Project Title: Right choice, right time: supporting young people to make evidence-based, preference-sensitive decisions about treatment for mild, moderate and severe depression

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beyondblue: the national depression and anxiety initiative
Main Messages

• We successfully developed and evaluated an online tool that supported young people and their clinicians to make decisions about treatment that were: 1) in line with the evidence and beyondblue Clinical Practice Guidelines; and 2) consistent with their personal preferences and values.

• The development process had several stages of consumer, caregiver and clinician involvement and involved a new systematic review on the effectiveness of psychological therapies for youth depression (undertaken by our broader research group).

• The evaluation showed that we helped young people to make a treatment decision, that they were less confused about what to do, and that they were more likely to choose a treatment option in line with the beyondblue Clinical Practice Guidelines.

• Young people were satisfied with the decision they made, felt involved in making the decision (reported high levels of shared decision making) and felt that the decision matched their personal preferences and values.

• At approximately eight weeks after using the decision aid, the majority (more than 80% for each treatment mode) of clients had been adherent to their chosen treatment, demonstrating a positive fit with their individual needs.

• At this same follow up time point depression scores were also significantly improved.

• When clients and clinicians were asked to provide feedback on each section of the decision aid, the majority of responses were positive, with only minor suggestions for how to improve the tool.

• Overall this study demonstrated that a decision aid for youth depression can help connect clients with the right treatment choice at the right time, resulting in positive outcomes for this often difficult to engage population.
Executive Summary

An online decision aid helps young people make good decisions about treatment for depression

Why did we conduct this study?
Depression is a common problem for young people, with about one in every five experiencing an episode of depression before they turn 18 years old. This is concerning, because experiencing depression as a young person can have negative consequences, including higher risk of suicide, disruptions to study and work, and deterioration in social and other relationships.
A number of treatment options are available to assist young people who experience depression. Treatment options that are known to be effective for many people are detailed in a document called the beyondblue ‘Clinical Practice Guidelines: Depression in Adolescents and Young Adults’. These guidelines assist health practitioners when considering best treatment options for different types of depression. One recommendation of these guidelines is to involve the young person in making a decision about their own care.

**What did we do?**

In order to support this recommendation, and to make sure that healthcare professionals have a way to use the guidelines in their everyday practice, we developed an online decision aid (or tool). The tool is designed to incorporate important information from the guidelines and present it in a way that young people, their caregivers, and their healthcare professionals can understand. It also invites young people to think about what matters to them specifically, so that they can make a decision in partnership with their healthcare professional that is based on *what works and what matters to them personally*.

We then evaluated the decision aid to see if it helped young people to make a treatment decision. We wanted to know:

- If young people and healthcare professionals found the decision aid helpful and useful;
- If young people would feel less confused about what to do after using the decision aid;
- If young people were able to make a decision;
- If the decision was in line with what the guidelines recommend;
- If the decision was in line with the young person’s preferences and values;
- If young people and their healthcare professionals were satisfied with this decision;
- If young people felt involved in making a decision about their own treatment;
- If young people would stick with the decision they made (be ‘adherent’) for at least 6-8 weeks;
- If young people would have lower depression scores at approximately 6-8 weeks after making their decision.
Main findings of the Right Choice, Right Time study

The evaluation was successful, with positive results in all areas we investigated:

✓ Finding 1: Young people and healthcare professionals reported finding the decision aid helpful and useful
✓ Finding 2: Young people reported feeling less confused about what to do after using the decision aid
✓ Finding 3: Young people were more able to make a decision after using the decision aid;
✓ Finding 4: After using the decision aid, young people were more likely to make a decision that was in line with the clinical practice guidelines;
✓ Finding 5: All of the young people reported that the decision was in line with their personal preferences and values;
✓ Finding 6: Young people and their health care professionals were highly satisfied with the treatment decision;
✓ Finding 6: Young people felt involved in making a decision about their own treatment;
✓ Finding 7: The majority of young people maintained their decision (i.e. they were ‘adherent’ to treatment) for at least 6-8 weeks;
✓ Finding 8: Young people had significantly lower depression scores at approximately 6-8 weeks after making their decision.

