Treatment for Adolescent Depression Study (TADS, as discussed in chapter 1) is the only study yet to compare fluoxetine, placebo, CBT, and combination treatment (fluoxetine and CBT) in a RCT.

Resource 5: Consultations with medical experts

Medical staff from OYH and headspace provided consultation in two different ways. Firstly, initial and overall responses to the DA were derived from the discussion and feedback of clinicians who were present when the DA was presented at a number of staff meetings. Secondly, four psychiatrists from OYH and two GPs from headspace individually provided further detailed comments in person during formal consultation on the design, content and format of the DA as drafts were progressed. Example paper-based decision aids were used during both of these processes, and detailed notes were taken; however, no formal analysis was undertaken on these notes.

Resource 6: Consultations with consumer experts

Two consumer reference groups provided feedback on drafts of the DA. The headspace Youth National Reference Group (hY-NRG) was comprised of past and present clients of the headspace centres around Australia. The group met for two days at regular intervals in Melbourne in order to work on local and national projects that promote youth participation. Additionally, they provided consultation to external projects such as the current one. Because of this model, all hY-NRG members were usually present at any given meeting, and indeed all 16 members provided feedback on the DA. On the other hand, the youth reference group from OYH, the Platform team, had a larger number of members, of which a smaller number could choose to attend consultations for any given project. Platform members who had previously faced the same decision as presented in the DA were asked to attend. As such, nine Platform members provided consultation on the development of the DA. Each team was consulted in person. Examples of paper based DAs were presented to each group and questions were asked informally about the content, design and functional aspects of the DA. Detailed notes were taken, however no formal analysis was conducted on these notes.

Resource 7: Consultations with caregiver experts

OYH has several 'carer peer support' workers, who are, or have been, caregivers for a client of OYH. Their role within the service is to call caregivers, who have been identified by clients, in order to provide support and advice about the service, information sources and to provide general support for the caregiver themselves during what can often be a confusing and distressing time. As such, they have a solid understanding of the concerns that a broad range of caregivers have. Additionally, the carer peer support workers provide consultation to projects such as the current one where caregiver involvement is relevant. Two carer peer support workers provided feedback for the DA development process.

Influence of resources on the DA

Table 1 describes the way in which the DA meets the requirements of the *'International Patient Decision Aids Standards instrument' (IPDASi)*. Situations where resources altered the design or content of the DA are also described.

Summary

The current phase of this study sought to develop an initial version of a DA in order to field-test it, a step that completes the development process. During the first phase three drafts were created, and it is the third draft that was used in the field-testing.

Table 1. A description of the way in which the decision aid fulfils the requirements of the *International Patient Decision Aids Standards instrument* (IPDASi).

Information: Providing information about options in sufficient detail for making a specific decision	
1. The decision support technology describes the health condition or problem (intervention, procedure or investigation) for which the index decision is required	• A description of depression was included in the first draft of the DA. • Feedback from youth reference groups and medical staff included that the DA was too long, too wordy, that the clients would be unlikely to read the description of depression and that it should be excluded. • Rather than exclude the description, a downloadable and printable fact sheet was instead included as a link on subsequent versions of the web-based DA. A printed fact sheet on depression was included in the information pack that accompanied the paper-based version of the DA.
2. The decision support technology describes the decision that needs to be considered (the index decision)	• The title includes a description of the decision that needs to be considered.
3. The decision support technology describes the options available for the index decision	• The 'Treatment' section of the DA describes the available treatment options. • In the first draft of the DA, written

	descriptions were also included in the text of the DA. Feedback from youth reference groups and medical staff included that the DA was too long, too wordy, that the clients would be unlikely to read the descriptions of the treatment options. • In subsequent versions of the DA, downloadable and printable fact sheets on CBT and antidepressant medication were included as links on the web-based DA and as printed fact sheets in the information pack that accompanied the paper-based version of the DA.
4. The decision support technology describes the natural course of the health condition or problem, if no action is taken.	• One of the treatment options included is to ‘do nothing’, thereby integrating the comparison between treatment and no treatment within the area of risk communication.
5. The decision support technology describes the positive features (benefits or advantages) of each option	• The potential benefits of each treatment option are described in the ‘Getting Better’ section of the DA.
6. The decision aid describes negative features (harms, side effects or disadvantages) of each option.	• The potential risks of each treatment options are described in the ‘Side Effects’ section of the DA.
7. The decision support technology makes it possible to compare the positive and negative features of the available options.	• Printable charts are available on the web-based version of the DA (on the pages ‘Getting Better’ and ‘Side Effects’) and as appendices to the paper-based version of the DA, which allow direct comparison of the potential risks and benefits.
8. The decision support technology shows the negative and positive features of options with equal detail (for example using similar fonts, order, and display of statistical information).	• Both the potential benefits and risks in the DA were presented in the same font style, colour and size (including any highlighting), in the same order and using the same formatting for statistical presentation.
Probabilities: Presenting outcome probabilities	
1. The decision support technology provides information about outcome probabilities associated with the options (i.e. the likely	• These probabilities are presented in the ‘Getting better’ and ‘Side effects’ sections of the DA.

consequences of decisions)	
2. The decision support technology specifies the defined group (reference class) of patients for which the outcome probabilities apply.	• This is detailed on the home page of the web-based version of the DA and on the cover of the paper-based version of the DA (identical to the home page).
3. The decision support technology specifies the event rates for the outcome probabilities (in natural frequencies).	• Natural frequencies (absolute risks) were used for both the percentages and graphs in the DA.
4. The decision support technology specifies the time period over which the outcome probabilities apply.	• The time period is specified for both the percentages and graphs in both formats of the DA.
5. The decision support technology allows the user to compare outcome probabilities across options using the same denominator and time period.	• The same denominator and time period are used for both the percentages and graphs in the DA.
6. The decision support technology provides information about the levels of uncertainty around event or outcome probabilities (e.g. by giving a range or by using phrases such as ''our best estimate is…'')	• Variations on the following text is included in both the 'Getting Better' and 'Side Effects' sections of the DA: "We can't tell you exactly what will happen for you – the numbers are based on research and tell you your CHANCE of getting better."
7. The decision support technology provides more than one way of viewing the probabilities (e.g. words, numbers, and diagrams).	• Percentages, natural frequencies and graphs are presented in the DA. • Youth reference groups reported that they preferred percentages and natural frequencies to graphs, however the graphs are included as downloadable and printable PDFs in the web-based DA, and as appendices in the paper-based DA to cater for different preferences. The use of percentages is supported by recent evidence (214, 215).
8. The decision support technology provides balanced information about event or outcome probabilities to limit framing biases.	• The information for both the potential benefits and risks of each treatment option is presented in a balanced way (e.g. same font, size and colour; graphs are the same colour and size). Where information is unavailable (e.g. potential risks of CBT, this is made clear).
Values: Clarifying and expressing values	

1. The decision support technology describes the features of options to help patients imagine what it is like to experience the physical effects.	- There are 21 possible side effects described and the potential benefit (i.e. improvement in depressive symptoms) depends on the individual and their initial experiences of depression. For these reasons, consumer reference group members felt that this criterion should be represented in the 'What matters to you' section rather than as descriptions in and of themselves. E.g. 'What side effects will I have?'
2. The decision support technology describes the features of options to help patients imagine what it is like to experience the psychological effects.	- There are 21 possible side effects described and the potential benefit (i.e. improvement in depressive symptoms) depends on the individual and their initial experiences of depression. For these reasons, consumer reference group members felt that this criterion should be represented in the 'What matters to you' section rather than as descriptions in and of themselves. E.g. 'Will therapy change the way I think about things?'
3. The decision support technology describes the features of options to help patients imagine what it is like to experience the social effects.	- There are 21 possible side effects described and the potential benefit (i.e. improvement in depressive symptoms) depends on the individual and their initial experiences of depression. For these reasons, consumer reference group members felt that this criterion should be represented in the 'What matters to you' section rather than as descriptions in and of themselves. E.g. 'Will people know that I am taking medication?'
4. The decision support technology asks patients to think about which positive and negative features of the options matter most to them.	- Based on the interview data and relevant literature, an interactive values clarification tool was included in the first draft of the DA. In subsequent consultations, however, clients reported that they would be unlikely to use it. Instead, they wanted the questions listed in the 'What matters to you' section, so

	that they could tailor discussions with their clinicians. The title of the section tries to encourage clients to consider the questions most relevant to their concerns.
Decision Guidance: Structured guidance in deliberation and communication	
1. The decision support technology provides a step-by-step way to make a decision.	• The DA is sequential and tries to eliminate decisional conflict on the last page.
2. The decision support technology includes tools like worksheets or lists of questions to use when discussing options with a practitioner.	• A list of questions is included in the 'What matters to you?' section.
Development: Using a systematic development process	
1. The development process included finding out what clients or patients need to prepare them to discuss a specific decision	• This was achieved by conducting interviews with clients and caregivers as reported in chapters 3 and 4.
2. The development process included finding out what health professionals need to prepare them to discuss a specific decision with patients	• This was achieved by conducting interviews with clinicians as reported in chapters 3 and 5.
3. The development process included expert review by clients/patients not involved in producing the decision support technology	• Youth reference groups and carer peer support workers were consulted before and during the drafting of the DA, providing expert consultation in terms of the content, design and format of the DA. None of these individuals were involved in producing the DA.
4. The development process included expert review by health professionals not involved in producing the decision aid.	• Medical professionals were consulted before and during the drafting of the DA, providing expert consultation in terms of the content, design and format of the DA. None of these individuals were involved in producing the DA.
5. The decision support technology was field tested with patients who were facing the decision.	• The 3rd draft of the DA was field tested with clients from two different services in order to complete the development process, and feedback from this field-testing resulted in the fourth and final draft of the DA.
6. The decision support technology was field tested with practitioners who counsel	• The 3rd draft of the DA was field tested with clinicians from two different

patients who face the decision.	services in order to complete the development process, and feedback from this field-testing resulted in the fourth and final draft of the DA.
Evidence: Using evidence	
1. The decision support technology (or associated documentation) provides citations to the studies selected.	• Citations of the studies used in the DA are included in the 'Background Information' section of the DA.
2. The decision support technology (or associated documentation) describes how research evidence was selected or synthesized.	• A description of how the research evidence was selected is included in the 'Background Information' section of the DA.
3. The decision support technology (or associated documentation) provides a production or publication date.	• A publication date appears on the DA.
4. The decision support technology (or associated documentation) provides information about the proposed update policy.	• Information about the proposed update policy is included in the 'Background Information' section of the DA.
5. The decision support technology (or associated documentation) describes the quality of the research evidence used.	• The quality of the research evidence used is described in the 'Background Information' section of the DA.
Disclosure: Disclosure and transparency	
1. The decision support technology (or associated technical documentation) provides information about the funding used for development.	• Information about the funding used for the development of the DA is included in the 'Background Information' section of the DA.
2. The decision support technology includes author/developer credentials or qualifications.	• The qualifications of the developer of the DA are included in the 'Background Information' section of the DA.
Plain Language: Using plain language	
1. The decision support technology (or associated documentation) reports readability levels (using one or more of the available scales).	• The readability levels of the DA are included in the 'Background Information' section of the DA.

Phase two: Field-testing the DA

The third draft of the DA was field-tested in order to complete the development process, a step often either neglected or poorly described by developers of DAs (216). The purpose of this phase was to gain feedback from both parties using the DA (client and clinician[1]) as they were actually engaging in the decision-making process. Feedback from clients and clinicians was obtained in phase one, however this involved asking individuals to comment based on decisions they had made in the past. Given the dynamic nature of decision-making processes, the current field-testing aimed to acquire *in situ* responses to the usefulness and acceptability of the DA.

Aims

1. To determine the acceptability of the format, design and content of the decision aid.
2. To determine the usefulness of the decision aid with regard to the content (i.e. information provision) and function (e.g. helping to make a decision).

Methodology

Setting

All participants were from either one of two services: Orygen Youth Health (OYH) and headspace Barwon. As described in chapter 3, OYH is a specialist youth mental health service for young people aged 15-24 living in the northwest metropolitan area of Melbourne, Australia. headspace Barwon is an enhanced general practice service for young people aged 12-25 living in and around the satellite city of Geelong, 75kms southwest of Melbourne.

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[1] Although the DA was designed to be able to be shared with caregivers where appropriate (e.g. to fulfil their desire for extra information), caregivers were not involved as participants in this process. This decision was made based on the interview data (as described in chapters 4 and 5), which highlighted that caregivers are not usually involved as decision makers with this age group. The approach taken, therefore, was to obtain feedback from caregivers in phase one but not phase two.

Participants

Slightly different sampling methods were used at each service. At the OYH Youth Mood Clinic, where most clients would be eligible for the study, all four psychiatrists agreed to be participants should they successfully recruit one or more clients. At headspace Barwon, two GPs who were most likely to see clients eligible for the study were nominated by the clinical coordinator, and agreed to participate should they successfully recruit one or more clients. All eligible clients were asked by their psychiatrist or GP respectively to participate in the study, and all clients approached agreed to do so, although one client failed to attend the scheduled appointment. In total, three clinicians and five clients participated in the field-testing of the DA.

Inclusion criteria

1. Young people aged 12-25 years old who have been diagnosed with MDD and are facing a decision about treatment options for moderate to severe depression, but who have not previously taken fluoxetine; who have sufficient language skills and intellectual capacity to provide informed consent and participate; and who are not currently experiencing a psychotic episode; or
2. Clinicians of participants in criterion 1.

Ethics approval

Ethics approval was obtained from the relevant local committee (Melbourne Health Research and Ethics Committee; reference number 2009.659; see Appendix B). Parental or guardian consent was obtained for participants aged less than 18 years old.

Procedure and materials

Medical clinicians of the two services were asked to participate in the field-testing of the DA. If agreeable, clinicians were asked to identify clients (as described below). They were also asked to act as participants in the study and provide feedback on the DA if one or more of their clients was involved in the field-testing. Rather than providing feedback on the DA for each of their clients who used the DA, they were simply asked to provide feedback at the end of the field-testing based on their use of the DA with all of their clients who had been involved. If none of the clients seen by the clinician participated, then they were not considered participants themselves and were not asked to provide feedback. A printed version of the DA was made available if a computer was not available for the consultation. Feedback was provided via a questionnaire. There was significant overlap in the items included in both the client and clinicians questionnaire, however there were some minor differences and these are indicated below as the items are described.