What does this mean in practice?

Young people experiencing depression need support to help them make treatment decisions that are based on evidence and consistent with their personal preferences and values. This offers the best chance for matching the right treatment at the right time for young people, which will likely improve their engagement in, and the clinical benefits of, treatment. Our treatment decision aid is acceptable and useful to young people with depression and their clinicians. We hope to next study whether the use of this aid will result in higher levels of clinical engagement, treatment adherence and response when compared with a control group.
The Report

Context
Depression is common in young people, with one in every five people experiencing a depressive episode before they turn 18 years old (1-3). Young people diagnosed with major depressive disorders (MDD) are likely to face a raft of challenges, not limited to the symptoms that they suffer. Young people are also at increased risk for negative outcomes across emotional, physical, social, and occupational domains (3-9), including higher rates of suicide (10). There are effective treatments for MDD (11), such as Cognitive Behavioural Therapy, yet young people often face a range of difficulties in seeking help and accessing treatment. Help seeking rates are low in this population (12-14), and a range of factors, such as stigma (15) and attitudes to treatment (16,17), will likely lead to a delay in, or barriers to, accessing treatment (18, 19). The importance of engaging young people that do reach a service is paramount, yet the engagement of young people in mental health treatment remains challenging (20).

The ‘beyondblue Clinical Practice Guidelines for Depression in Adolescents and Young Adults’ provides a comprehensive review of evidence-based treatment options for different types of depression, including mild-moderate and moderate-severe. It also promotes the need to tailor treatment decisions to individuals, as well as to consider their preferences (good practice points 11 and 12) (21). Implementation strategies are needed that promote the uptake of evidence-based, guideline-concordant treatment options at the same time as encouraging young people to become actively involved in their own care.

The use of treatment decision aids that facilitate shared decision making (SDM) is one way to approach this dilemma, and there has been recent enthusiasm for the application of SDM to the area of youth mental health (22, 23), including depression (24, 25). Decision aids are evidence-based tools that provide information about guideline-concordant treatment options and invite users (clinician/s and client, plus caregiver/s where appropriate) to explore client values and preferences in relation to the treatment options. These aids have demonstrated effectiveness for decision-related outcomes (e.g. reducing decisional conflict) in non-psychiatric adult populations (26). In doing so, the information exchange between clinician and client is supported and a treatment choice informed by evidence and individual
client preferences can be chosen, which opens up the possibility of reducing decisional conflict, while at the same time increasing client satisfaction, engagement and adherence to the chosen treatment option.

There is an emerging body of work demonstrating the importance of shared decision making for treatment decisions for adults diagnosed with depressive disorders. In a recent randomised trial testing the effectiveness of a decision aid (in the format of ‘choice cards’) for antidepressant use, Le Blanc et al (1) found that the intervention resulted in greater knowledge, satisfaction, involvement in the decision and lower decisional conflict, without increasing the duration of the consultation time. This is supported by earlier work undertaken by Loh et al (2), who conducted a randomised trial to test an online decision aid for adult depression. Participants using the decision aid were more satisfied and more involved in making the decision, and the use of the decision aid again did not increase consultation time. Additionally, the Quality Improvement in Depression study showed that higher levels of shared decision making resulted in higher levels of satisfaction (3) and increased the likelihood of guideline concordant care and symptom reduction (4). To date, no decision aid has been evaluated that focuses on treatment choices for youth depression.

To test the effectiveness of a decision aid on outcomes for young people, a large randomised controlled trial (RCT) is required. However RCTs must be informed first by pilot studies that confirm the ‘proof of concept’. Although there is very strong face validity in the concept of a decision aid for youth depression, exploratory work must first be undertaken to provide the foundation upon which future RCTs can be conducted.

In earlier work, we demonstrated the complex nature of decision making in youth depression. Qualitative interviews with clinicians (5) and clients and caregivers (6) found that whilst a SDM model was almost unanimously endorsed, there was a lack of available tools to facilitate SDM. In order to address this, a prototype decision aid was developed to support treatment decision making for young people with moderate-severe depression, and was piloted with five young people (7). Although these results were favourable, the decision aid supported only one level of depression severity and did not allow for the potentially fluctuating nature, or persisting course, of depressive symptoms. To provide more
comprehensive support, this project sought to develop a decision aid that supported decisions faced by young people experiencing mild, mild-moderate or moderate-severe depression.

Research questions
1) Do young people and clinicians find the decision aid appropriate and useful?
2) Does a decision aid help young people and clinicians to make evidence-based, guideline-concordant decisions?
3) Does a decision aid help young people and clinicians to make (client) preference-sensitive decisions?
4) Do young people and clinicians feel involved in the decision making process after using the decision aid?
5) Do young people feel satisfied with the decision, adhere to the treatment choice and have lower depression scores 6-8 weeks after using the decision aid?
6) Do young people feel less confused about treatment choice (have lower 'decisional conflict') 6-8 weeks after using the decision aid?
7) Does the decision aid result in a change of treatment choice?

Implications
Supporting young people to make decisions about treatment for depression that are based both on evidence and personal preferences and values offers the best chance for matching them with the right treatment at the right time. Connecting young people with effective treatment in a timely manner can help to ease the burden of depressive symptoms experienced during the current depressive episode and minimise the potential negative aspects of depression, such as a decline in social and occupational functioning, or relapse. Providing a positive decision making experience also offers a chance to engage this vulnerable, and traditionally tenuously engaged, group. Facilitating shared decision making at this age not only provides the best chance for the young person to improve their mental health, but also teaches them key skills in how to make informed decisions about their own care that can be used in future decisions about mental and general physical health.
The evaluation of the decision aid yielded positive results, and the benefits of the decision aid for those interested in policy and service provision include:

- Implementation strategy for translating high quality evidence;
- A model that promotes client-centred care (e.g. which is recommended by both the beyondblue Clinical Practice Guidelines and the Victorian Mental Health Act);
- An inexpensive, online tool that requires little training for the clinician (merely familiarisation to increase confidence for use in clinical sessions) and was used in existing consultation time;
- An effective way to decrease decisional capacity, promote guideline concordant care, facilitate shared decision making (involvement in decision making), and increase both client and clinician satisfaction with the decision, leading to good adherence and reduction in depressive symptoms.

**Approach**

This study involved two phases: 1) Development of an online decision aid for youth depression; and 2) Evaluation of this decision aid. As such the approach to each phase is described below in turn.

**Part 1: Development of the decision aid**

**Theoretical framework**

An important starting point for the development of any decision aid is the theoretical framework that drives the design processes. Without such consideration, the quality of these processes are compromised and provide a poor foundation from which to build the format and content of the tool (8). This decision aid was based on two main theoretical frameworks: 1) the International Patient Decision Aids Standards (IPDAS); and 2) the Ottawa Decision Support Framework (ODSF). The IPDAS cover each stage of development, implementation and evaluation processes. Both the IPDAS and ODSF are based on a number of relevant theories, such as decision analysis (9); theory of reasoned action (9); conflict theory (conflict model of decision making) (10); expectancy value theory (expectancy value model) (11); and prospect theory (framing bias theory) (12).
Consultation with consumers, caregivers and clinicians

To ensure the quality and relevance of the decision aid, we engaged consumers, caregivers and clinicians in a number of ways before and throughout the project. The way in which we consulted each group depended on their availability and needs. For example, caregivers were met with in small groups; consumers participated in focus groups; and clinicians provided input during their regular team meetings. These occurred during both the development and evaluation phases, involved viewing each version of the decision aid, and provided invaluable information about the design, content (including language used in the tool), format and function of the tool as well as how the tool was used in clinical practice. Additionally, the decision aid was based on previous work that had strong involvement for each of these three groups, including both consultation and formal research interviews (5-7).