Clients were identified by their treating psychiatrist or GP and informed about the study. If agreeable, the researcher met with clients immediately prior to their usual appointment with the psychiatrist or GP during which a decision was due to be made about treatment for depression. Further information was provided about the study by the researcher and clients, or their legal guardian if aged less than 18 years, and informed consent was obtained. Part of the client version of the questionnaire was administered before they had the decision-making consultation with their clinician. This was so that questions relating to their ‘choice predisposition’ (see below) could be administered before they made the decision. The remaining items were administered after the consultation.

Items in the questionnaire used for both the clinician (see Appendix C) and the client (see Appendix D) were based on the Ottawa Decision Support Framework (211), an evidence-based, theory driven approach to the development of DAs specifically for health related decisions (for appraisal, see (216), also discussed above). Questionnaire items included: 1) *demographics* and details of relevant participant characteristics (including the Control Preferences Scale (217), which asks about preferred role in making health decisions); 2) questions related to the *decision faced* (for clients only), such as the Stage of Decision Making scale (218), which assesses how close somebody is to making a decision; 3) *acceptability of the design and format* via general questions about the graphics and layout; 4) *acceptability of the content* via asking participants to rate the acceptability of each section of the DA, and items relating to the length of the DA and whether or not participants perceived it to be ‘balanced’; 5) *usefulness of the information* via items ‘b’, ‘c’, ‘i’, and 'm' of the Decisional Conflict Scale and an item asking whether there was enough or too much information; and 6) *usefulness in terms of function* via an item about the usefulness of the DA, an item about whether or not the DA made the decision easier, items 'a', 'd-f', 'j-l', and 'n-p' of the Decisional Conflict Scale (219), and an adapted version of the Choice Predisposition Scale (220) (for clients only), which assesses knowledge of treatment options, current preference for treatment option and level of certainty about this preference. The Choice Predisposition Scale was administered before and after the decision-making consultation in order to assess whether or not a decision was made or changed, and to assess knowledge of treatment options.

Data analysis

Thematic analysis, as described in chapter 3, was used to analyse the open-ended questions. For questionnaire items that were scored, the present study did not seek to make statistical comparisons with the data. Rather, these were used to highlight (i.e. via extreme scores) areas of the DA that need improvement. Amendments to the DA were subsequently made based on the responses.

Results

Participants

Three clinicians and five clients participated in the field-testing of the DA: one clinician and two clients from headspace Barwon and two clinicians and three client from OYH. The three male clinicians, two psychiatrists and general practitioner, were aged 27, 38 and 57 years old. The five clients, three females and two males, were aged 15, 16, 17, 17, and 20 years old. All but one was facing their first treatment decision for a mental disorder and none of the participants had a comorbid disorder.

On the Control Preferences Scale, two clinicians reported that they preferred to share responsibility for deciding which treatment is best for their clients, and one clinician reported that they preferred to make the final decision about which treatment is to be used, but that they seriously consider their clients' opinions. Clients had a range of preferences. Two clients reported that they preferred to share responsibility for deciding which treatment is best for their doctors; one client reported that they preferred to make the final decision about their treatment after seriously considering their doctor's opinion; one client preferred that the doctor makes the final decision about which treatment will be used but seriously considers their opinion; and one client preferred to leave all decisions regarding treatment to his doctor.

Acceptability of the DA

In terms of the design and format of the DA, all participants (i.e. both clinicians and clients) found it to be acceptable. No suggestions were made in terms of changes to layout or the use of graphics.

The content of the DA also appeared to be generally acceptable to all participants. All of the clinicians rated the acceptability of each section of the DA as either 'good' or 'excellent'. Clients did the same; except for one client who felt that the 'side effects' and 'what matters to you' sections were of a 'fair' standard (reasons for which are described below). Overall, however, all participants felt that the length of the DA and the amount of information was 'just right'. All participants also found the DA to be 'balanced', although one clinician added a caveat, that it was "possible too dependant on TADS".

Usefulness of the DA

When asked about the amount of information in the DA, all but one of the clinicians and all but one of the clients felt that it was 'just right'. One client felt that there was too much information in the 'side effects' and 'what matters to you' sections, but he could not specify which individual items should be removed. He felt that they contained too much information, had too much writing, and that they should be simpler and easier to read. One clinician said that the 'side effects' section had too much information. On the relevant items of the decision conflict scale, all participants either 'agreed' or 'strongly agreed' that they 1) knew the benefits of each option; 2) knew the risks and side effects of each option; 3) had enough advice to make a choice; and 4) felt like they had made an informed choice.

In terms of the function of the DA, that is whether or not it helped clients to make a decision, clinicians all felt it was useful. One clinician described it as a “revelation” and said that it was a “very powerful educational tool that educates doctors and patients alike”. Another clinician said that it was a good “visual cue” and that “often when talking to patients it is good to have messages visually, which definitely helps to make a decision”. One client felt that it made his decision more difficult because he had to “think about it more” than if the doctor just told him what to do, but he found it very useful to see more side effects listed. The remaining four clients found it useful in helping them to make a decision. One client felt the DA was useful because it “told me more about (the decision)” and although she felt she would get some knowledge from talking with the doctor, she felt that “this gave me more”. Another client reported that the DA was useful because it “changed my mind” about the treatment option and he was “feeling more positive because my chances of getting better are higher”. Other comments from clients included that it was “good to see right there treatment options – I’ve never had it put in writing before and I like that it’s more than someone’s opinion and that I’m being told what everyone gets told”; that it was good because “it had the things that I usually tend to ask” listed; that it was good to “see side effects listed so when I take medication I won’t feel like something’s going awry” if she experiences a side effect; and that the graphs were “fun to look at and compare, they were easier to read than the percentages”.

Items on the decisional conflict scale relating to usefulness were generally rated as ‘agree’ or ‘strongly agree’ by all participants, however there were some exceptions. None of the clients felt that ‘the decision is easy for me to make’. Three clients disagreed that they were ‘clear about which benefits matter most to me’, one client disagreed that he was ‘clear about which risks and side effects matter most to me’, and was client disagreed that she was ‘clear about the best choice for me’ and felt ‘sure about what to choose’. This same client was the only participant whose level or certainty decreased slightly after using the DA (discussed below). The client clarified in the ‘any further comments’ section that this decisional conflict was present before using the decision aid; that she still felt that the DA was useful; and that the discussion with her doctor had led to the decrease in certainty, whereby she was slightly less sure about refusing medication.

Other items relating to the function of the DA included a comparison of Choice Predisposition Scale before and after the consultation. Before using the DA, one client did not know his options, and the remaining four clients reported knowing either two or three (doing nothing, counselling, antidepressant medication). After using the DA, three clients listed all four treatment options (doing nothing, counselling, antidepressant medication and both counselling and antidepressant medication). The remaining two clients reported the same knowledge as before using the decision aid (counselling and antidepressant medication).

The treatment option that each client was considering before the consultation and the option that they chose afterwards are presented in table 2, along with the level of certainty they described and the initial stage of decision making they reported before using the DA. Four clients changed their decision after using the DA to opt for a combination of both counselling and antidepressant medication, and one client decided to stay with her original decision to select counselling only. For two of the clients their level of certainty was reasonable high (80%) and did not change after using the DA. For another two, their level of certainty was lower to begin with (30% and 60%) and after using the DA they felt 100% certain about their respective choices. However, for one client her level of certainty decreased slightly, although she did not attribute this to the DA (as discussed above).

Table 2. Treatment options chosen by clients before and after using the decision aid.

Client	**Stage of decision making**	**Treatment choice before**	**Level of certainty before**	**Treatment choice after**	**Level of certainty after**
01	I haven't begun to think about the choices, but I am interested in doing so	Counselling	80% sure	Counselling and antidepressant medication	80% sure
02	I am considering the options now	Antidepressant medication	80% sure	Counselling and antidepressant medication	80% sure

03	I am close to selecting an option	Antidepressant medication	60% sure	Counselling and antidepressant medication	100% sure
04	I have already made a decision and am unlikely to change my mind	Counselling and antidepressant medication	30% sure	Counselling and antidepressant medication	100% sure
05	I am considering the options now	Counselling	89% sure	Counselling	81% sure

Lastly, participants were asked to provide further comments about what they liked about the DA and what they felt should be improved. Comments from clinicians included that it "gave a firm statement of consensus" about treatment outcomes, that it had "informed content at a very sophisticated level", that it "presented facts simply and clearly" and that "irrefutable statistical facts" meant that it was a "powerful tool". One clinician noted, however, that familiarity was needed before using the DA in order to minimise the time it took to work through the decision. Another clinician liked that he could give the client a copy of the DA so that he "didn't have to cover all the points" in the session, but that they could act as a "prompt" for him, which was "really good, really useful". Clients felt that it "looked alright", "helped doctors to explain stuff", was "simple" and "easy to read", that it was "good that it could make me understand more about it" and "good to see ratings of how medication and counselling can help". Similarly, one client said she was "just happy to see a counsellor now" and now felt that "medication will help and make my life better, make me happier". This same client reported that prior to using the DA she was worried about antidepressant medication making her "go more mad in the long run" and that being prescribed medication or seeing a counsellor would result in her losing custody of her child but that these fears had been alleviated during discussions in the 'what matters to you' section. One suggestion for improvement came from a client who said that she would have liked to know how alcohol would affect the medication.

Changes made to the DA based on field-testing

Overall, the data suggest that both clients and clinicians found the DA to be acceptable and useful. Aspects that could be improved, as identified by extreme scores and general feedback in the questionnaires, included the level of information included and the degree to which decisions were based on client values. Actions taken based on these data are described below.

Participants felt that there was the right amount of information overall, but one client felt there was too much information in the 'side effects' and 'what matters to you' sections, and one clinician felt the same about the 'side effects' section. Given that several clients also said that they liked the list of side effects and would refer to it in the future, the list was kept as part of the DA but was included as a printable PDF. This way, the 'side effects' page looked clearer visually (less information up front) but the information was still retained for future reference. Items in the 'what matters to you' page were reduced slightly where there come some overlap in content.

Although clients reported that the decision was not easy to make, this may not be directly related to the DA but rather the nature of the decision itself. However, the fact that clients did not generally feel that the decision they made reflected their own values, suggests that a values clarification exercise may be useful. Such an exercise was included in earlier drafts of the DA, but was subsequently taken out because of strong feedback during consultations with consumer reference groups that they would not use it and did not like it. The 'what matters to you' section was designed and included based on this feedback. It is possible that the merit of a values clarification exercise may only be felt once actually making the decision. It is also possible that either the members of the consumer reference group or the participants of the field testing are not representative of all clients. As a compromise, in the final version of the DA a values clarification exercise is included as an optional component of the DA that clients can choose to undertake if they feel uncertain about what matters to them. This values clarification exercise was based not only on the current data, but also feedback from the initial development process (phase one, including findings presented in Chapter 4 that demonstrate that clients prefer different levels of involvement at different times and any decision support need to be flexible and accommodate these differences) and the ODSF.

One final issue highlighted in the field-testing was that the DA influenced the decision made. Although all clients chose guideline concordant treatment options, the DA was designed to support decision-making processes rather than influence treatment choice. It may be that the change in treatment choice would have occurred anyway without the use of the DA (i.e. after discussing treatment options with their clinician during treatment decision making as usual), however further testing using a randomised controlled trial comparing the DA to treatment decision making as usual is needed to explore this issue.

The final DA is attached in Appendix E and includes the downloadable PDFs available in the DA (also available at www.depressiondecisionaid.com; password 'SDM').

Discussion

This chapter has described the development of the first publicly available DA developed specifically for youth mental health. The choice of decision to investigate, namely treatment for depression, was an important starting point due to the number of young people locally and globally who face such a decision.

The DA was informed by relevant theories and empirical evidence, and developed in accordance with international standards. Furthermore, input from clients, caregivers and clinicians was sought at salient time points in the development process. The comprehensive development process also involved field-testing with clients and clinicians, a criterion of the IPDAS (158) and item in the IPDASi (159) that is often neglected or poorly reported (216).

The DA appears to be acceptable and useful to both clinicians and clients from primary care and specialist mental health services. Field-testing was conducted with a small number of participants, however, and was undertaken to refine the DA rather than test the effectiveness of it.

Additionally, the approach taken to focus on acceptability using the ODSF, does not provide data on all aspects related to feasibility, namely demand, implementation, practicality, adaptation, integration, expansion, and limited efficacy of the DA (221). Further research is also needed to explore the effectiveness of the DA in terms of whether or not it helps clients make decisions and whether it increases outcomes such as satisfaction, adherence, and knowledge about depression and treatment options. This DA adds to the growing field of YSDM (e.g. (164, 202, 203), and offers a basis for the development of further DAs in other areas of youth mental health.

Chapter 8: Discussion and recommendations

Discussion

Summary of research findings

Young people diagnosed with MDD are likely to experience a range of challenges, not limited to the symptoms that they suffer. In addition to the symptoms that are associated with MDD, young people are at increased risk for negative outcomes across emotional, physical, social, and occupational domains (1, 8, 9, 13-15, 18), including higher rates of suicide (10). Yet MDD is common in young people, with one in every five people experiencing a major depressive episode before they turn 18 years old (14, 19, 20). There are effective treatments for MDD (37), such as CBT, yet young people will also face numerous difficulties in seeking help and accessing treatment. Help seeking rates are low in this population (54-56), and a range of factors, such as stigma (65) and attitudes to treatment (66, 67), will likely lead to a delay in, or barriers to, accessing treatment (69, 70). Chapter 1 of this thesis highlighted the need to make the most of the opportunity that arises when a young person diagnosed with MDD does overcome these challenges and presents to a service, and introduced treatment decision making for young people diagnosed with MDD as the focus of this study.

Models of decision making were presented in chapter 2, before the results of a narrative review of treatment decision making for young people diagnosed with MDD were discussed. The results revealed a significant lack of studies in the area. Owing to this gap, related areas of research were considered, including: preference for involvement; preference for treatment options; beliefs about treatment options, particularly antidepressant medication; and two studies investigating treatment decision making for adults diagnosed with MDD. One relevant study exploring the experiences and beliefs of young people diagnosed with MDD was located, and results suggested that involvement in treatment decision making was important for engagement in treatment and services (122, 123). This study, along with the other areas of literature reviewed, indicated that young people diagnosed with MDD are likely to want to be involved in treatment decision making in some way; that they are likely to have varying preferences for treatment options; that they are likely to have pre-existing beliefs about antidepressant medication and other treatment options; and that all of these areas may impact on help seeking and engagement (68, 91, 94-99, 101, 104-108, 110-121, 191, 222).