Establishment of a working group

A working group was established to oversee the development of the decision aid, with a specific focus on translating the necessary evidence to support each decision included in the tool. Members included investigators Dr Magenta Simmons (expertise in youth shared decision making) and Dr Sarah Hetrick (expertise in youth depression and systematic reviews), as well as external partners Prof Lyndal Trevena (general practitioner with expertise in shared decision making, including the development of decision aids, and primary care) and Dr Joanne McKenzie (biostatistician with expertise in systematic reviews). A number of decisions were made by this working group to determine the way in which evidence was translated for the decision aid. Examples of key decisions made are presented in Table 1. Screen shots of the decision aid are available upon request.
Table 1. Key decisions made by the decision aid working group

<table>
<thead>
<tr>
<th>Decision faced by clients according to guidelines</th>
<th>Mild depression</th>
<th>Mild to moderate depression</th>
<th>Moderate to severe depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifestyle changes and/or guided self help</td>
<td>CBT vs. no CBT</td>
<td>CBT vs. CBT + SSRI medication</td>
<td></td>
</tr>
</tbody>
</table>

| Decision about type of psychological therapy | N/A | Although there is evidence that both CBT and IPT are effective for the treatment of youth depression, we chose to present information on CBT alone due to the higher availability of CBT (both in person and online via eheadspace) in Australia. |

| Decisions about levels of evidence | It was deemed that there was insufficient high quality evidence (e.g. randomised trials) to use for this decision and so instead we presented key information for each different option in a comparable way. | Although there was adequate high quality evidence (i.e. randomised trials), there was no current systematic review. To fill this gap, our broader research team undertook a systematic review of the effectiveness of psychological therapies in youth depression (manuscript in preparation). | There was sufficient evidence in existing systematic (e.g. Cochrane) reviews to translate the evidence for this section. |

1Cognitive behavioural therapy; 2Selective serotonin reuptake inhibitors; 3Interpersonal psychotherapy

Part 2: Evaluation of the decision aid

Setting

The evaluation of the decision aid was undertaken at two headspace Centres (Glenroy and Craigieburn) in the northern suburbs of Melbourne, which are enhanced primary care services with a focus on youth mental health for young people aged 12-25 years.

Sample

Any headspace clients were included if they scored 5 or more on the PHQ-9 and were able to use the decision aid and provide informed consent. Any clinician who consented to use the decision aid with their client and complete questionnaires was included.
Procedure

Clinician participants were recruited during and after staff meetings. Clinician participants were provided with an instructional session to build confidence in using the decision aid. Client participants were identified by clinicians and referred to the study. After referral, those who provided informed consent to participate undertook a baseline assessment. Following this, the decision aid was used during their next appointment (which sometimes occurred on the same day as, but after, the baseline assessment) at the conclusion of which the decision assessment was performed. Participants were contacted at approximately six weeks after their decision assessment to complete the follow up assessment measures (see Table 2). Clinician participants also completed measures at the decision- and follow up- time points.

Table 2. Assessment time points and respective measures.

<table>
<thead>
<tr>
<th></th>
<th>Baseline assessment</th>
<th>Decision assessment</th>
<th>Follow up assessment</th>
</tr>
</thead>
</table>
| **Client participants** | • Depression severity (QIDS, PHQ-9)  
  • Decisional conflict (DCS)  
  • Initial treatment choice/plan (to compare with treatment selection after use of DA)  
  • Demographics | • Sections of DA used  
  • Feedback on each section used  
  • Decisional conflict (DCS)  
  • Decision made (and whether it was guideline concordant)  
  • Reason for decision (i.e. was it based on client preferences)  
  • Satisfaction with decision (SWD)  
  • Level of perceived involvement (SDM-Q) | • Depression severity (QIDS, PHQ-9)  
  • Decisional conflict (DCS)  
  • Adherence to treatment (e.g. number of therapy appointments attended; medication adherence; lifestyle changes made)  
  • Satisfaction with decision (SWD)  
  • Any changes in treatment decisions |

| **Clinician participants** | • Sections of DA used  
  • Feedback on each section used  
  • Reason for decision (i.e. was it based on client preferences)  
  • Satisfaction with decision (SWD) | • Satisfaction with decision (SWD)  
  • Any changes in treatment decisions |

Ethics

This study received ethics approval from the University of Melbourne Behavioural Sciences Human Ethics Sub-Committee (reference number 1339306) and conforms to the provisions of the Declaration of Helsinki (as revised in Tokyo 2004), available at http://www.wma.net/en/20activities/10ethics/index.html.
**Results**

**Participants**

Overall, 66 clients provided informed consent to participate in the study. Of these 66, 57 (86.36%) used the decision aid and completed post-decision assessments. Of these 57, 48 (84.21%) completed the follow up assessment (see **Figure 1**).

**Figure 1.** Recruitment rates and reasons for attrition
Client participants were aged between 13 and 25 years with a mean age of 18.53 years (SD=3.42). 54 (81.8%) identified as female; 11 (16.7%) identified as male (including one participant who identified as a transgender male) and one participant (1.5%) identified as demigender (partially identifies as female). In terms of depression severity, 12 (18.2%) had PHQ-9 scores suggesting mild depression; 17 (25.8%) mild-moderate depression; and 37 (56.1%) moderate-severe depression.

A small majority of the participants had been at headspace for less than one month, and more than 80% had been seen for less than two months (see Figure 2). Thirty-five participants (53.0%) had previously received treatment for depression: 10 (15.9%) had received counselling (e.g. CBT); 3 (4.8%) had taken medication; 15 (23.8%) had tried both counselling and medication; and 4 (6.3%) had tried something else (herbal medication; music; “squeezing ice (and) writing on myself”; and “inpatient service”).

![Figure 2. Proportion of participants (%) according to length of time at headspace.](image)

In total, 23 clinician participants were involved. Of these, 20 (87%) were female and 3 (13%) male. In terms of professional background and role, six were working in the Youth Access Team (five registered or clinical psychologists and one provisional psychologist); 16 were private practitioners (14 registered or clinical psychologists, two occupational therapists);
and one general practitioner. Clinician participants used the decision aid with between one and nine clients, with the mean number of times being 2.48 (SD=2.19).

**Use of decision aid sections**
Both client and clinician participants were asked which sections of the decision aid they used. All client reported using the mood questionnaire, ‘what matters to you’, ‘treatment options’ and ‘your decision’ sections, and only 14 (24.6%) used the ‘information’ section. Clinicians reported using the mood questionnaire in 12 (24%) consultations, the ‘what matters to you’ section in 16 (32%) consultations, the ‘treatment options’ section (the main section clinicians were asked to use) in 51 (100%) consultations, the ‘your decision’ section in 44 (88%) consultations, and the ‘information’ section in 19 (38%) of consultations.

Data were missing for 16 consultations, and this may account for the discrepancy between client and clinician reported usage of each section, although some discrepancies remain (e.g. only 14 clients reported using the ‘information’ section, whereas clinicians reported that it was used in 16 consultations). It is possible, however, that clinicians encouraged clients to use a section (e.g. look at the information in the waiting room after the consultation; or print out information for the client to take home) but the client chose not to do so.

**Were clients able to make a decision?**
Client participants were asked if they had made a decision about treatment before and after using the decision aid. The McNemar test was used to compare ability to make a decision for those client participants with both baseline and decision assessment data. Ability to make a decision changed significantly after using the decision aid ($p=.022$). Clients were more able to make a decision after using the decision aid (96.5%) than before (78.8%). At follow up, all clients had made a decision about treatment.

**Was the decision in line with client preferences and values and were they satisfied with it?**
Client participants were asked if the chosen treatment was the one that they most preferred and if it matched their personal needs and preferences. 53 (100%) of clients endorsed both of these items. Clients were also asked to complete the Satisfaction With Decision (SWD) scale, a 6-item 1-5 Likert scale with a maximum score of 30 where higher scores indicate
higher satisfaction with the decision. Scores ranged from 16-30, with a mean score of 25.84 (SD=3.14). Given that those who were unable to make a decision also completed this scale, these results indicate high levels of satisfaction with the decisions made. Clinician participants were also asked to rate how satisfied with the decision, and did so for 49 decisions. The range was 13-30 with a mean score of 25.41 (SD=3.70), also indicating high levels of satisfaction.