Given the importance of treatment decision making for young people diagnosed with MDD, yet absence of any studies exploring such issues specifically, the current study had a major focus on conducting qualitative interviews with clients, caregivers and clinicians about treatment decision making for young people diagnosed with MDD. Chapter 3 presented the methodological approach taken, chapter 4 presented results from interviews with service users (i.e. clients and caregivers), and chapter 5 presented results from interviews with service providers (i.e. clinicians). Thematic analysis was used (142), within a social constructionist epistemology (138-140), in order to obtain rich descriptions of experiences of, and beliefs about, treatment decision making from these three perspectives. Clients and caregivers were asked to talk about a variety of experiences from different decisions, clinicians, and services. Clinicians were recruited from a range of service settings. Accounts were therefore obtained about a broad array of experiences from encounters with public and private; and primary and tertiary care settings.

Overall, results from the data highlighted several key points. Despite service users reporting varied experiences in terms of how involved they had been in treatment decision making, all participants advocated for some form of collaborative approach to treatment decision making. Clients and clinicians endorsed such an approach for very similar reasons, including that it could help with areas such as engagement and adherence, and also that it was a right that should be afforded to clients so that they could feel autonomous and empowered in a developmentally appropriate way.

However, the descriptions of involvement advocated for by participants underscored the need for collaborative approaches of treatment decision making to be dynamic and flexible. This was the case because client preference for involvement over time was not static and changed according to a number of factors. Additionally, flexibility was required as clinicians reported the need to maintain their professional responsibilities when it came to issues such as the risk of the client hurting themselves or others. Clients and clinicians saw the inclusion of caregivers as optional. Additionally, there was a distinction made between decision-making processes, such as exchanging information and deliberating on this information, and who actually made the decision.

The sharing of relevant, meaningful information was valued, as was the consideration of client values and preferences in relation to the potential risks and benefits of treatment options. What constituted involvement was not limited to information sharing and deliberation. Rather, it involved qualitative characteristics of the relationships between those involved in the process, such as feelings of trust, engagement and comfort (e.g. feeling comfortable to express concerns or treatment preferences).

Barriers to achieving this were identified, and there was a synergy between those identified by clients and clinicians. Barriers included those related to individuals (e.g. clinician style; severity of depression symptoms), services (e.g. length of appointments; waiting lists), and broader factors (e.g. stigma; lack of research with young people diagnosed with MDD). Suggestions of ways to overcome some of these barriers and improve treatment decision making included provision of information that was up to date, accessible, relevant, meaningful and interactive.

Given the clear preference for, and focus on, a collaborative approach to treatment decision making as described by participants in the interview data, chapter 6 concentrated on SDM and DAs. A literature review was undertaken to appraise evidence for SDM in youth mental health. Again, due to the lack of evidence for this specific area, related literature was considered, including studies with adults diagnosed with any mental disorder. Studies that were reviewed included those investigating existing levels of SDM; RCTs of SDM interventions, including DAs; non-randomised studies of SDM interventions; collaborative care models (CCMs); and studies measuring the effect of treatment choice or client involvement.

The review found that existing levels of SDM are likely to be low in mental health areas. Four SDM interventions designed to address this issue have been tested in RCTs (174-178). The results of these studies suggests that a SDM approach, when used for mental disorders such as schizophrenia, depression or substance abuse in adults, is likely to improve at least one relevant outcome, such as increased involvement, knowledge, satisfaction or a reduction in drug use and psychiatric symptoms. This is supported by non-randomised studies of SDM interventions, which showed promise in terms of increasing client involvement and satisfaction (179-187). Clients are likely to have varying preferences for treatment options, and it is probable that affording them choice of treatment options will result in better engagement, satisfaction and depression scores (101, 191-198). Equally, involving individuals diagnosed with MDD in their care is likely to lead to increased guideline concordant care, adherence and client satisfaction (118, 223).

All of this research is based on studies with adults. The closest intervention to a SDM model tested in young people diagnosed with MDD is a CCM (146, 224). This CCM was effective in improving depression scores, and increasing satisfaction and quality of life for young people, at least in the short term. Although no SDM interventions specifically had been tested for young people diagnosed with mental disorders, there is growing enthusiasm in this area of YSDM (164, 202, 203) and a number of studies are currently underway.

Adding to this emerging field of YSDM, a DA for young people diagnosed with MDD facing a decision about treatment choice was developed as part of the current study. The development process, including field-testing, was presented in chapter 7. This evidence-based DA was developed using a rigorous process, applying *International Patient Decision Aids Standards* (158, 159), and was informed heavily by the interview data presented in chapters 4 and 5, as well as extensive consultation with relevant stakeholders. Field-testing of the DA led to a small number of changes, such as the inclusion of an optional values clarification exercise, however it also demonstrated that the DA was acceptable and useful to both clients and clinicians.

Comparison with previous research

The current study supports findings from interview data with adults diagnosed with MDD (87, 121), including that clients value information but receive little of it and seek it elsewhere (e.g. on the internet); that a range of barriers exist to both help seeking and involvement in treatment decision making; that clients wish to be involved in treatment decision making, but that preference for involvement changes over time and the degree of involvement preferred may be different for different clients. The importance of spirituality, as described in focus groups with adults diagnosed with MDD (110), was not found in this study. It is not clear whether this is related to the age of the clients in the current sample or other demographic variables.

In addition to the research with adults described above, a previous study with young people diagnosed with MDD also found that information is valued by clients, yet these young clients often feel that they are not provided with sufficient information by clinicians to make a decision and so therefore seek information elsewhere (122, 123). These same interview data also found that the way young people felt about clinicians was important for how they viewed, and engaged in, treatment. In the present study, clients and caregivers also valued qualitative aspects of their interactions with clinicians. For example, it was important to know that clinicians cared; for clients and caregivers to feel respected; and to be able to trust clinicians. Equally, if clients and caregivers didn’t feel this way, then they reported disengaging from services. Clinicians also acknowledged these aspects of care as important for the engagement of clients and caregivers. This lends weight to the proposition by Entwistle and Watt (2006) (85) that models of decision making should consider the way in which those involved (e.g. client and clinician) feel not only about the decision-making process, but also each other.

Broader aspects of treatment decision making not specific to MDD are also supported by the current study. As seen in Edwards and Elwyn’s (2006) (89) data from interviews with primary care patients (with non-psychiatric disorders), clients distinguished between the decision-making processes (i.e. the analytical stages of decision making described in SDM models (83, 84)) and who actually makes the decision about which treatment choice to select.

Therefore, preference for involvement might be the same, or different, for each of these tasks. Further, SDM models should place an emphasis on shared decision-making processes rather than who takes on the role of making the final decision.

Significance of findings

This study is the first to consider the experiences and beliefs about treatment decision making for young people diagnosed with MDD, from the perspective of clients, caregivers and clinicians. This study fills a gap in the knowledge about the context in which young people diagnosed with MDD find themselves making treatment decisions, and provides the basis on which to build a body of work in the area of YSDM. This DA is unique because it is for adolescents and young adults, who are no longer children, but who may prefer and/or require parental or caregiver involvement. As such, it is the first DA designed for young people, rather than their parents (e.g. (225)). The development process of the DA was based on the latest evidence and theoretical frameworks; involved significant consultation with relevant stakeholders; and was field-tested to ensure its acceptability and usefulness.

Importantly, this study provides empirical data that can contribute to the development of YSDM frameworks (e.g. (203)) and how clinical guidelines that advocate for the inclusion of young people in treatment decision making (e.g. (26, 30)) might be practically realised.

Limitations of the study

As mentioned in chapters 4 and 5, limitations of the interview data include the small sample size; the possibility that participants agreed to take part in the study because they had strong views; the fact that participants were asked to recall events rather than describe them as they were happening; and that each group (clients, caregivers and clinicians) were not necessarily related to each other, that is, they were not discussing the same instances as each other, but rather talking about their experiences in general.

There are additional limitations relating to the DA. Testing the effectiveness of the DA was outside the scope of this study, and this will need to be established in order to understand the benefits of such a tool compared with treatment decision making as usual. Issues related to dissemination and implementation are likely to pose challenges and will need to be considered carefully (86). Furthermore, the evidence upon which the tool is based needs to be kept up to date. New evidence about the effectiveness of treatment options for young people diagnosed with MDD will need to be incorporated into the risk communication sections and may change the content considerably. Depending on the results of future research and the resultant evidence base, the decision about which treatment choice to select may become easier or more difficult to make.

Future research

There are several possible direct extensions of this study. Firstly, the DA could be compared with treatment decision making as usual in a RCT to determine the effectiveness of the DA in terms of whether or not a decision is made; knowledge (e.g. of the potential risks and benefits of treatment options) before and after the decision-making consultation; client and clinician satisfaction; adherence to treatment; and clinical outcomes such as depression severity scores. Decision support tools other than DAs (e.g. decision grids (226) or key questions that clients can ask clinicians (227)) may also be worth investigating alone or in comparison to SDM tools for young people diagnosed with MDD. Additionally, there is merit in considering how a DA can be embedded in other clinical tools, for example monitoring the progression of symptoms, suicidality and treatment after a decision is made.

It is possible that the focus of future work should not rest solely on establishing effectiveness of the DA. It may be more clinically relevant and pragmatic to establish efficacy on a smaller scale and then focus instead on issues related to the implementation of the DA (228), including factors predicting behavioural change in clinicians which lead to more evidence-based practice (229, 230), including use of the tool.

In terms of broader research areas, there is a need for interventions that promote involvement in decision making and the systematic availability of quality, evidence-based information across all mental disorders. In doing so, the barriers to implementing SDM across different clinicians, different services, and different models of care need careful consideration. The development and evaluation of training programs for clinicians, and possibly clients and caregivers, in how to participate in SDM may be part of this process.

Further advancement of this area, including the development of additional DAs for youth mental health, will open up the possibility of improved decision making experiences for young people. This in turn has the potential to improve key clinical outcomes, an essential objective given the compromised trajectories faced by young people diagnosed with MDD and other mental disorders.

Practical implications of the research

Clinical guidelines advocate for the inclusion of young people in decision-making processes and the current study supports this. The difficulty that clients reported getting accepted into services demonstrates that there is an onus on services to maximize efforts to engage clients once accepted. Given that clients reported a direct relationship between involvement and outcomes such as engagement, adherence and satisfaction with services, the importance of at least offering clients involvement in the decision-making process was highlighted. This is particularly true for clinicians or services that either precluded involvement, or from which clients readily disengaged.

The factors that influence desire for involvement will not always be evident to clinicians and therefore involvement should be negotiated explicitly (rather than assuming the level of involvement that the client desires and/or can cope with) and repeatedly (because desire to be involved is likely to change over time). Caregiver involvement should be negotiated explicitly and on an individual basis. Caregivers should be supported with the necessary information about mental disorders and treatment options, particularly when they are responsible for key tasks outside of the clinical sessions (such as filling prescriptions and monitoring risk levels).

Interventions such as DAs are likely to be useful in several areas of youth mental health. As the field of YSDM evolves, consideration will need to be given to the areas that most need decisional support. Development, maintenance (e.g. incorporating new evidence), dissemination and implementation of such tools will require investment from researchers and services alike. This study confirms the need for such decisional support in at least one area of youth mental health, and provides justification for careful consideration of the ways in which guidelines advocating for the involvement of clients are implemented and realised.

Conclusions

Treatment decision making for young people diagnosed with MDD is a complex and dynamic process that needs to be flexible for both the needs of the client (e.g. preference for involvement) and clinician (e.g. professional responsibilities). The presence or absence of caregiver involvement is an optional aspect of treatment decision making. The provision of information and consideration of client preference for involvement are two key aspects of decision-making processes in this area, and DAs that facilitate SDM are one way to support such aspects. The DA developed for this study not only works to address the need for evidence-based information and consideration of client preference, but also contributes to the growing field of YSDM. This area of research has the potential to improve the treatment decision making practices for young people diagnosed with MDD and in turn increase client satisfaction, adherence and clinical outcomes.

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Appendix A: Ethics approval certificates for interviews with clients, caregivers and clinicians

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MELBOURNE HEALTH

Mental Health Research and Ethics Committee Approval Certificate

The MHREC operates in accordance with the *NHMRC National Statement on Ethical Conduct in Human Research 2007*

This is to certify that

MHREC Project No: **2008.19** **Approval date: 04/06/2008** **Expiry date: 30/06/2010**

Project Title: **Experience of treatment decision making for young people with depressive disorders: Focus groups with clients, carers and clinicians**

Principal Investigator:
Professor Anthony Jorm
ORYGEN Research Centre
Locked Bag 10
Parkville VIC 3052

Sponsored by: N/A

Protocol No: N/A

Participant Information and Consent Forms: Version 2, dated 21 May 2008 (Participant) and Version 2, dated 21 May 2008 (Parent/Guardian)

Investigator Brochure: N/A

Conducted at: ORYGEN Youth Health and headspace **have been approved**.

This proposal meets the requirements of the *NHMRC National Statement on Ethical Conduct in Human Research 2007.*

It is now your responsibility to ensure that all people conducting this research project are made aware of which documents have been approved.

This approval is subject to ongoing, current and valid insurance coverage throughout the duration of the conduct of the study.

You are required to notify the Manager of the Mental Health Research and Ethics Committee of:

- Any change in the protocol and the reason for that change together with an indication of ethical implications (if any) by submitting an amendment to the study;
- Serious adverse effects on subjects and the action taken to manage them, including an amended Patient Information and Consent Form where appropriate;
- Any unforseen events;
- Your inability to continue as Principal Investigator, or any other change in research personnel involved in the study;
- A delay of more than 12 months in the commencement of the project; and
- The actual date of commencement of the study.

You are required to submit the following reports to the Mental Health Research and Ethics Committee:

- An Annual Report every twelve months for the duration of the project; and
- A detailed Final Report at the conclusion of the project.

The Mental Health Research and Ethics Committee may conduct an audit at any time.

An extension of the project beyond the stated conclusion date should be sought from the Mental Health Research and Ethics Committee.

Signed:

Michelle Clem

Michelle Clemson
Manager
Mental Health Research and Ethics Committee

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MELBOURNE HEALTH

RESEARCH DIRECTORATE

10 December 2008

Professor Anthony Jorm
ORYGEN Research Centre
Locked Bag 10
Parkville
VIC 3052

Dear Anthony,

RE: MHREC 2008.19 Experience of treatment decision making for young people with depressive disorders: Interviews with clients, carers and clinicians
Thank you for submitting the following correspondence:

A *Request for Approval of Amendments Form* dated 13 November 2008 enclosing:

- A request to extend recruitment to the general public;
- Updated Module One, Version 4, dated 13 November 2008; and
- Appendix 7 – Recruitment Poster for Participants, Version 3, dated 13 November 2008.

The Mental Health Research and Ethics Committee have reviewed and **approved** the above amendment at its meeting on Wednesday 3 December 2008.

Yours sincerely,

Michelle Clemson

Ms. Michelle Clemson
Manager
Mental Health Research and Ethics Committee

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MELBOURNE HEALTH

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Manager
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Assistant Manager
Ms Angela Gray
Dr Sarah Rickard

Research Ethics Manager- Mental Health
Ms Michelle Clemson

Chairs

Human Research Ethics Committee
Prof. Peter Colman

Institutional Biosafety Committee
Prof. Stephen Jane

Mental Health Research & Ethics Committee
Dr Tom Peyton

27 October 2008

Professor Anthony Jorm
ORYGEN Research Centre
Locked Bag 10
Parkville
VIC 3052

Dear Anthony,

RE: MHREC 2008.19 Experience of treatment decision making for young people with depressive disorders: Interviews with clients, carers and clinicians

Thank you for submitting the following correspondence:

A *Request for Approval of Amendments Form* dated 21 July 2008 enclosing:

- Updated protocol to use individual interviews instead of focus groups to collect data;
- Module 1 Version 3 dated 21 July 2008;
- Appendix 1 Questionnaire for Clients Version 3 dated 20 July 2008;
- Appendix 2 Questionnaire for Carers Version 3 dated 20 July 2008;
- Appendix 3 Questionnaire for Clinicians Version 3 dated 20 July 2008;
- Appendix 4 Interview Schedule for Clients Version 2 dated 20 July 2008;
- Appendix 5 Interview Schedule for Carers Version 2 dated 20 July 2008;
- Appendix 6 Interview Schedule for Clinicians Version 2 dated 20 July 2008;
- Appendix 7 Recruitment Poster for Clients and Carers Version 2 dated 20 July 2008;
- Appendix 8 Participant Information and Consent Form Version 3 dated 20 July 2008;
- Appendix 9 Participant Information and Consent Form (Parent/Guardian) Version 3 dated 20 July 2008; and
- Appendix 10 Debriefing Protocol Version 2 dated 21 July 2008.

The Mental Health Research and Ethics Committee have reviewed and **approved** the above amendment at its meeting on Wednesday 6 August 2008.

Yours sincerely,

Michelle Clemson

Ms. Michelle Clemson
Manager
Mental Health Research and Ethics Committee

Appendix B: Ethics approval certificates for field-testing of the decision aid

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MELBOURNE HEALTH

Mental Health Research and Ethics Committee Approval Certificate

The MHREC operates in accordance with the *NHMRC National Statement on Ethical Conduct in Human Research 2007*

This is to certify that

MHREC Project No: **2009.659** **Approval date: 17/02/2010** **Expiry date: 16/02/2013**

Project Title: Pilot testing of two decision aids for youth mental health

Principal Investigator: Professor Tony Jorm
NHMRC Australia Fellow
ORYGEN Youth Health Research Centre

Protocol No: Version 2 dated 5 January 2010

Participant Information and Consent Form: Version 1 dated 13 November 2009 (Participant and Parent/Guardian)

Other: Questionnaire

Conducted at: ORYGEN Youth Health **has been approved.**

This proposal meets the requirements of the *NHMRC National Statement on Ethical Conduct in Human Research 2007.*

It is now your responsibility to ensure that all people conducting this research project are made aware of which documents have been approved.

This approval is subject to ongoing, current and valid insurance coverage throughout the duration of the conduct of the study.

You are required to notify the Manager of the Mental Health Research and Ethics Committee of:

- Any change in the protocol and the reason for that change together with an indication of ethical implications (if any) by submitting an amendment to the study;
- Serious adverse effects on subjects and the action taken to manage them, including an amended Patient Information and Consent Form where appropriate;
- Any unforseen events;
- Your inability to continue as Principal Investigator, or any other change in research personnel involved in the study;
- A delay of more than 12 months in the commencement of the project; and
- The actual date of commencement of the study.

You are required to submit the following reports to the Mental Health Research and Ethics Committee:

- An Annual Report every twelve months for the duration of the project; and
- A detailed Final Report at the conclusion of the project.

The Mental Health Research and Ethics Committee may conduct an audit at any time.
An extension of the project beyond the stated conclusion date should be sought from the Mental Health Research and Ethics Committee.

Signed:

Michelle Clem

Michelle Clemson
Manager, Mental Health Research and Ethics Committee

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OFFICE FOR RESEARCH

MELBOURNE HEALTH

Executive Director of Research
Professor Ingrid Winship

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Dr. Angela Watt

Manager Human Research Ethics Committee
Ms. Angela Gray

Manager Governance & Mental Health Research
Dr. Sarah Rickard

Chairs
Human Research Ethics Committee
Professor Peter Colman

Institutional Biosafety Committee
Dr. Chris Birch

Mental Health Research & Ethics Committee
Dr. Tom Peyton

15th September 2011

Prof Anthony Jorm
ORYGEN Youth Health Research Centre
Locked Bag 10
PARKVILLE VIC 3052

Dear Prof Jorm,

RE: MHREC Project 2009.659 - Pilot testing of two decision aids for youth mental health.

Thank you for submitting the following correspondence:

A Request for Approval of Amendment form dated 29th August 2011 enclosing:

- Module One – Change of Site for Recruitment
- Orygen Youth Health Participant Information And Consent Form – For Clinicians Version 2 dated 8th September 2011
- Appendix #2: Clinician Questionnaire Version 1 dated 28th July 2011

I am pleased to advise that the Human Research Ethics Committee reviewed and approved the amendment(s) to the above named project.

Yours sincerely

Ms. Angela Gray
Manager - Human Research Ethics Committee

Appendix C: Questionnaire administered to clinicians during the field-testing of the decision aid

Your feedback about the depression decision aid

1. Age ____

2. Gender Male / Female

3. Profession (e.g. psychologist) ____

4. Years working in that profession ____

5. Years working in youth mental health ____

6. Number of your clients who have used this decision aid ________________________

7. Number of clients who have used this decision aid *with you* ________________________

[8. Control Preferences Scale (adapted)]

In this section, please choose the type of decision making role that you prefer the most when it comes to decisions about treatment options for your clients in general (please tick one box only):

☐ I prefer that my clients make the final decision about their treatment after seriously considering my opinion.

☐ I prefer that I make the final decision about which treatment will be used but seriously consider my client's opinion.

☐ I prefer that my clients and I share responsibility for deciding which treatment is best for them.

☐ I prefer for my client to make the decision about with treatment they will receive.

☐ I prefer for my client to leave all decisions regarding treatment to myself.

[9. Acceptibility]

We would like to know what you think about the decision aid.

Please answer the following questions to show what you think about the way the information was presented on:

	Poor	**Fair**	**Good**	**Excellent**	**Did not use**
a. Home.	☐	☐	☐	☐	☐
b. Treatment.	☐	☐	☐	☐	☐
c. Getting better.	☐	☐	☐	☐	☐
d. Side effects.	☐	☐	☐	☐	☐
e. What matters to you.	☐	☐	☐	☐	☐
f. Making a decision.	☐	☐	☐	☐	☐
g. Fact sheets.	☐	☐	☐	☐	☐
h. Graphs.	☐	☐	☐	☐	☐

i. The length of the decision aid was (tick one):
☐ Too long
☐ Too short
☐ Just right

j. The amount of information was (tick one):
☐ Too much information
☐ Too little information
☐ Just right

k. I found the decision aid (tick one):
☐ Balanced (e.g. provided information equally)
☐ Biased towards one or more of the options (please provide additional details)

____

l. Did you find this decision aid useful?
☐ Yes
☐ No

Comments: ____

m. Do you think that your clients found this decision aid useful? ☐ Yes
☐ No

Comments: ____

n. What did you like about the decision aid?

____

____

o. What suggestions do you have to improve the decision aid?

____

____

p. In terms of the length of consultation, do you feel that using the decision aid:

☐ Increased consultation time

☐ Had no effect on consultation time

☐ Decreased consultation time

q. Do you think that the graphics and layout are acceptable?
☐ Yes ☐ No

Comments: ____

r. Any further comments: ____

____

[10. Decisional Conflict Scale (adapted)]

Please rate the degree to which you agree with the following statements:

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
a. The decision aid helped me to inform my clients about which options are available to them.	☐	☐	☐	☐	☐
b. The decision aid helped me to inform my clients about the benefits of each option.	☐	☐	☐	☐	☐
c. The decision aid helped me to inform my clients about the risks and side effects of each option.	☐	☐	☐	☐	☐
d. The decision aid helped me to understand which benefits matter most to my clients.	☐	☐	☐	☐	☐
e. The decision aid helped me to clarify which risks and side effects matter most to my clients.	☐	☐	☐	☐	☐
f. The decision aid helped me to clarify which is more important to my clients (the benefits or the risks and side effects).	☐	☐	☐	☐	☐
j. The decision aid helped my clients to make a decision about treatment.	☐	☐	☐	☐	☐
k. The decision aid helped my clients to feel sure about what to choose.	☐	☐	☐	☐	☐
m. The decision aid helped my clients to make an informed choice.	☐	☐	☐	☐	☐
n. The decision aid helped my clients to make a decision based on what was important to them.	☐	☐	☐	☐	☐
o. I believe that my clients will stick with their decisions.	☐	☐	☐	☐	☐
p. I believe that my clients are satisfied with their decisions.	☐	☐	☐	☐	☐

Appendix D: Questionnaire administered to clients during the field-testing of the decision aid

Questionnaire **Part A**: Please complete this section **before** using the decision aid

1. Age ____

2. Gender Male / Female

3. Currently in full time study or work? Yes / No

Comments ____

4. Country you were born in ____

5. Country your mother was born in ____

6. Country your father was born in ____

7. Main language spoken at home ____

8. Diagnosis/diagnoses ____

____

____

____

____

9. Is this the first decision you have had to make about treatment for mental health issues?

☐ Yes ☐ No (please provide details below of past decisions and treatment)

____

____

____

____

____

____

[10. Control Preferences Scale]

In this section, please choose the type of decision making role that you prefer the most when it comes to decisions about treatment options for you (please tick one box only):

☐ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.

☐ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.

☐ I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

☐ I prefer to make the decision about with treatment I will receive.

☐ I prefer to leave all decisions regarding treatment to my doctor.

[11. Stage of Decision Making]

In terms of your treatment options, at this time, would you say you:

☐ Haven't begun to think about the choices.

☐ Haven't begun to think about the choices, but am interested in doing so.

☐ Are considering the options now.

☐ Are close to selecting an option.

☐ Have already made a decision, but am still willing to reconsider.

☐ Have already made a decision and am unlikely to change my mind.

[12. Choice Predisposition (adapted)]

We would like to know what your opinion is about your treatment options at present.

a. Are you clear about what your treatment options are?

☐ No ☐ Yes (please list them below)

Option 1: ____

Option 2: ____

Option 3: ____

Option 4: ____

Option 5: ____

Option 6: ____

b. If you were asked right now to make a choice about treatment options, which one would you choose?

____

c. How sure are you about this choice?

|____________|____________|____________|____________|____________|

↓ ↓

Completely unsure Completely
sure

0% 20% 40% 60% 80% 100%

Questionnaire **Part B**: Please complete this section **after** using the decision aid

[1. Choice Predisposition (post-, adapted)]

We would like to know what your opinion is about your treatment options after using the decision aid.

a. Are you clear about what your treatment options are?

☐ No ☐ Yes (please list them below)

Option 1: ____

Option 2: ____

Option 3: ____

Option 4: ____

Option 5: ____

Option 6: ____

b. If you were asked right now to make a choice about treatment options, which one would you choose?

____

c. How sure are you about this choice?

Completely unsure					Completely sure
0%	20%	40%	60%	80%	100%

[2. Acceptability]

We would like to know what you think about the decision aid you have just used.

Please answer the following questions to show what you think about the way the information was presented on:

	Poor	Fair	Good	Excellent	Did not use
a. Home.	☐	☐	☐	☐	☐
b. Treatment.	☐	☐	☐	☐	☐
c. Getting better.	☐	☐	☐	☐	☐
d. Side effects.	☐	☐	☐	☐	☐
e. What matters to you.	☐	☐	☐	☐	☐
f. Making a decision.	☐	☐	☐	☐	☐
g. Fact sheets.	☐	☐	☐	☐	☐
h. Graphs.	☐	☐	☐	☐	☐

i. The length of the presentation was (tick one):

☐ Too long ☐ Too short ☐ Just right

j. The amount of information was (tick one):

☐ Too much information ☐ Too little information ☐ Just right

k. I found the decision aid (tick one):

☐ Balanced (e.g. provided information equally)
☐ Biased towards one or more of the options (please provide details):

____

l. Did you find this decision aid useful? ☐ Yes ☐ No

Comments: ____

m. What did you like about the decision aid?

____

n. What suggestions do you have to improve the decision aid?

____

o. Feedback about this questionnaire/any further comments:

____

____

p. Do you think that the graphics and layout are acceptable?