*Did clients feel involved in making the decision?*

Perceived involvement (shared decision making) in the decision making process was measured using the Shared Decision Making Questionnaire (SDMQ) (13). The SDMQ is an 11-item scale with 4-point Likert responses, resulting in a minimum score of 11 and a maximum score of 44. Client participants completed the SDMQ after using the decision aid, and scores ranged from 29-44 with a mean score of 37.36 (SD=4.30), indicating high levels of perceived involvement in making a decision about their own treatment.

*Decisional conflict*

Client participants completed the Decisional Conflict Scale (DCS) (14) before and after using the decision aid. The DCS is a 16-item measure that uses a 0-4 Likert scale. It has a total score range of 0-100, where higher scores indicate higher decisional conflict (undesired outcome). There was a significant reduction in decisional conflict scores between baseline (M=37.91, SD=17.65) and after using the decision aid (M=21.08, SD=13.35); t(56)=8.11, p<0.001.

*Was the treatment chosen in line with the beyondblue Clinical Practice Guidelines?*

Client participants were asked about their preferred treatment before and after using the decision aid. Assessments were then made as to whether or not the choice was in line with recommendations from the clinical practice guidelines. Examples of decisions that were deemed non-guideline concordant include: 1) client participants with mild depression who opted for antidepressant medication (with or without CBT); 2) client participants with any depression severity who opted for medication alone (without trying CBT first); 3) client participants with moderate-severe depression who opted for lifestyle changes and/or guided self help. The McNemar test was used to compare whether or not the decision was guideline
concordant for decision choice before and after using the decision aid (excluding those who were unable to decide). Whether or not the preferred choice was guideline concordant changed significantly after using the decision aid ($p=.004$). Clients were more likely to make a decision that was guideline concordant after using the decision aid (92.6%) than before (70.2%).

Follow up assessments

The original aim was to follow up client and clinician participants between 6-8 weeks after the decision aid was used. In instances where the participants were unable to complete follow up assessments within this timeframe, assessments were still conducted and the time between decision and follow up assessments was recorded. Alternatively, if a person was unable to complete the follow up assessment after the required time they were seen. The time to follow up was most affected across the holiday period, resulting in a range of 5-28 weeks (M= 8.26; SD=4.19).

Did the treatment changed during the follow up period?

At follow up, there was clinician-rated data for 46 client participants. Of these, 35 (76.1%) were still engaged in the original treatment choice. Of the 11 clients who had changed their treatment, five had not engaged in their treatment; one had stopped because they were ‘better’; one was in crisis too often to undertake psychological therapy; one had gone on to develop first episode psychosis and treatment had changed in line with this; one had over-reported depressive symptoms at the time of making a decision and so treatment had been revised in line with this (to a guideline concordant treatment option); and one client had required family therapy but the family had failed to engage.

Were clients and clinicians still satisfied with the decision that had been made?

At follow up, client and clinician participants were asked to rate how satisfied they were with the decision that had been made at the time of using the decision aid. There were data for 45 clients, ranging from 16-30 with a mean score of 25.91 (SD=3.98). Clinician participants rated a total of 45 decisions, ranging from 17-30 with a mean of 25.31 (SD=3.62). This indicates that both clients and clinicians were still very satisfied with the decision-making processes at approximately eight weeks after the decision was made.
Were clients adherent to the chosen treatment option?

Client-reported adherence data were available for 47 participants. Due to the fact that some clients engaged in more than one treatment, adherence data are available for 89 ‘courses’ of treatment (27 courses of lifestyle changes or guided self help; 45 courses of CBT; and 17 courses of medication) and frequency data are available for 83 ‘courses’ of treatment (with details about frequency missing in six cases).

For each treatment type, client participants were asked three investigator-devised open-text questions. For example, for CBT participants were asked: ‘How regularly have you been attending appointments? (e.g. weekly, fortnightly, monthly etc.)’; ‘For how long have you been doing this therapy?’; and ‘Have you missed any scheduled appointments? If so, how many?’. Responses were then coded in terms of frequency and adherence (see Table 3-5). Adherence was categorised into full adherence; minor non-adherence (80% or more sessions attended); moderate non-adherence (50-79% of sessions attended) and non-adherence (<50% of sessions attended).