☐ Yes ☐ No

Comments: ____

[3. Decisional Conflict Scale]

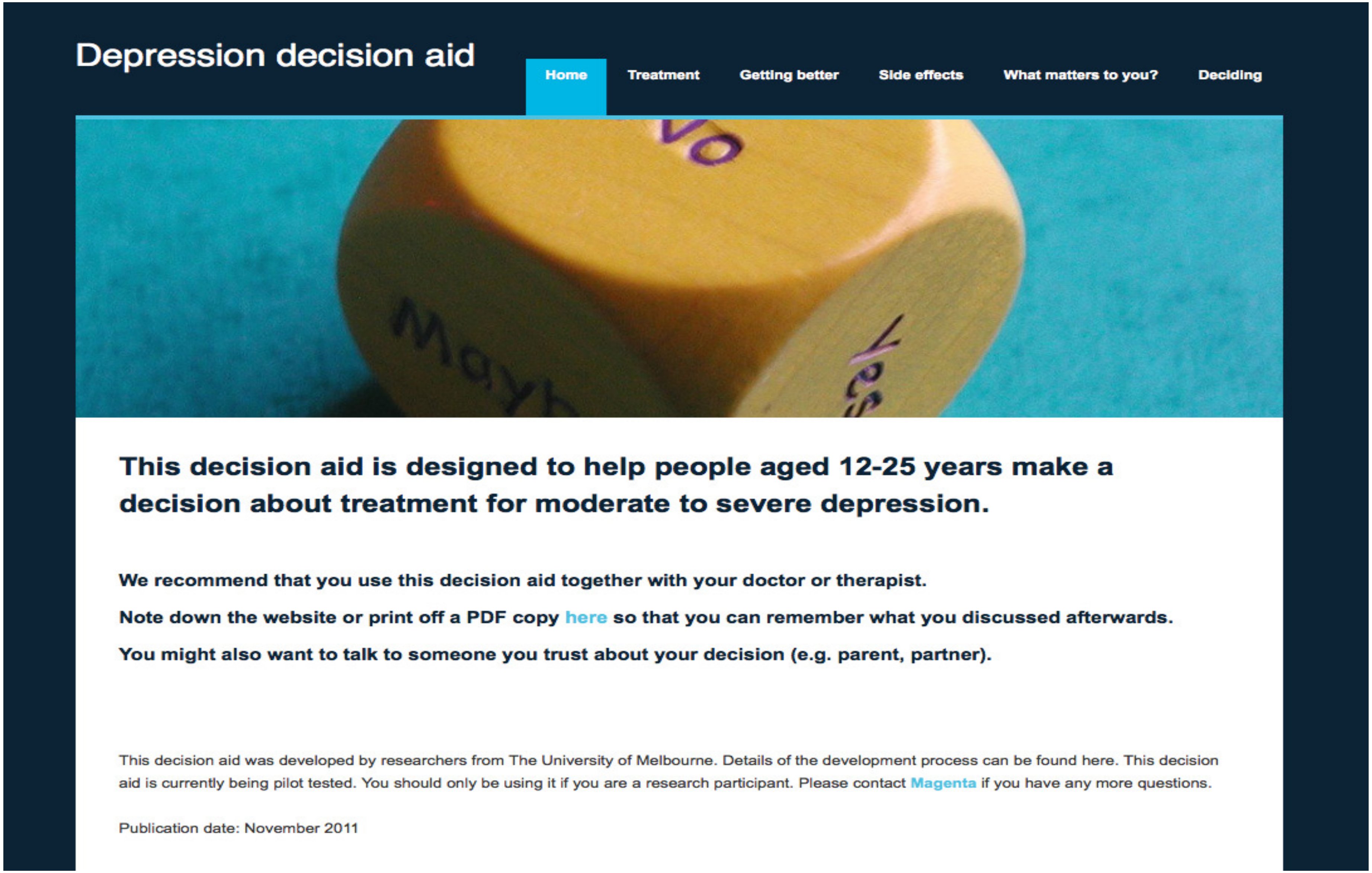
My difficulty in making this choice.

Considering the option you prefer, please answer the following questions:

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
a. I know which options are available to me.	☐	☐	☐	☐	☐
b. I know the benefits of each option.	☐	☐	☐	☐	☐
c. I know the risks and side effects of each option.	☐	☐	☐	☐	☐
d. I am clear about which benefits matter most to me.	☐	☐	☐	☐	☐
e. I am clear about which risks and side effects matter most to me.	☐	☐	☐	☐	☐
f. I am clear about which is more important to me (the benefits or the risks and side effects).	☐	☐	☐	☐	☐
g. I have enough support from others to make a choice.	☐	☐	☐	☐	☐
h. I am choosing without pressure from others.	☐	☐	☐	☐	☐
i. I have enough advice to make a choice.	☐	☐	☐	☐	☐
j. I am clear about the best choice for me.	☐	☐	☐	☐	☐
k. I feel sure about what to choose.	☐	☐	☐	☐	☐
l. the decision is easy for me to make.	☐	☐	☐	☐	☐
m. I feel I have made an informed choice.	☐	☐	☐	☐	☐
n. My decision shows what is important to me.	☐	☐	☐	☐	☐
o. I expect to stick with my decision.	☐	☐	☐	☐	☐
p. I am satisfied with my decision.	☐	☐	☐	☐	☐

Appendix E: Web-based decision aid for young people aged 12-25 years with moderate to severe depression who are facing a decision about what treatment option is best for them, including downloadable attachments

NB: The downloadable attachments are presented at the end of the decision aid in the order in which they appear as links on the decision aid website.



Depression decision aid

This decision aid is designed to help people aged 12-25 years make a decision about treatment for moderate to severe depression.

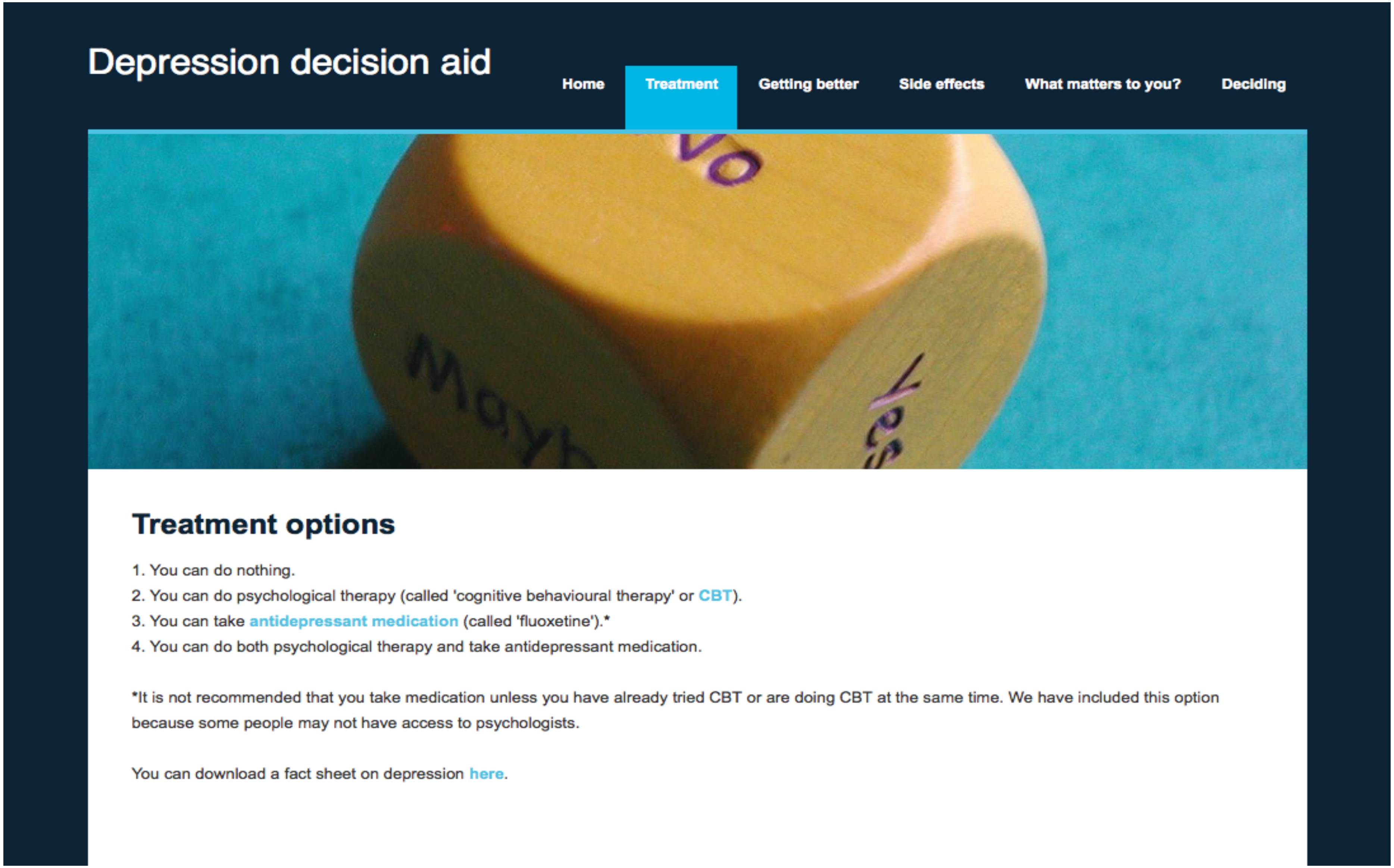
We recommend that you use this decision aid together with your doctor or therapist.

Note down the website or print off a PDF copy here so that you can remember what you discussed afterwards.

You might also want to talk to someone you trust about your decision (e.g. parent, partner).

This decision aid was developed by researchers from The University of Melbourne. Details of the development process can be found here. This decision aid is currently being pilot tested. You should only be using it if you are a research participant. Please contact Magenta if you have any more questions.

Publication date: November 2011

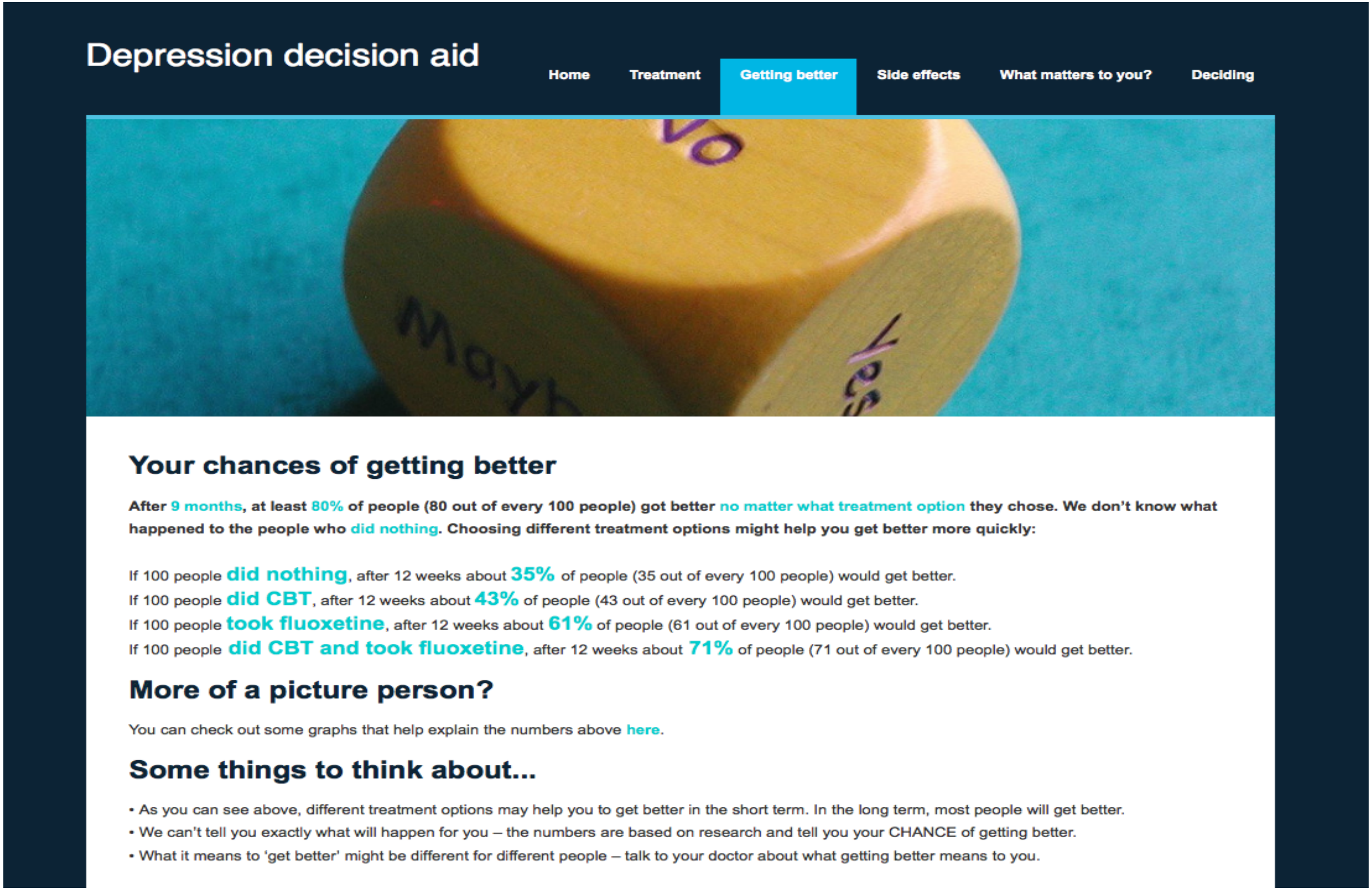


Treatment options

1. You can do nothing.
2. You can do psychological therapy (called 'cognitive behavioural therapy' or CBT).
3. You can take antidepressant medication (called 'fluoxetine').*
4. You can do both psychological therapy and take antidepressant medication.

*It is not recommended that you take medication unless you have already tried CBT or are doing CBT at the same time. We have included this option because some people may not have access to psychologists.

You can download a fact sheet on depression here.



Depression decision aid

Your chances of getting better

After 9 months, at least 80% of people (80 out of every 100 people) got better no matter what treatment option they chose. We don't know what happened to the people who did nothing. Choosing different treatment options might help you get better more quickly:

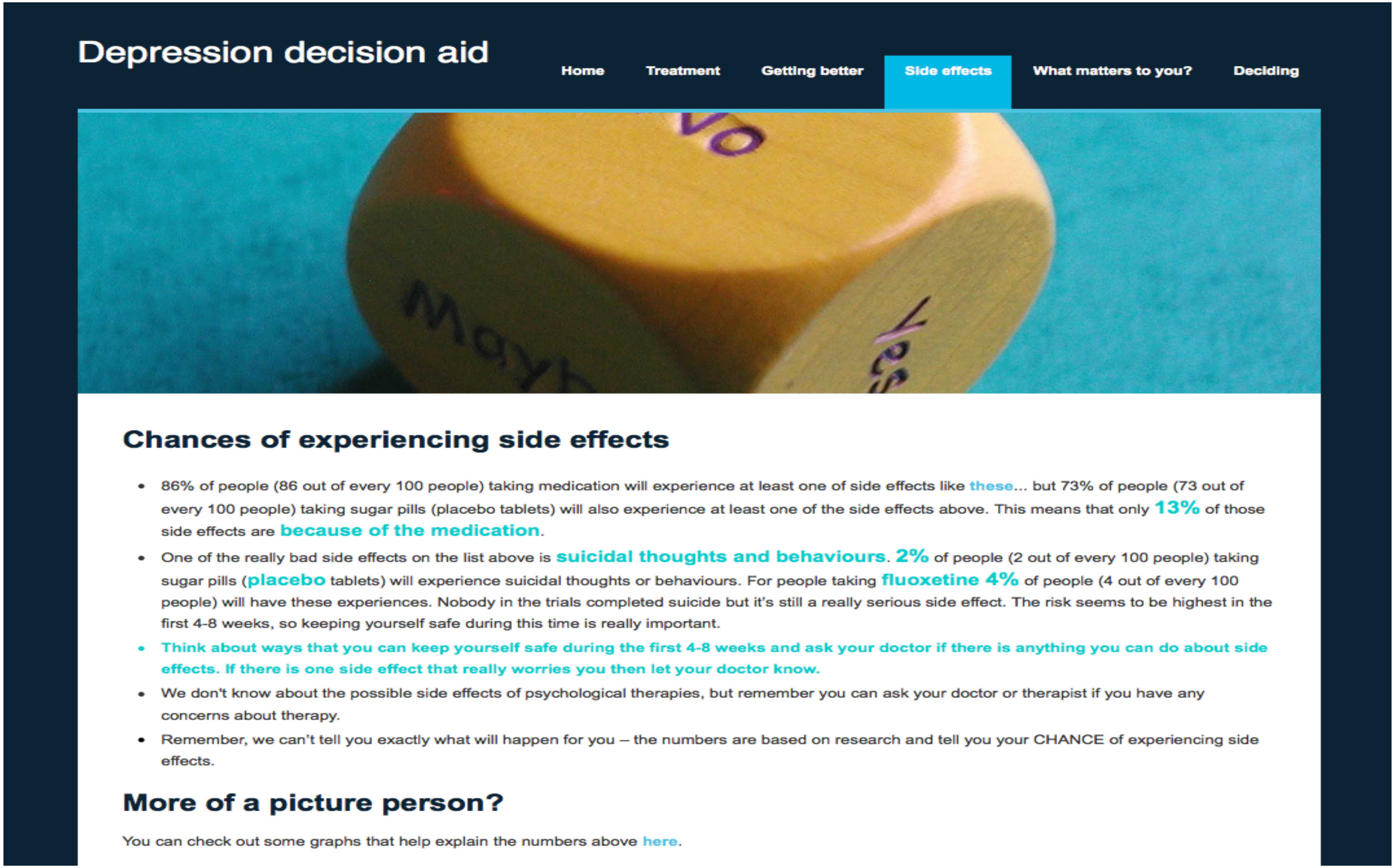
If 100 people **did nothing**, after 12 weeks about **35%** of people (35 out of every 100 people) would get better.
If 100 people **did CBT**, after 12 weeks about **43%** of people (43 out of every 100 people) would get better.
If 100 people **took fluoxetine**, after 12 weeks about **61%** of people (61 out of every 100 people) would get better.
If 100 people **did CBT and took fluoxetine**, after 12 weeks about **71%** of people (71 out of every 100 people) would get better.

More of a picture person?

You can check out some graphs that help explain the numbers above here.

Some things to think about...

- As you can see above, different treatment options may help you to get better in the short term. In the long term, most people will get better.
- We can't tell you exactly what will happen for you – the numbers are based on research and tell you your CHANCE of getting better.
- What it means to 'get better' might be different for different people – talk to your doctor about what getting better means to you.



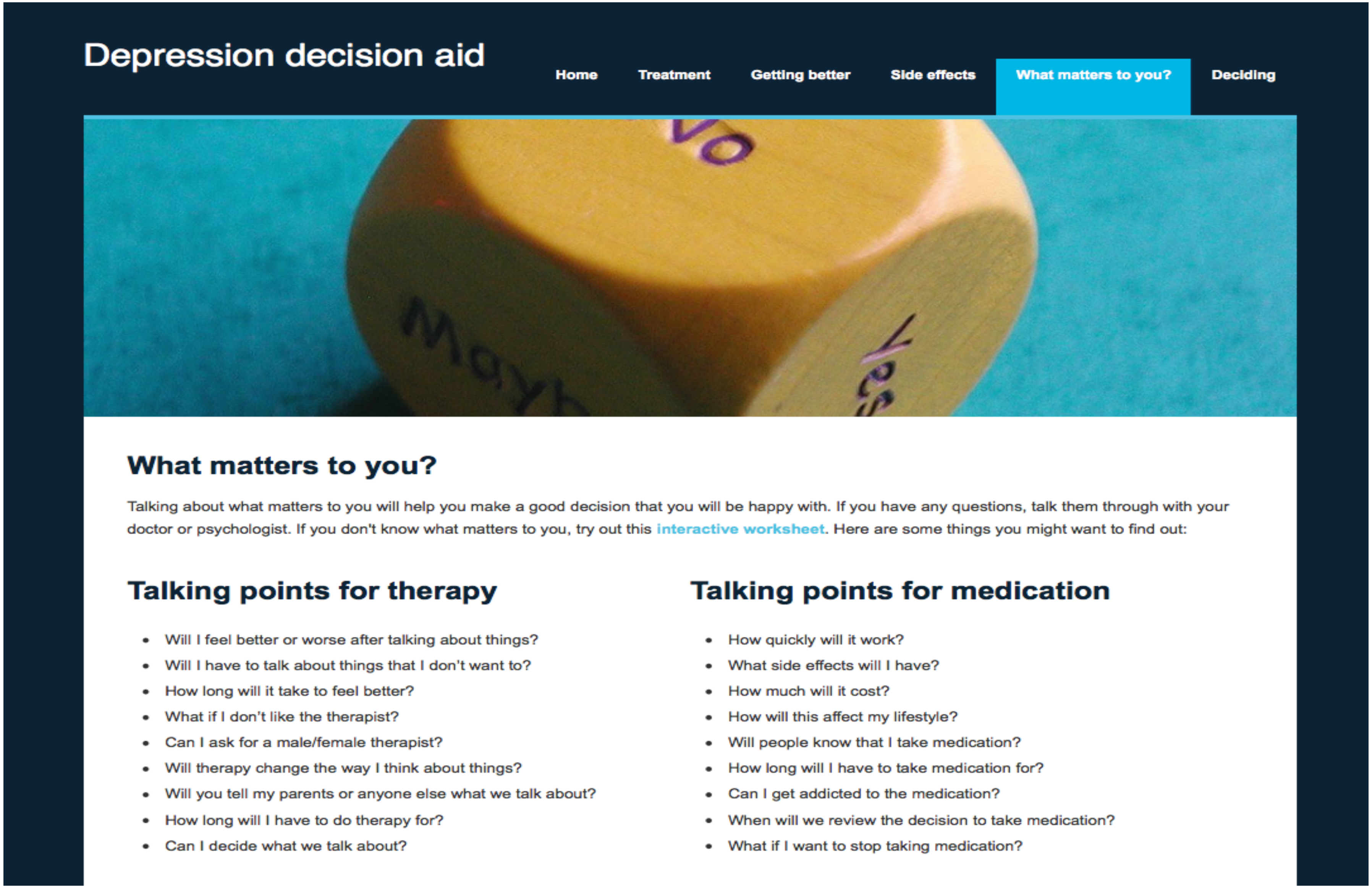
Depression decision aid

Chances of experiencing side effects

- 86% of people (86 out of every 100 people) taking medication will experience at least one of side effects like **these**... but 73% of people (73 out of every 100 people) taking sugar pills (placebo tablets) will also experience at least one of the side effects above. This means that only **13%** of those side effects are **because of the medication**.
- One of the really bad side effects on the list above is **suicidal thoughts and behaviours**. **2%** of people (2 out of every 100 people) taking sugar pills (**placebo** tablets) will experience suicidal thoughts or behaviours. For people taking **fluoxetine 4%** of people (4 out of every 100 people) will have these experiences. Nobody in the trials completed suicide but it's still a really serious side effect. The risk seems to be highest in the first 4-8 weeks, so keeping yourself safe during this time is really important.
- **Think about ways that you can keep yourself safe during the first 4-8 weeks and ask your doctor if there is anything you can do about side effects. If there is one side effect that really worries you then let your doctor know.**
- We don't know about the possible side effects of psychological therapies, but remember you can ask your doctor or therapist if you have any concerns about therapy.
- Remember, we can't tell you exactly what will happen for you – the numbers are based on research and tell you your CHANCE of experiencing side effects.

More of a picture person?

You can check out some graphs that help explain the numbers above **here**.



Depression decision aid

What matters to you?

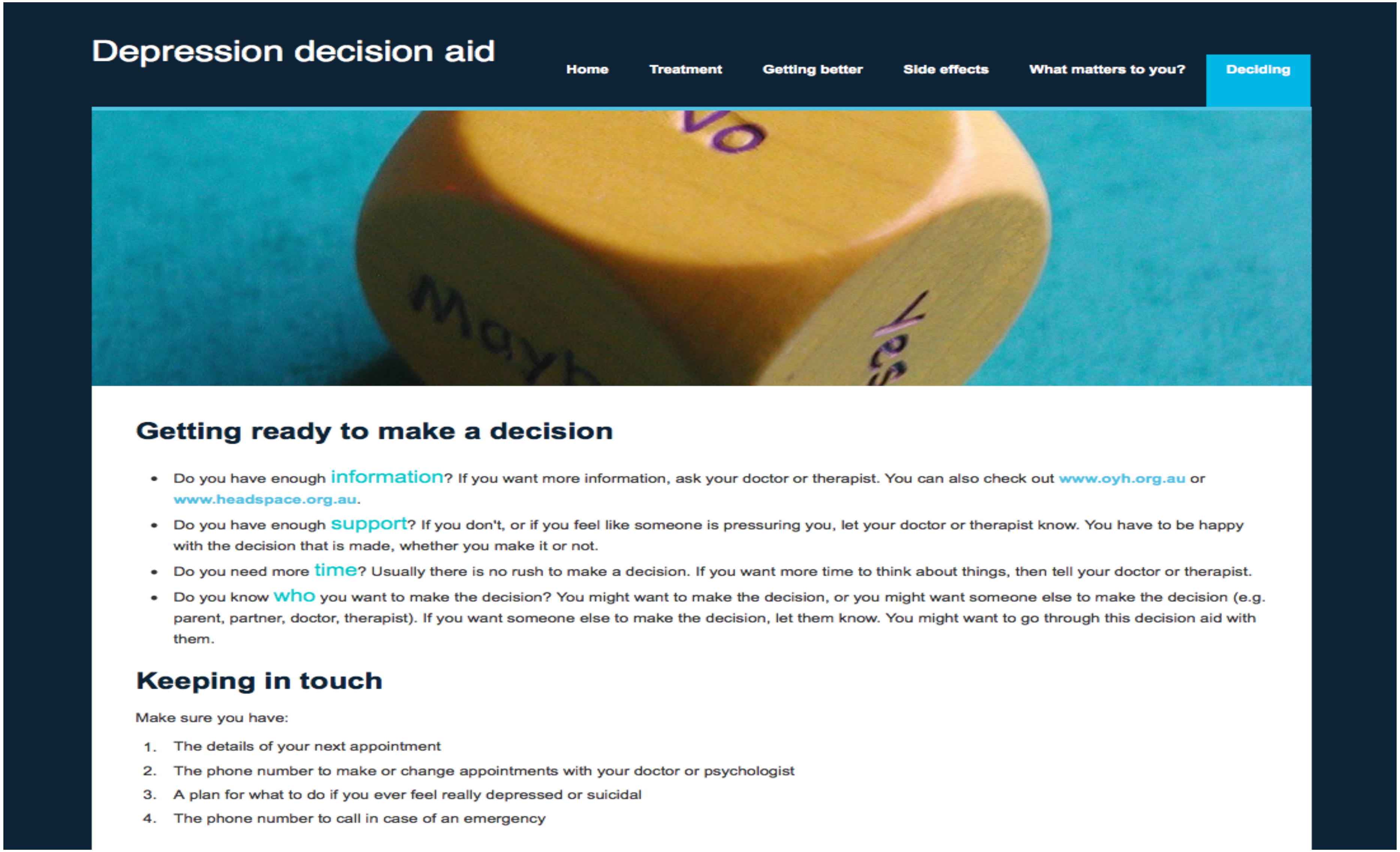
Talking about what matters to you will help you make a good decision that you will be happy with. If you have any questions, talk them through with your doctor or psychologist. If you don't know what matters to you, try out this interactive worksheet. Here are some things you might want to find out:

Talking points for therapy

- Will I feel better or worse after talking about things?
- Will I have to talk about things that I don't want to?
- How long will it take to feel better?
- What if I don't like the therapist?
- Can I ask for a male/female therapist?
- Will therapy change the way I think about things?
- Will you tell my parents or anyone else what we talk about?
- How long will I have to do therapy for?
- Can I decide what we talk about?

Talking points for medication

- How quickly will it work?
- What side effects will I have?
- How much will it cost?
- How will this affect my lifestyle?
- Will people know that I take medication?
- How long will I have to take medication for?
- Can I get addicted to the medication?
- When will we review the decision to take medication?
- What if I want to stop taking medication?



Depression decision aid

Getting ready to make a decision

- Do you have enough information? If you want more information, ask your doctor or therapist. You can also check out www.oyh.org.au or www.headspace.org.au.
- Do you have enough support? If you don't, or if you feel like someone is pressuring you, let your doctor or therapist know. You have to be happy with the decision that is made, whether you make it or not.
- Do you need more time? Usually there is no rush to make a decision. If you want more time to think about things, then tell your doctor or therapist.
- Do you know who you want to make the decision? You might want to make the decision, or you might want someone else to make the decision (e.g. parent, partner, doctor, therapist). If you want someone else to make the decision, let them know. You might want to go through this decision aid with them.

Keeping in touch

Make sure you have:

1. The details of your next appointment
2. The phone number to make or change appointments with your doctor or psychologist
3. A plan for what to do if you ever feel really depressed or suicidal
4. The phone number to call in case of an emergency

Background information

Decision aid for young people aged 12-25 years who face a decision about treatment for moderate to severe depression

Evidence

In selecting the research evidence for this decision aid, we referred to one published (1) and one unpublished (2) Cochrane systematic reviews. The results of both of these reviewed confirmed that there is only one study that has compared the four relevant treatment options in this age group (CBT, fluoxetine, placebo and both CBT and fluoxetine) using a randomised controlled design. The data from this study, the Treatment for Adolescent Depression Study (TADS; (3-7)), were used to determine the absolute risk of potential risks and benefits in the decision aid. This study used a high quality design (randomised controlled trial), however concerns have been raised about the study (8). Although future research is needed in this area, this study provides the best current understanding of the likely outcomes for young people diagnosed with MDD.

Update policy

This decision aid will be updated in conjunction with updates conducted for the relevant Cochrane systematic reviews. Additionally, if any new evidence becomes available that will have a significant effect on the available and/or appropriate treatment options, then the decision aid will be updated as soon as possible.

Readability levels

The text in the decision aid is at a Flesch-Kincaid grade level of 7.2.

Developers

This decision aid was developed by Magenta Simmons [BA (Hons)], a Doctor of Philosophy (PhD) Candidate at the University of Melbourne, under the supervision of Professor Tony Jorm [BA(Hons) (Qld), MPsych, PhD (NSW), GDipComp (Deakin), DSc (ANU), FASSA] and Doctor Sarah Hetrick [MA, DPsych (Clin)].

Funding

This decision aid was developed by Magenta Simmons as part of her PhD studies. This PhD was funded by an Ian Scott Scholarship from Australian Rotary Health (ARH). You can read more about ARH here: www.arh.org.au.