For lifestyle changes and guided self-help, 18/22 (81.8%) of client participants reported engaging in these activities on a daily, weekly or fortnightly basis; and 4/22 (18.2%) reported moderate non-adherence (see Table 3).

Table 3. Adherence and frequency of clients engaged in lifestyle changes and/or guided self-help.

<table>
<thead>
<tr>
<th></th>
<th>Daily</th>
<th>Several times a week</th>
<th>Weekly</th>
<th>Fortnightly</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full adherence</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Minor non-adherence</td>
<td>11</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>Moderate non-adherence</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Not adherent</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
For CBT, 35/43 (81.4%) of client participants had weekly to fortnightly sessions; 3/43 (7.0%) had fortnightly to monthly sessions; and 5/43 (11.6%) had moderate non-adherence (see Table 4).

**Table 4.** Adherence and frequency of clients engaged in CBT.

<table>
<thead>
<tr>
<th></th>
<th>Weekly</th>
<th>Weekly to fortnightly</th>
<th>Fortnightly</th>
<th>Fortnightly to monthly</th>
<th>Monthly</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full adherence</td>
<td>10</td>
<td>4</td>
<td>11</td>
<td>0</td>
<td>2</td>
<td>27</td>
</tr>
<tr>
<td>Minor non-adherence</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Moderate non-adherence</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Not adherent</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

For medication, 16/17 (94.1%) of participants had full adherence or minor non-adherence to daily doses (see Table 5).

**Table 5.** Adherence and frequency of clients taking medication.

<table>
<thead>
<tr>
<th></th>
<th>Daily</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full adherence</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Minor non-adherence</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Moderate non-adherence</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not adherent</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Only one client had ceased medication during the follow up period. The subgroup of clients who reported adherence data for medication included a mix those who chose medication (in addition to CBT) at the time of using the decision aid and four participants who had not (see Table 6).
Table 6. Details of who did and did not report adherence data for medication at follow up according to those who did and did not choose it as a treatment option after using the decision aid.

<table>
<thead>
<tr>
<th></th>
<th>Reported adherence data for medication at follow up</th>
<th>Follow up data not available</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chose medication and CBT after using the decision aid</strong></td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td><strong>Did not choose medication at time of using the decision aid</strong></td>
<td>4 (3 of whom reported taking medication before using the decision aid and 1 of whom commenced medication during the follow up period)</td>
<td>-</td>
</tr>
</tbody>
</table>

Did depression improve over time?

Depression was measured using the PHQ-9 at both baseline and at follow up assessment time points. There was a significant reduction in decisional conflict scores between baseline (M=14.04, SD=5.22) and at follow up (M=11.38, SD=5.60); t(47)=4.06, p<.001.

Client feedback on the decision aid

Sections of the decision aid used

Clients were asked which sections of the decision aid they used. All clients used the mood questionnaire, ‘what matters to you’ and ‘treatment options’ sections, however only 14/57 (24.6%) used the additional ‘information’ section. Full analyses of both client and clinician feedback data are available upon request.

Summary of client feedback

Overall, the proportion of positive feedback on the Right Choice Right Time decision aid was 74% (see Figure 3), with the majority of clients finding each section helpful. Most participants felt that the mood questionnaire was useful in helping them reflect on their mood, and identify particular areas in which they were struggling. Clients appreciated being asked about what mattered to them, and being able to share this with their clinician in order to inform treatment planning. Being able to view the evidence and information about relevant treatment options was seen as helpful in choosing the most fitting treatment, and most people found this valuable in exploring treatment options with their clinician.
Overall, the Your Decision section was viewed as a helpful way to document treatment decisions, but sometimes its relevance was seen more as a review of the previous sections. Fewer participants used the information section, but those who did use it largely found it helpful and appropriate in content and tone. From those comments that were neutral, mixed, or negative, the main suggestions were that:

- The decision aid works best when it’s most aligned with the stage the client is at – some people decide faster, some need more time;
- The decision aid should allow for people to easily compare a range of options and find more information as relevant to their needs;
- Treatment planning needs to be flexible and holistic, so options should not box people in;
- The online iPad format was easy to use, but a brighter and more diverse colour palette could enhance the style.