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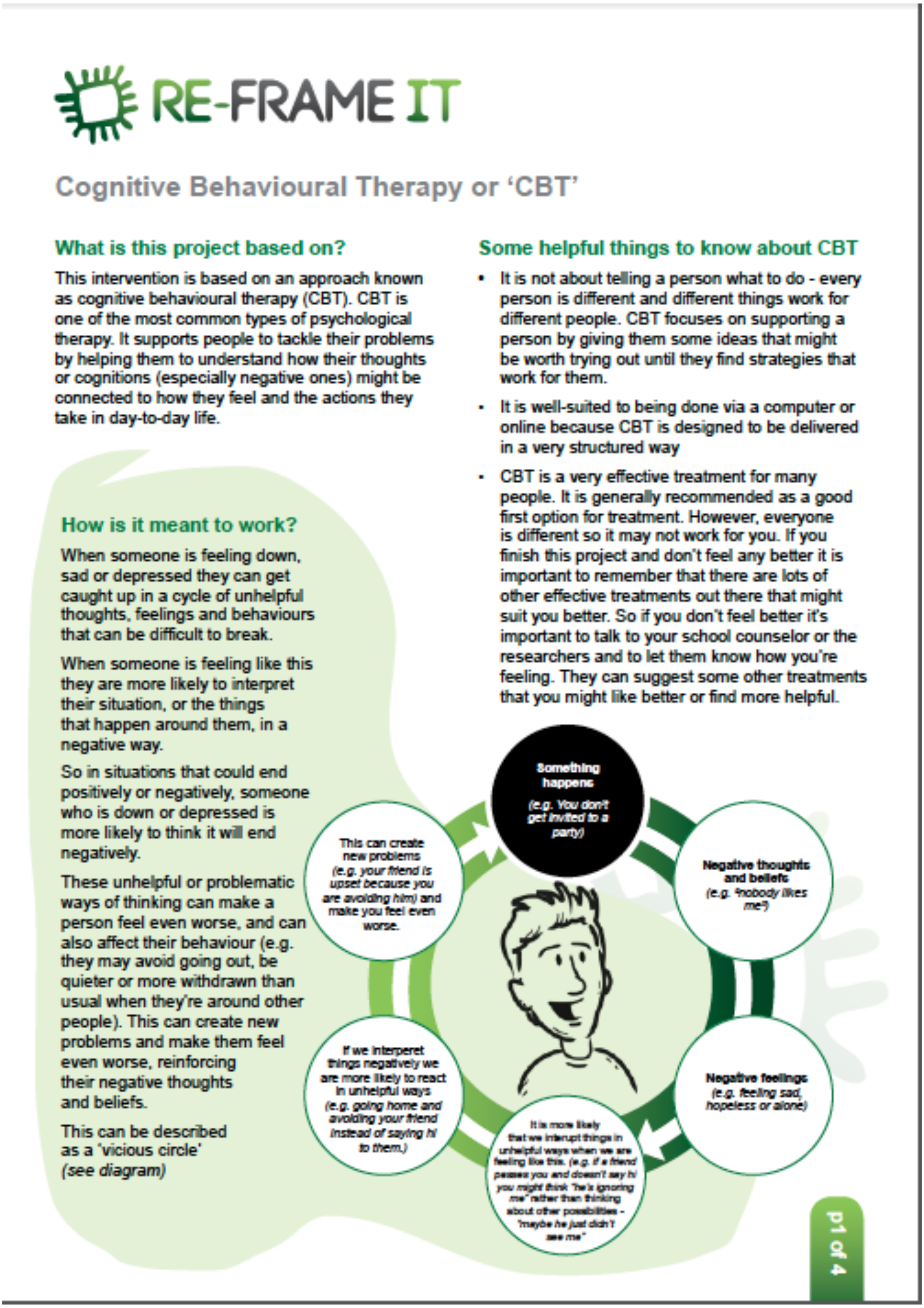

RE-FRAME IT

Cognitive Behavioural Therapy or 'CBT'

What is this project based on?

This intervention is based on an approach known as cognitive behavioural therapy (CBT). CBT is one of the most common types of psychological therapy. It supports people to tackle their problems by helping them to understand how their thoughts or cognitions (especially negative ones) might be connected to how they feel and the actions they take in day-to-day life.

How is it meant to work?

When someone is feeling down, sad or depressed they can get caught up in a cycle of unhelpful thoughts, feelings and behaviours that can be difficult to break.

When someone is feeling like this they are more likely to interpret their situation, or the things that happen around them, in a negative way.

So in situations that could end positively or negatively, someone who is down or depressed is more likely to think it will end negatively.

These unhelpful or problematic ways of thinking can make a person feel even worse, and can also affect their behaviour (e.g. they may avoid going out, be quieter or more withdrawn than usual when they're around other people). This can create new problems and make them feel even worse, reinforcing their negative thoughts and beliefs.

This can be described as a 'vicious circle' *(see diagram)*

Some helpful things to know about CBT

- It is not about telling a person what to do - every person is different and different things work for different people. CBT focuses on supporting a person by giving them some ideas that might be worth trying out until they find strategies that work for them.
- It is well-suited to being done via a computer or online because CBT is designed to be delivered in a very structured way
- CBT is a very effective treatment for many people. It is generally recommended as a good first option for treatment. However, everyone is different so it may not work for you. If you finish this project and don't feel any better it is important to remember that there are lots of other effective treatments out there that might suit you better. So if you don't feel better it's important to talk to your school counselor or the researchers and to let them know how you're feeling. They can suggest some other treatments that you might like better or find more helpful.

Something happens *(e.g. You don't get invited to a party)*

Negative thoughts and beliefs *(e.g. "nobody likes me")*

Negative feelings *(e.g. feeling sad, hopeless or alone)*

It is more likely that we interupt things in unhelpful ways when we are feeling like this. *(e.g. if a friend passes you and doesn't say hi you might think "he's ignoring me"* rather than thinking about other possibilities - *"maybe he just didn't see me"*

If we interperet things negatively we are more likely to react in unhelpful ways *(e.g. going home and avoiding your friend instead of saying hi to them.)*

This can create new problems *(e.g. your friend is upset because you are avoiding him)* and make you feel even worse.

p1 of 4

CBT works by helping a person to recognise, understand and try to break this cycle.

It does this by:

(i) Helping people to identify situations that can make them feel unhappy or stressed out.

(ii) Helping people to recognize patterns in their thinking and behaviour that may be contributing to these negative feelings.

(iii) Focusing on trying to change unhelpful patterns of thinking to more realistic, helpful and problem-solving thinking - this is the 'cognitive part', or the 'C' in 'CBT'.

(iv) Also, since people often stop doing things that they used to enjoy when they're feeling really sad or upset (e.g. spending time with friends, playing sport), CBT supports a person to go back to doing the things that they used to enjoy, that makes them feel good or gives them a sense of achievement. This part of CBT is called 'behavioural activation' – the 'B' in CBT. It is an important part of CBT, because we know that we can feel worse if you are doing less fun things and that doing more fun stuff can help you to feel better.

What kinds of things do you do as part of this project?

This project uses some of the more common techniques used in CBT plus, 1 or 2 other things and these are all described below:

Emotional/mood recognition – this part of CBT focuses on helping a person to be better able to recognize and name different feelings or emotions (both positive and negative ones). It usually happens at the beginning of CBT sessions or online modules. This can be helpful as often when we are feeling distressed our emotions and moods can be confusing and difficult to understand. It is important to remember that everyone can cope with some amount of distressing feelings, but the amount a person can cope with can change day-to-day and in different situations. This part of CBT is about figuring out how much distress you can tolerate, how much is too much and some of the things you can do to help yourself.

Thought identification - Everyone has patterns to the way they think in different situations. It can be difficult to identify these patterns, particularly when we are feeling upset or distressed because all of our feelings and thoughts can get jumbled up. This part of CBT focuses on separating your thoughts from your feelings so you can identify the unhelpful thinking patterns that 'switch on' when something bad happens, or when you are feeling upset, stressed out or distressed. Once you can identify these thought patterns it's much easier to figure out which ones may be causing you problems and making you feel worse. When you know this, you can begin to work toward trying to change these problematic ways of thinking.

Help-seeking – often young people find it difficult to ask for help when they're feeling distressed or experiencing problems. Part of CBT focuses on exploring ways in which talking to other people about your difficulties might help you to feel better.

Activity scheduling – this is part of the 'behavioural' side of CBT - it focuses on scheduling (or planning) enjoyable and goal-directed activities into each day. These are different for each person and might be simple things, like talking to a friend, going to the shop or listening to music. It might also involve rewarding yourself with a pleasurable activity after doing something you may find less pleasurable or difficult, for example going out with a friend after you have completed your homework.

Problem solving – instead of focusing on how to make problems 'go away', it can be helpful to think about how to cope better with problems when they do come up. Problem solving is an important part of CBT. It focuses on supporting a person to better cope with problems by (i) taking a step back and thinking things through when they are faced with a problem; (ii) considering a range of different ways that they could respond to the problem before reacting and (iii) thinking about the consequences of each one of these options (e.g. is it likely to make things better or worse) before deciding which approach to take.

Detecting and challenging problematic thinking – this is a very important part of CBT. It focuses on identifying patterns of thinking that are problematic or unhelpful but are common when we are feeling down or depressed, or stressed or anxious. For example:

1. **'Automatic negative thinking'** – This refers to a tendency to automatically think about things that happen in a negative way (it is called 'automatic' as it is something a person does without realising it). For example, a person passes their friend John in the street and John doesn't acknowledge them. An automatic negative thought would be 'John hates me'. An alternative, more helpful thought would be 'maybe John didn't see me' or 'John looks really pre-occupied – I hope he's OK'.
2. **'Over-generalisation'** – This refers to a tendency to over-generalise from one experience interpreting it as being true of how things are 'in general'. For example, after getting a bad grade a person thinks "I can't do anything right, I fail at everything I do" rather than thinking "I just didn't do to well in this test/assignment". Or after a break-up a person thinks "nobody will ever want me, I am unlovable" rather than thinking that this particular relationship didn't work out.
3. **'Mental filtering'** – This refers to ignoring or dismissing the positive, and focusing on the negative in day-to-day experiences. For example, after getting feedback that an assignment or job was done really well but there are one or two small things to improve on for next time, all a person can think about is that there were mistakes.
4. **'Black and white thinking'** – This refers to a tendency to think about things in terms of extremes (i.e. either everything is "really good" or "really bad").

A summary/review of what you've learned - The last session usually involves reviewing all of the techniques you have learned during these sessions.

Activities and practice – In order to help you to practice these techniques and figure out what ones are most helpful to you, CBT also involves some simple activities for you to do each week. This might include things like identifying helpful or unhelpful thoughts, filling in a mood diary or talking to people about your feelings.

You will also have the opportunity to email the psychologists running the study with any questions you may have or to put messages on the message board for the person monitoring the site, and you can do this at any time during the project. The research team running the study can also suggest some useful books or other reading or websites that you might find helpful if you would like them to.

What is an ‘unhelpful coping behaviour’?

When a person is facing a problem or experiencing distress, they might try a range of different things to try to solve the problem or to make themselves feel better. We call these behaviours ‘coping strategies’.

Some coping strategies are generally more helpful than others (e.g. talking to someone versus shutting yourself in your room to block out difficult feelings), and some can be helpful some of the time, but not all of the time (e.g. you can avoid your homework sometimes - you shouldn’t work all the time - but you can’t always avoid it). When people use unhelpful coping strategies, it is usually because they don’t have a better strategy to rely on (i.e. they are reacting or coping in the best way they can at that time).

CBT focuses on helping a person to identify what coping strategies they are using and think about whether these strategies are generally helpful or unhelpful (i.e. Do they make me feel better or worse at the time? How do they make me feel afterwards – e.g. the next day? What effect do they have on what happens afterwards?).

CBT does not try to take away any unhelpful coping strategies that a person has. Instead it focuses on supporting a person to develop a wide range of new strategies that they can draw on in difficult situations so they are less likely to need to resort to an unhelpful coping strategy to get by.

Does it work?

CBT for young people has been tested in more well-designed studies than most other forms of psychological therapy. It has been shown to work well for lots of difficulties that young people have, for example, for young people who are feeling down or depressed.

There is not enough evidence at this stage to say whether or not CBT delivered online is effective in treating depression and other problems in young people as this is a very new area of research. However because CBT is structured and seems to suit being online, and because heaps of people use the internet these days it seems like a good idea to try. The research that has been conducted to-date is promising, suggesting that CBT delivered online may be effective in treating anxiety and depression in adolescence.

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Orygen YOUTH Health

Medications for DEPRESSION

3A

Antidepressants are a group of medications that are commonly used to treat clinical depression or major depression. When used correctly they can be extremely effective by reducing the symptoms of depression, such as extreme sadness and feelings of hopelessness. Current research suggests that treatment for depression is even more effective if medication is coupled with counselling.

How do they work?

Antidepressants work by restoring the brains ability to use "feel good" chemicals. These chemicals, such as serotonin, are believed to be the chemicals that enable us to feel happy and calm. It's estimated that 60-70 % of people who have major depression are helped by initial antidepressant medication. Antidepressants also work well for less severe types of depression, including if the following symptoms are present; experiencing a recent loss of pleasure in surroundings, restless sleep, waking very early in the morning, loss or increase of appetite or feelings of hopelessness or guilt. Antidepressants are also seen to be effective in the treatment of anxiety – *see the info. sheet on 'Medications used for anxiety 1A'.*

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What are the different types of antidepressants?

> Antidepressant medications fall into several categories, or classes, including serotonin reuptake inhibitors (SSRI's), tricyclic antidepressants and monoamine oxidase inhibitors (MAOI's). SSRI's are the most commonly used. Each type of antidepressant works in a different way. If the antidepressant prescribed doesn't work, the doctor may try one from the same group or a different group. Some people may need to try several different antidepressants before they find the one that works best for them.

How soon will it take to work?

Antidepressants, on average, take from 3 to 8 weeks to work but some people see results in 2 weeks. The medication needs to be taken as prescribed, this is written on the packet. Some symptoms might get better quicker than others – for example sleep problems may improve before mood improves.

How much is needed and how is it taken?

The amount or dose of antidepressant that a person requires can vary depending on the type of antidepressant, body chemistry, age and body weight. Amounts are generally started low and raised gradually over time, until the desired effect is reached, whilst balancing side effects.

Some antidepressants are taken in the morning and some at night – it will be written on the packet when the medication should be taken. If it is not on the instructions the prescribing doctor can be asked.