![Figure 3. Nature of overall client feedback about decision aid](image)

*Clinician feedback on the decision aid*

As with the client feedback, overall, the proportion of positive feedback from clinicians on the Right Choice Right Time decision aid was 73% (see Figure 4), with the majority of
clinicians finding most sections helpful. Neutral or mixed feedback accounted for 20% of responses, and only 7% of responses were negative.

Despite being provided with their clients’ mood questionnaire results, most clinicians did not give feedback the Mood Questionnaire, as they did not perceive that they had actively used this section of the decision aid with their client. Those who did give feedback felt that the mood questionnaire was useful in helping them gain insight into their clients’ mood, and recognizing particular areas they may be struggling with – particularly when risk issues were identified.

Most clinicians also did not give feedback on the What Matters To You section. However, those who did give feedback mostly responded positively - they appreciated knowing more about what mattered to their clients and being able to use this insight to inform treatment planning.

The Treatment Options section was seen as highly useful in presenting the evidence for relevant options, but if information was presented later in the process it was viewed as less helpful. Suggestions for improvement included making the graphs easier to view, allowing for more personalised and holistic treatment plans by combining options such as CBT and exercise, and adding additional information about other evidence-based psychotherapies.

Responses to the Your Decision section were mixed – it was viewed as a helpful way to ascertain client preferences and document treatment decisions, but again timing was an important factor. The Information section was seen as youth-friendly, useful and appropriate in content and tone.
The purpose of this study was ‘proof of concept’ in preparation for rigorous testing using a randomised controlled trial (RCT) design. Based on the results of this study, we believe the an RCT comparing the decision aid with treatment decision making as usual is warranted (see below under ‘Future research’).

Additional resources
Aside from the decision aid itself, the results of this study have been presented at a number of conferences, including:


- **Simmons MB, Elmes A, Trevena L, Hetrick SE.** Right Choice, Right Time: Involving Consumers in Making Decisions about Evidence-Based Care for Youth Depression. Oral presentation at the 2015 25th TheMHS Annual Conference; Canberra, Australia.

International Shared Decision Making and International Society for Evidence Based Health Care Conference; Sydney, Australia.

Additionally, this project formed part of a winning application for the 2015 TheMHS Early Career Researcher Awards (in the category of Excellence) and a presentation was given based on this and other work:

- Simmons MB. Shared Decision Making in Youth Mental Health. Oral presentation at the 2015 25th TheMHS Annual Conference; Canberra, Australia.

Several publications are in preparation, including: 1) on the development of the decision aid detailing the methods used to translate evidence for risk communication; and 2) the main results paper.

Further research
This proof of concept study set out to determine whether a decision aid for youth depression could facilitate a shared decision making process between the client and their clinician, resulting in a decision that both parties were happy with and that was consistent with the evidence and client preferences and values. A research question that stems directly from this is whether or not we can support ongoing decision making to keep young people well engaged in their chosen treatment. As such, we would now like to investigate adjunctive functions for the decision aid that are comprehensive yet very simple and short questions items to complete on a weekly basis. For example, one proposed model is for the young person to use the decision aid with their clinician to choose a treatment option. Once this has been done, they would receive an electronic message each week before their appointment (e.g. CBT) or scheduled task (e.g. exercise) that includes:

- Reminders of the appointments or tasks (e.g. exercise) related to their chosen treatment with a brief video from a young person with lived experience promoting recovery and hope and encouraging them to attend their appointment or undertake their activity;
- Monitoring of depressive symptoms to see if their chosen treatment is working or not;
- Any change in suicidality risk so that it is able to be addressed in session without having to wait for a risk assessment;
- Revisiting the decision to see if they are still happy with their choice;
- Providing feedback about their treatment to inform ongoing review with clinician;
• Allowing the person to nominate any life event from the past week or topic that they want to be the priority of their next appointment.

Within this extension work, we also plan to test a model by which mechanisms of action are proposed and tested. We are also interested at using participatory research methods to help improve the quality and relevance of the enhanced aspects of the decision aid that promote clinical engagement.
References