If a dose is missed it is best to take it when remembered unless it is very near the time for the next dose. If it is near the time of the next dose, just take that dose – not a double dose.

It is usually recommended that people take antidepressants for at least 6-12 months but this varies depending on symptoms. Antidepressants should not be stopped abruptly as, although not addictive, some people experience withdrawal symptoms such as nausea, diarrhoea, restlessness, sleep problems and nightmares. Antidepressants are usually reduced slowly before being completely stopped.

Possible side effects

All medications have the potential to have side effects but they vary from person to person. The list below is some of the more common side effects that could be experienced. This means a person may have no side effects or one or many. More side effects are listed in the packet of the antidepressant. Some side effects can be mistaken for some of the symptoms of depression so they should be discussed with the prescribing doctor. Alcohol and street drugs should be taken with caution when taking an antidepressant, as the effect is unpredictable (unknown).

Possible side effects of SSRI's: anxiety, nausea, headache, difficulty sleeping, sweating, dry mouth, loss of appetite, sexual dysfunction, drowsiness, dizziness and constipation.

Side effects of SSRI's generally pass after the body gets used to the antidepressant, usually within 1-2 weeks. Side effects should be discussed with the doctor, especially if they worry the person. SSRI's are not addictive and are difficult to overdose on.

Precautions: SSRI's can interact with other medications (including other antidepressants) and even herbal/natural medicines such as St John's wort. It is important to tell the doctor what other medications are being taken.

What to avoid/Precautions:

Alcohol and street drugs should be avoided or taken with caution when taking an antidepressant, as the effects are unpredictable (unknown). It is best to discuss with the prescribing doctor what other medications are being taken as they can have an effect on the antidepressant. Even "natural" medicines such as St. John's wort can interact with an antidepressant.

Orygen YOUTH Health

DEPRESSION + Young People

3

Depression is common. Among Australians aged 12-25 years, depression is the most common mental health problem.

(1). Around 1 in 4 young people will have had a depressive disorder by the end of their adolescence

(2). It's important that you get support if you are feeling depressed.

The consequences of untreated depression can often be quite serious and can include performing poorly at school and/or work, losing friends and family supports, substance abuse and a high risk of suicide.

What are normal feelings and what's depression?

People use the word depression in different ways. We all feel down or sad from time to time. It's just part of being human. But, it's important to know when depression is becoming a problem. It's also important to know the difference between depression and sadness. Sadness is a feeling that is a reaction to something, like a break-up or losing someone. Depression becomes an illness or a problem when the feelings of sadness last for a lot longer than normal and seem to cast a dark cloud over life, stopping someone from enjoying most things and from taking part in activities that used to be enjoyable and easy to do.

Types of depression

There are three main types of depression:

- > Major depression
- > Dysthymia
- > Bipolar disorder

AWAREN

Major Depression

Major depression is the depressive illness people are most familiar with. Major depression usually happens in episodes. A depressive episode tends to build up slowly over a couple of weeks or more.

Young people often experience depression in the same way adults do, with the exception that they often have more mood swings or are more irritable and sensitive than usual. This can make major depression difficult to diagnose as some people may just believe the problem to be "teenage problems".

The typical symptoms of major depression in a young person include:

- > Longstanding feelings of unhappiness, moodiness and irritability. Some people also have feelings of emptiness or numbness
- > Losing interest and pleasure in activities that were once enjoyed
- > Loss of appetite and weight (although some young people may turn to comfort foods, overeat and therefore put on weight)
- > Difficulty sleeping, or sometimes staying in bed most of the day
- > Tiredness, lack of energy and motivation or alternatively feeling worried or tense.
- > Difficulty concentrating and/or making decisions
- > Feeling bad, worthless or guilty and generally being self-critical and self-blaming
- > Negative or "down on yourself" thoughts
- > Preoccupation with dark and gloomy themes and thoughts of death or suicide

Dysthymia

The difference between depression and dysthymia is one of intensity. Dysthymia is often described as a milder version of major depression but often goes on for longer, sometimes many months. People with dysthymia can often complete day to day tasks, but may do so with less interest, while feeling down, and with less confidence and enjoyment. Dysthimia also affects a persons sleeping and eating as well as energy levels and concentration.

Compared to major depression, dysthymia has fewer physical symptoms but can have more emotional symptoms such as gloomy and dark thoughts. Dysthymia, like major depression, still requires treatment.

Bipolar disorder

Bipolar disorder (or manic-depression as it used to be called), is when someone experiences periods of depression (as described above) and periods of mania (extreme highs).

Mania can present as being "over the top" in happiness or anger. A person experiencing mania can be very talkative and excited, so much so you may not understand them. They can have lots of energy, not want to sleep and come up with lots of ideas. The person is not usually aware of their symptoms.

There are two types of bipolar disorder, Bipolar I and Bipolar II. Bipolar I is when someone has a period of depression for a few days or weeks and then a period of mania or vice versa. Bipolar II is when someone becomes depressed and then quickly changes from that low mood to a "high" and then back again multiple times in a short space of time (day or week).

It is important for someone with bipolar disorder to seek treatment and help from a counsellor or psychologist

Other problems

Sometimes young people with a depressive disorder may have other mental or physical health problems. For instance some people with depression may also suffer from anxiety problems (i.e. excessive worry), or have a drug use problem (cigarettes/alcohol/illegal drugs).

Suicidal thoughts are common amongst young people with depression so those who appear to be at risk of self-harm or suicide need immediate assistance. Serious concerns should lead to getting the support of close, trusted friends or family, removing all available things that can be used to suicide (eg tablets, firearms) and mental health follow up. You can call your local hospital or local mental health service for support. There are 24hr mental health teams that can see people who are suicidal at any time of the day, wherever they are.

Advice and Referral

If you are working with a young person who appears depressed and you are not sure what to do, it is always best to contact someone with experience in this field and discuss the situation with them.

Treatment of depression should be carried out by workers with training and experience in dealing with mental health problems. Referral to a GP, a trained counsellor or specialist mental health worker may be necessary.

Getting help

> It's important to talk about your problems. Seek help and talk to someone you trust such as a parent, teacher, school counsellor, family member or friend. Your local doctor or GP is usually very experienced in knowing what is and isn't depression so seek help from them. Most people recover from depression after seeking professional help. Counselling has proven effective in the treatment of depression, especially Cognitive Behaviour Therapy (CBT).

> Eating healthily and exercising can not only keep you fit but can also help your mood. Practising relaxation, writing your feelings down, reducing stress and avoiding alcohol and other drugs can also help, but remember some days may be good and other days not as good, overcoming depression can take time. .

DISCUSS

Services at Orygen Youth Health - Clinical Program (OYH-CP)

www.oyh.org.au

Orygen Youth Health Clinical program is able to assist some young people (15-24) with anxiety disorders who live in Western or Northwestern Metropolitan Melbourne.

To make a referral or get some advice contact the **OYH-CP** Triage worker on 1800 888 320 or via the paging service on 03 9483 4556.

For children and teenagers under 15 years of age living in Western or Northwestern Metropolitan Melbourne contact RCH Mental Health Service on 1800 445 511.

For further information regarding mental health and information in other languages visit:

> www.betterhealth.vic.gov.au

> www.sane.org.au

> www.healthinsite.gov.au

> www.ybblue.com.au

> www.beyondblue.org.au

> www.reachout.com.au

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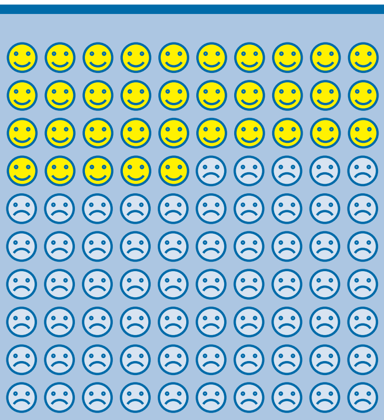
(1). Australian Institute of Health and Welfare. Young Australians: their health and wellbeing, Canberra, 2007.

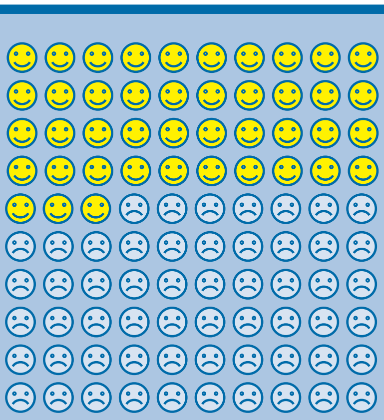
(2). Oakley Browne M, Wells J, Scott K, McGee M (2006). Lifetime prevalence and projected lifetime risk of DSM-IV disorders in Te Rau Hinengaro: the New Zealand Mental health Survey (NZMHS). *Australian and New Zealand Journal of Psychiatry*; 40: 865-874.

GETTING BETTER



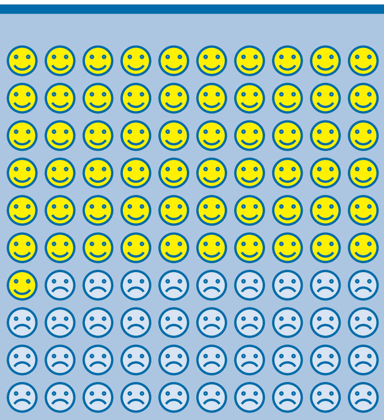
DOING NOTHING

After 12 weeks, 35% of people (35 out of every 100 people) got better even if they did nothing.



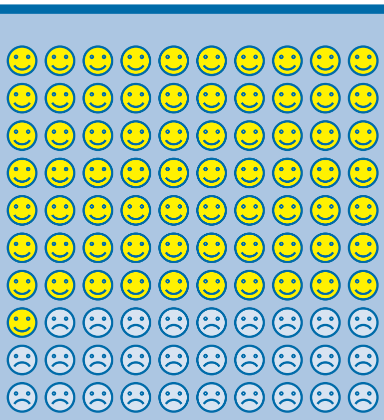
TALKING THERAPY

After 12 weeks of CBT, 43% of people (43 out of every 100 people) got better.



MEDICATION

After 12 weeks of taking fluoxetine, 61% of people (61 out of every 100 people) got better.



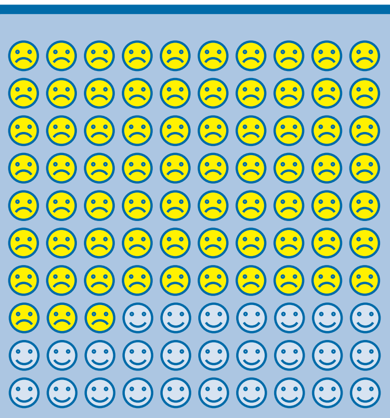
DOING BOTH

After 12 weeks of CBT and taking fluoxetine, 71% of people (71 out of every 100 people) got better.

Possible side effects of antidepressant medication (fluoxetine)

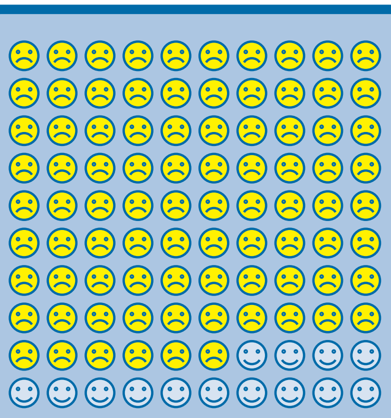
- Altered dreaming
- Anxiety
- Diarrhoea
- Drowsiness
- Dry mouth
- Eating less
- Feeling weak
- Flu syndrome
- Less or more sleep
- Nausea
- Nervousness
- Problems with blood vessels and blood pressure
- Rash
- Sexual side effects
- Sinus pain
- Sore throat
- Suicidal thoughts and behaviour
- Sweating
- Tremors (e.g. shaky hands)
- Upset stomach
- Yawning

SIDE EFFECTS



NOT TAKING MEDICATION (PLACEBO)

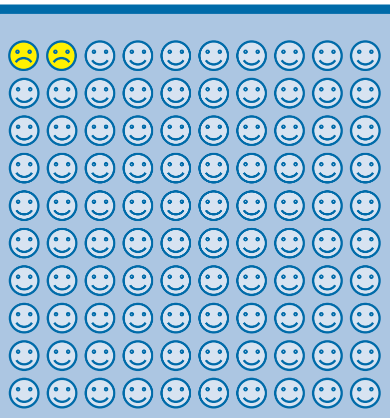
After 12 weeks, 73% of people (73 out of every 100 people) experienced at least one of the listed side effects even though they weren't taking active medication.



TAKING MEDICATION (FLUOXETINE)

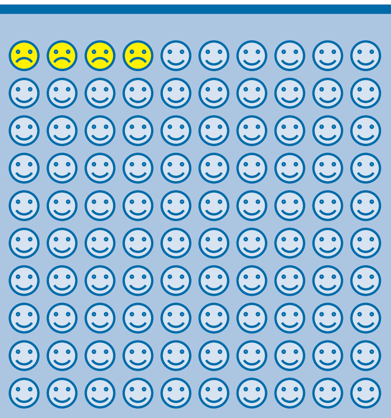
After 12 weeks, 86% of people (86 out of every 100 people) experienced a side effect. 13% (13 out of every 100 people) was probably due to the medication.

SUICIDAL THOUGHTS AND BEHAVIOUR



NOT TAKING MEDICATION (PLACEBO)

After 12 weeks of taking placebo (sugar pill), 2% of people (2 out of every 100 people experienced suicidal thoughts or behaviour.



TAKING MEDICATION (FLUOXETINE)

After 12 weeks of medication (fluoxetine), 4% of people (4 out of every 100 people) experienced suicidal thoughts or behaviour.

What matters to you?

Things that make me want to take antidepressant medication (fluoxetine)

________________________________ ___/5
________________________________ ___/5
________________________________ ___/5

Things that make me NOT want to take antidepressant medication (fluoxetine)

________________________________ ___/5
________________________________ ___/5
________________________________ ___/5

Things that make me want to try counselling (CBT)

________________________________ ___/5
________________________________ ___/5
________________________________ ___/5

Things that make me NOT want to try counselling (CBT)

________________________________ ___/5
________________________________ ___/5
________________________________ ___/5

What matters to you?

1. Have a read through the 'talking points' in the 'what matters to you' section of the decision aid.
2. Think about what matters most to you. Also try to think about the chances of this happening.
3. Talk to your clinician (e.g. doctor) if you have any questions about this.
4. Write down anything that makes you want to try either medication or counselling.
5. Write down anything that makes you NOT want to try either medication or counselling.
6. Give each item a rating out of 5, where 1 means it matters a little bit to you and 5 means it matters a lot to you.
7. Once you've done this, see if you can choose (or rule out) a treatment option based on what matters to you.

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2011

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